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"Older Adults with ASD: The Consequences of Aging." Insights from a series of special interest group meetings held at the International Society for Autism Research 2016–2017

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ABSTRACT

A special interest group (SIG) entitled "Older Adults with ASD: The Consequences of Aging" was held at the International Society for Autism Research (INSAR) annual meetings in 2016 and 2017. The SIG and subsequent meetings brought together, for the first time, international delegates who were members of the autistic community, researchers, practitioners and service providers. Based on aging autism research that is already underway in UK, Europe, Australia and North America, discussions focussed on conceptualising the parameters of aging when referring to autism, and the measures that are appropriate to use with older adults when considering diagnostic assessment, cognitive factors and quality of life in older age. Thus, the aim of this SIG was to progress the research agenda on current and future directions for autism research in the context of aging. A global issue on how to define 'aging' when referring to ASD was at the forefront of discussions. The 'aging' concept can in principle refer to all developmental transitions. However, in this paper we focus on the cognitive and physical changes that take place from mid-life onwards. Accordingly, it was agreed that aging and ASD research should focus on adults over the age of 50 years, given the high rates of co-occurring physical and mental health concerns and increased risk of premature death in some individuals. Moreover, very little is known about the cognitive change, care needs and outcomes of autistic adults beyond this age. Discussions on the topics of diagnostic and cognitive assessments, and of quality of life and well-being were explored through shared knowledge about which measures are currently being used and which background questions should be asked to obtain comprehensive and informative developmental and medical histories. Accordingly, a survey was completed by SIG delegates who were representatives of international research groups across four continents, and who are currently conducting studies with older autistic adults. Considerable overlap was identified across different research groups in measures of both autism and quality of life, which pointed to combining data

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and shared learnings as the logical next step. Regarding the background questions that were asked, the different research groups covered similar topics but the groups differed in the way these questions were formulated when working with autistic adults across a range of cognitive abilities. It became clear that continued input from individuals on the autism spectrum is important to ensure that questionnaires used in ongoing and future are accessible and understandable for people across the whole autistic spectrum, including those with limited verbal abilities.

1. Introduction

Autism Spectrum Disorder (ASD)[1] has for many decades been known as a lifelong neurodevelopmental disorder, which may have profound effects on intellectual ability and psychological functioning, general ability, and life outcomes (Howlin et al., 2004; Howlin et al., 2013; Howlin et al., 2014). However, autism research has to date largely neglected the life outcomes and trajectories for older adults diagnosed with the condition (Michael, 2016; Mukaetova-Ladinska et al., 2012; Smith et al., 2012). This has led to recent reports attempting to identify priorities for research on aging and ASD (e.g. Happé & Charlton, 2011; Howlin et al., 2015; Damiano et al., 2014). Several other co-existing conditions, such as anxiety, depression, Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive-Compulsive Disorder (OCD; Lever & Geurts, 2016) are associated with their own sets of psychological difficulties that can affect general wellbeing and autonomous living (Hofvander et al., 2009; Kats et al., 2013). All these factors converge on several key areas that point to the need for better understanding of the experiences of autistic individuals as they grow older. Moreover, long-term mental health difficulties, such as depression, are known to be associated with cognitive difficulties in typical aging (McClintock et al., 2010), and with increased risk of neurocognitive disorders (i.e. dementia; Bauman, 2010) in the general population (Evans & Mottram, 2000). The findings from many studies in the typical aging literature suggest that cognitive aging can be observed after 50 years of age with declines observed in processing speed (Salthouse, 1996); attention (McCabe et al., 2010), metacognitive ability (Mäntylä et al., 2010), executive functions (Craik & Bialystok, 2006; Friedman & Miyake, 2017), memory (Craik & Byrd, 1982; Rabbitt, 2016) and general intellectual ability (Salthouse, 2004; Anderson & Craik, 2017; and see Hedden & Gabrieli, 2004 for review of lifespan changes and stability). More broadly, during the course of aging, changes in the domains of memory, executive function, and fluid intelligence affect psychological functioning and well-being. This includes functional skills for independent daily living and life management, including the ability to perform more demanding activities such as employment, planning skills, spatial orientation and navigation, taking one's medication and even remembering a doctor's appointment or someone's name (McDaniel & Einstein, 2000). In this respect, age-related cognitive decline can have far-reaching and devastating effects on an individual's general functioning and independence, leading to social isolation and poorer quality of life (Crook et al., 1986; Hedden & Gabrieli, 2004; Salthouse et al., 2003; Salthouse, 2004; Woods et al., 2015). Further, neurocognitive research involving the study of the interaction between the changes in the nervous system and changes in brain regions may provide clues to the cognitive mechanisms that underlie how individuals learn and process information. For instance, the impairments observed in cognitive functioning within certain clinical groups are similar to those observed in persons with brain trauma or developmental disorders (Cappelletti et al., 2014; Dempster, 1992). These similarities indicate that particular brain regions are be implicated in learning and memory across the lifespan. For instance, frontal brain regions (associated with executive function) and the hippocampus and related structures of the medial temporal lobe (associated with memory) have been shown to decline in volume and functional connectivity with increasing age (e.g. Raz et al., 2005; Craik & Rose, 2012a, Craik & Rose, 2012b; Ferreira et al., 2016) – a picture that corresponds to the cognitive and brain profiles of patients with amnestic and dementia pathologies (Hedden & Gabrieli, 2004). For individuals on the autism spectrum, a similar profile has been identified, in relation to atypical functional connectivity between associated brain regions at various developmental stages (e.g. Boucher et al., 2012; Just et al., 2012), including middle-older age (40–65 years; Braden et al., 2015). In turn, these brain differences in autistic individuals are accompanied by selective cognitive difficulties, such as executive function and memory (Boucher et al., 2012; Braden et al., 2015; Hill, 2004; but see Mottron & Burack, 2001). The parallels that can be drawn between cognitive difficulties in younger autistic individuals and the similar profile of difficulties seen in typical age-related cognitive decline, suggests that autistic individuals may present as prematurely cognitively old (Bowler, 2007). If true, then these findings highlight important considerations of how growing older might affect the cognitive abilities and functioning of older autistic adults and whether early developmental profiles present an increased risk of cognitive decline associated with dementia and co-existing mental health conditions (Braden et al., 2015; Croen et al., 2015; but see Oberman & Pascual-Leone, 2014).

The risk of onset of dementia, including Alzheimer's disease which is the most common (62%) cause of dementia, increases dramatically with older age (Lewis et al., 2014; Prince et al., 2014). An estimated 2% of adults aged 65–69 years have dementia

[1] The diagnostic term autism spectrum disorder (ASD) follows the DSM-5 guidelines (APA, 2015) and includes autism, autism spectrum and Asperger's diagnoses that were previously classified under DSM-III and DSM-IV-TR guidelines. The term 'autism' can be used both as a general term for what we think of as the essential core of ASD, or it can be a clinical sign or feature of individuals with ASD (as in 'autistic aloneness' or showing signs of autism - i.e. withdrawal from or reluctance to engage in two-way social interaction). For clarity of expression, the terms ASD and autism are used in this manuscript to denote the above descriptions. When describing individuals on the autism spectrum, we acknowledge that many different terms are used by the autism community, as the preferred language used by autistic people and their families, and professionals (Kenny, Hattersley, Molins et al., 2016). In this paper, we use identify-first terminology (i.e. autistic individual; autistic adult etc.).

(1.8% female; 1.5% male), increasing to 25% (men) to 33% (women) by age 85 years or older (Stuart-Hamilton, 2006, p. 197; Lewis et al., 2014; Prince et al., 2014) – some research suggests even higher risks for Alzheimer's disease in almost half of all adults in older age (85+ years; Bishop et al., 2010). The various forms of dementia are associated with fronto-temporal lobe dysfunction – the domains associated with executive and memory functions (Bishop et al., 2010) – and are thought to exacerbate the effect of age-related cognitive decline and poor quality of life (Knapp et al., 2007; Lewis et al., 2014). In ASD, little is known of the risk of dementia in older age. One study (Croen et al., 2015) reported prevalence rates of 1.9% (men) to 3.2% (women), for dementia in autistic adults. Another study has speculated that cognitive "hyperplasticity" (Oberman & Pascual-Leone, 2014, p.341), which could explain the cognitive and behavioural profiles seen in early development (Oberman & Pascual-Leone, 2008), may offer protection from dementia in older age when plasticity is typically reduced. However, the possible factors associated with dementia-related protection or risk in ASD are under-researched and still poorly understood (Wright et al., 2016). Consequently, because very little research has included older autistic adults, much less is known about how the process of aging affects the quality of life of autistic individuals and the need for long-term care (Happé & Charlton, 2011; Howlin et al., 2015; Mukaetova-Ladinska et al., 2012). We aimed to address the gap in knowledge by bringing together, for the first time, an international consortium of researchers, professionals and autistic adults to discuss the issues related to aging and autism, with implications for future research and clinical applications.

Based on ongoing work concerning the cognitive changes associated with aging in ASD and their impact on quality of life (e.g., Braden et al., 2017; Lever & Geurts, 2015; Powell et al., 2017; Roestorf & Bowler, 2016; Roestorf, Howlin et al., 2018; van Heijst & Geurts, 2015), a series of Special Interest Group (SIG) meetings was held at the 2016 and 2017 annual meetings for the International Society for Autism Research (INSAR). These were co-led by the first and last author of the present article. The SIG objectives focused on three priorities for Aging and ASD derived from recent reports (e.g. "Getting On Policy Report", National Autistic Society, 2008; Pellicano, Dinsmore, & Charman, 2014a, Pellicano, Dinsmore, & Charman, 2014b; "Autistica's Research Strategy 2015-20″, Autistica, 2014), which were:

(1) *Later life autistic traits and diagnosis of ASD*: for earlier referral and/or interventions, better diagnostic tools, and post-diagnostic support of autistic adults;
(2) *Cognitive aging in ASD:* for a better understanding of the age-related cognitive changes associated with aging in ASD and potential risk factors for cognitive declines associated with dementia;
(3) *Treatment and care of older adults:* with respect to general wellbeing, physical, and mental health across the autistic adult's lifespan.

These priorities were provided as starter points for a more in-depth discussion to determine how the autism research community can develop more collaborative research in order to maximise validity and generalisability of findings and conclusions. Delegates in the first SIG meeting (N = 53) included representatives from nine countries (UK, Netherlands, Italy, Norway, Denmark, USA, Canada, Australia, Taiwan). In that meeting, which was held at INSAR Baltimore, USA in May 2016, delegates were asked to discuss the above three priorities in small groups and to identify and report back on two key points related to them. Delegates elected to participate in one of the three discussion groups related to the above themes, based on their specific area of research interest. The discussion points for each priority were: (a) to identify the primary question to be addressed, potentially in a collaborative research effort; (b) to discuss one single challenge that needed to be overcome when studying this specific age group and provide a potential solution to this challenge. The main outcomes from these discussion groups are reported below.

2. Global issues about aging and ASD

An issue that transcended the priority areas was the question of how to define 'aging' when referring to ASD. Whilst it was acknowledged that aging is a broad concept that spans developmental issues relating to the transition from child to adulthood to considerations of care and cognitive change in individuals older than 65 years, it was also agreed that research on aging in autism should focus on individuals over 50 years of age. The consensus was that this relatively arbitrary boundary is appropriate, especially as autism is associated with premature death in some cases (mean age 54 years; Hirvikoski et al., 2016) which may be accelerated by a wide range of co-existing medical conditions (Croen et al., 2015; Zerbo et al., 2018). Thus, recent research has highlighted greater co-occurring health conditions and mental health needs in ASD compared to the general population (Hirvikoski et al., 2016; Fortuna et al., 2016; Happé et al., 2016; and see Lever & Geurts, 2016). Moreover, relatively few have access to appropriate services in adulthood and across their lifespan (Wright et al., 2016). The co-occurrence of one or more physical or mental health conditions is reported in at least 50–84% of autistic individuals (Hirvikoski et al., 2016; Hofvander et al., 2009; Lever & Geurts, 2016) but little is known about the health and social support services available for older autistic adults who may need continued support related to autistic traits, co-occurring mental health difficulties or daily living skills (Fortuna et al., 2016; Hirvikoski et al., 2016; Nicolaidis et al., 2014; Seltzer et al., 2004; and see Wright et al., 2016). The cumulative effect of long-term psychiatric co-existing conditions on cognitive functions and quality of life is largely unknown (Howlin & Moss, 2012; Howlin et al., 2015; Kats et al., 2013). In addition, the use of pharmacological treatments for co-existing conditions may further affect cognitive difficulties, such as memory (Joss et al., 2003). These factors pose particular challenges for autistic individuals as they grow older and may be exacerbated in the case of those individuals who are unable to live independently, since support from family members is likely to be reduced as parent caregivers themselves approach old age and end of life (Howlin et al., 2015). The implications of these factors are that many autistic adults will continue to require social care support across the lifespan (Parr, 2016; D'Astous et al., 2016; Howlin et al., 2013). Moreover, there is a growing awareness of the risk factors associated with multiple co-occurring complex health conditions and reduced life expectancy in

ASD, with potentially greater risks for individuals with impaired cognitive ability, including those with intellectual disabilities (ID) and epilepsy (Hirvikoski et al., 2016; Mouridsen et al., 2008). Consequently, as co-existing ID is an important factor in the context of premature death (Hirvikoski et al., 2016), future discussions are needed to determine how this might impact on the suggested old age boundary for aging and autism research.

2.1. Topic (1): Late life autistic traits and diagnosis of ASD

2.1.1. Key questions

Anecdotes from autistic self-advocates and practitioners confirmed that receiving a diagnosis of ASD in later life was a life changing event. Clinicians face multiple challenges in identifying the clinical features of autism in older adults, especially in the ways these may differ from the symptoms shown by a younger autistic individual and across a range of abilities. This can result in undiagnosed older adults failing to be identified by social or healthcare services (Brugha et al., 2011; Wright et al., 2016). The key question that emerged from this discussion topic was*: 'What does ASD look like in older individuals?*' This led to a secondary question: *'What questions should be asked to obtain appropriate background information about medical and developmental histories in older autistic adults in order to reach a reliable diagnosis?*'.

2.1.2. Challenges to addressing key question(s) and potential solutions

A major issue associated with research on aging and autism is the participation of the full spectrum of older autistic individuals. Some individuals may be unable to take part in research because of limited verbal or cognitive ability. Thus, a collaborative effort is needed by aging and autism researchers to ensure that individuals with limited verbal skills can be included in related research, and to adequately address the research priorities of autistic adults, their families and partners (Autistica, 2014; Pellicano, Dinsmore, & Charman, 2014a, Pellicano, Dinsmore, & Charman, 2014b; Warner et al., 2018; and see Autistica, 2018). In others, social isolation may result in their failing to be aware of requests for research participation; still others may have been undiagnosed or misdiagnosed in earlier life and therefore never have received an ASD diagnosis or may not present themselves as autistic. This raises further questions about the factors that prevent older adults from receiving a diagnosis. These may include 'masking' of symptoms, which seems particularly prevalent in women (Lai et al., 2015); the degree of co-existing conditions and autism-related symptoms, which may fall under the threshold of some diagnostic methods (Happé & Charlton, 2011; Roestorf, Gaigg, Williams & Bowler, 2018) and differences or strengths in cognitive abilities, educational attainment and social-cognitive function (2014, Howlin et al., 2013) that may enable or inhibit individuals from participation in research (Pellicano, Dinsmore, & Charman, 2014a, Pellicano, Dinsmore, & Charman, 2014b). SIG delegates also recommended that healthcare professionals need to be better informed of the age-related conditions and cognitive changes that can occur at various life stages, and how these changes may specifically affect older autistic adults.

2.2. Topic (2): Cognitive aging, decline, and dementia risk

2.2.1. Key questions to ask

The discussion centred around how researchers and clinicians could reach consensus on the cognitive assessment measures appropriate for older autistic adults, given wide differences in verbal and intellectual ability across the autism spectrum. The primary question that emerged from this discussion topic was: *'How do we define the core assessments of basic cognitive function, that are appropriate for autistic individuals across the spectrum of ability and across the lifespan?'* This led to a second question: *'How do these measures need to be adapted for reliable assessments that are age-appropriate, ability-specific and gender-relevant?'*.

The question of cultural relevance was raised in relation to race/ethnicity and how future assessments are adapted to culturally specific requirements. Regarding cultural diversity, it was suggested that shared insights from the international consortium of researchers may to some extent facilitate this knowledge. However, more work is needed to understand the scope of implications for the collection of sensitive personal information in line with data protection regulations of each country or region.

2.2.2. Challenges to address key question(s) and potential solutions

The challenges to reaching a consensus on measurement include identifying measures that are sensitive to age-related changes and can characterise the diagnostic differences on the autism spectrum whilst remaining appropriate for use with autistic individuals with and without co-existing ID. A key consideration includes methods of identifying ‘missing groups’ of individuals with autism who do not self-refer for research and who may be lost in the community. These may include, for example, individuals over the age of 21 years who are no longer in social or health-related services; those with co-existing ID; or older autistic individuals in residential care. Moreover, measures need to be robust to practice effects when tracking long-term outcomes in longitudinal research. Issues were also raised around appropriate referral to healthcare services for individuals with multiple physical and mental health conditions, and the need to establish a better understanding of the long-term effects of pharmacological treatments on cognitive decline in later life. It was recognised that insights from related work on the age-related cognitive changes in typical development (i.e. gerontology; Wright et al., 2016) and neuropsychological conditions (e.g. schizophrenia, Down’s syndrome, Parkinson’s; e.g. Coppus et al., 2006; Croen et al., 2015; Starkstein et al., 2015a; Starkstein et al., 2015b) may provide clues for what could be expected of aging in ASD. Such research is also important for identifying the potential risk factors for age-related cognitive impairments in later life and markers of cognitive decline associated with dementia (Coppus et al., 2006; Croen et al., 2015). The consensus was that there was a need for future work to define a (small) set of cognitive measures based mainly on current studies that already focus on cognitive aging (Lever

& Geurts, 2015; Powell et al., 2017; Roestorf & Bowler, 2016) and to draw from existing cognitive test sets in comparable fields of study (e.g. Charlton et al., 2009; Salthouse, 2011).

2.3. Topic (3): Treatment and care of older adults

2.3.1. Key questions

The discussion raised several issues relating to treatment pathways, care plans and the measurement of outcomes and the effect of co-existing conditions and long-term medication use on life course outcomes. The primary question that emerged from this discussion topic was: *'Which aspect(s) of physical and mental health intervention need to be addressed in ASD?'* and a related question: *'What are the effects of psychopharmacology and overuse of medication in autistic adults as they grow older?'*.

2.3.2. Challenges to address question(s) and potential solution(s)

The main challenges identified centred on the life expectancy of older autistic adults, increased risk of mental health problems and suicidality, and ASD-related co-existing conditions including epilepsy and ID which are related to cognitive and behavioural difficulties in adulthood (Howlin et al., 2014; Totsika et al., 2010). These issues highlight the need for effective health care management across the lifespan and raise the importance of understanding health-related effects on cognitive decline and increased risk of dementia in later life (Croen et al., 2015; and see Howlin & Moss, 2012; Michael, 2016). A suggested potential first step towards a solution was to make an inventory of all the interventions different countries have already successfully implemented so these can be adapted to fit local needs and health care systems.

2.4. Possible ways for the autism research community to address the issues raised in the SIG

Across the three discussion topics – later life diagnosis, cognitive function/decline in aging, and treatment and care of older adults, there was considerable overlap in the issues raised. Furthermore, two issues consistently featured as factors that are currently hindering the progress of research on aging and ASD. These issues are: (i) identification of the core questions and factors that need to be addressed on aging and ASD; and (ii) developing support for studies through collaboration and sharing of resources to achieve more effective research outcomes. Delegates agreed that a centralised database would better facilitate collaborations between researchers, practitioners, and the autism community. Such a database might include information about research protocols,

Table 1
Surveys results regarding the use of applied measures of ASD, background information and wellbeing in research with older autistic adults.

Domain	Measures	Survey responses	Countries[a]			
		$N_{studies}$ = 21	UK	NL	USA	AU
ASD traits	SRS-2	15	x		x	x
	AQ	9	x	x	x	
	SCQ	5	x		x	
	Other[1]	12	x	x	x	x
Background questions	Age (birth date)	22	x	x	x	x
	Gender (birth; identity)	22	x	x	x	x
	Age of diagnosis	20	x	x	x	x
	Living situation	19	x		x	x
	Employment status	19	x	x	x	x
	Medication use	19	x	x	x	x
	Education level	18	x	x	x	x
	Other diagnosis now or in the past	18	x	x	x	x
	Relationship status	15	x	x	x	x
	Other[2]	21	x	x	x	x
Well-being/Quality of Life	WHOQOL-BREF	15	x	x	x	x
	Other[3]	17	x	x	x	x

Notes: SRS-2: Social Responsiveness Scale–Second Edition (Constantino & Gruber, 2012; Constantino et al., 2003).
AQ: Autism Spectrum Quotient (Baron-Cohen et al., 2001).
SCQ: Social Communication Questionnaire (Rutter et al., 2003).
WHOQOL-BREF: World Health Organisation Quality of Life assessment–Short Form (WHOQOL Group, 1998).

[1] TAS-20 (Toronto Alexithymia Scale; Bagby et al., 1994); SSQ (Sensory Sensitivity Questionnaire; Minshew & Hobson, 2008); IRI (Interpersonal Reactivity Index; Davis, 1983).

[2] Impact of ASD diagnosis, alcohol/drug use, diagnoses in family members, history of dementia/Alzheimer's disease/Parkinson's disease in family members, current motor coordination issues, social network/support system (e.g. Croen et al., 2015).

[3] PWI-A (Personal Wellbeing Index–Adult version; Cummins, 2002); WEMBS (Warwick & Edinburgh Mental Well-Being Scale; Tennant et al., 2007); Quality of Life Questionnaire (Schalock & Keith, 1993).

[a] Respondents were from international research groups in the following countries (cities): UK (England: Cambridge; Newcastle; London); Netherlands (Amsterdam); USA (Virginia; Arizona; North Carolina; Pennsylvania; Wisconsin; California; Georgia; Utah; Washington State; Missouri); Australia (New South Wales; Victoria).

methodologies and recent research findings. A centralised resource could also facilitate an increase in research participation by making studies accessible to individuals across a range of abilities and locations. Such data pooling would need to comply with General Data Protection Regulations (GDPR; Information Commissioner's Office, 2018).

3. Post-SIG developments

The discussions from topics addressed during the first SIG raised several primary questions which were taken up at a special meeting, which was held at Newcastle University in November 2016. There, a subgroup of researchers, practitioners and autistic advocates convened to discuss further the theme of how to ensure the sharing of information and effective approaches to data collection, internationally (UK, Netherlands, USA, Australia). As a result, a survey was developed in order to gain a more complete view of the measures that are currently being used in research on old age in ASD. The survey encompassed three domains that emerged from the first SIG meeting, regarding: (i) the measurement of ASD traits in older adults; (ii) how to obtain comprehensive background developmental and medical history; and (iii) measuring wellbeing and quality of life across the lifespan. This survey was emailed to 78 individuals, who took part in the first SIG and the subsequent Newcastle meeting, including the six large cohort studies of older autistic adults (*d'arc initiative*, The Netherlands; *The Ageing with Autism Project*, United Kingdom; *Adult Autism Spectrum Cohort-UK*, United Kingdom; and ongoing research projects in UK, Australia and USA). The survey data formed the basis of discussions at the second SIG meeting, which was held at INSAR San Francisco, USA in May 2017. The meeting was attended by 53 delegates from 12 countries (UK, Netherlands, Denmark, Sweden, Norway, Italy, USA, Canada, Argentina, Australia, Taiwan, Korea). Subsequently, a further post-SIG survey was circulated to ensure that other researchers and practitioners who were collecting data on old age ASD could add information about the measures they used in their studies. The findings from these discussion groups and the two surveys are presented in Table 1, together with a breakdown of measures used in each region.

3.1. ASD traits in older adults

According to the survey responses, the most commonly used diagnostic screening measures were the Autism Quotient (AQ; Baron-Cohen et al., 2001; Hoekstra et al., 2008; Hoekstra et al., 2011) and the Social Responsiveness Scale–Second Edition (SRS-2; Constantino et al., 2003; Constantino & Gruber, 2012; and see Bölte et al., 2008; Bölte, 2012). Most studies included at least one of these measures (AQ $N_{studies} = 9$; SRS-2 $N_{studies} = 15$), while some studies included both measures ($N_{studies} = 6$). Other measures were used (see Table 1) but these were often specific to a single study. Both the AQ and SRS-2 have advantages and disadvantages. The AQ is freely available in a wide range of languages (e.g. Wakabayashi et al., 2006; Hoekstra et al., 2008). Although the SRS-2 is not free of charge, it is available in many languages (e.g. Bölte, 2012) and contains more detail on the social domain. However, it is not known how valid they are with an older population or how sensitive they are in measuring change across the life span. Recent evidence suggests that co-existing mental health conditions, such as anxiety, may mediate the sensitivity of the SRS-2 in reliably detecting autistic traits (South et al., 2017). One other measure, the Social Communication Questionnaire (SCQ; Rutter et al., 2003), was used in several studies ($N_{studies} = 5$). The SCQ is available in various languages but is not free of charge and presents similar challenges to the AQ and SRS-2. In addition, there are currently no ASD diagnostic tools or screening instruments that solve the problem of gathering information on early development (Wigham et al., 2018), or include normative data for those over 55 years of age. A potential solution regarding normative data for older adults is to share data across research groups, as is done in other areas of research (e.g. the Advanced Neuropsychological Diagnostics Infrastructure, ANDI; de Vent et al., 2016). We suggest a similar framework for pooled data to establish norms in ASD aging research, and as a potential approach to the management of data collection and reporting of results. Furthermore, there was a consensus that information is also needed from autistic adults themselves, about their lived experiences of the diagnostic process and the impact of their diagnosis.

3.2. Background information, diagnostic and medical history and cognitive assessment

Given that the primary interest was in aging, it was considered important to check the familial history of neurodegenerative disorders such as dementia and Parkinson's disease. Regarding the measures of ASD traits and other background information, discussions focusing on the reliance on self and/or other (i.e., caregiver) report are continuing. Many of the ongoing studies on aging and ASD (identified in the SIG discussions and survey responses), reported the inclusion of individuals who are cognitively able to complete self-report questionnaires. Consequently, several of the measures suggested above are less appropriate for those individuals with an intellectual disability.

In this discussion group, some cognitive measures were discussed which align with the previous SIG (2016) discussions. Overall, regarding the cognitive measures, there was less consensus between the research groups since the nature of cognitive assessment is typically driven by specific research aims. It was acknowledged that clear methodological differences exist between the types of cognitive assessments available in terms of the domains of measurement, and the administration methods (e.g. paper and pencil; computerised). Consequently, more work is needed to explore the utility of specific cognitive measures for use with older adults across both the autism spectrum and the range of intellectual ability usually found in the autistic population.

3.3. Well-being and quality of life

Regarding the measurement of well-being/quality of life most studies included the short form World Health Organisation Quality

of Life Assessment (WHOQOL-BREF, WHOQOL Group, 1998; Skevington et al., 2004; Mason et al., 2018; for an overview of well-being measures, see Ayres et al., 2017). A recent study also showed that this measure can be used successfully with autistic individuals although some items might be interpreted differently (McConachie et al., 2017). In order to overcome this difficulty, additional autism-specific items have been developed (McConachie et al., 2017). One of the benefits of the WHOQOL-BREF is that it has been used in a wide range of groups and is available free of charge in many languages. More importantly, it asks about the individual's satisfaction with life domains rather than making assumptions about the value of specific aspects of life. In this way, normative assumptions (e.g. about having a range of friends) are not hindering measuring the autistic perspective. As mentioned earlier, discussions about the appropriateness of measures have emphasised that questionnaires need to be ability- and age-range inclusive and sensitive to change across the lifespan. For example, the Personal Well-being Index (PWI; Cummins, 2002) has a separate version for individuals with an intellectual disability (Cummins & Lau, 2005). Moreover, the choice of which measures to use is guided by the research focus – is the measure being used for comparative purposes or for service-oriented purposes?

4. Discussion

Several outcomes have emerged in the two-year period encompassing the SIG and Newcastle meetings. First, the programme of meetings ensured that, for the first time, a broadly representative international group of researchers, practitioners, and autistic advocates came together to discuss on-going work on aging and ASD, which may not as yet be published. Whereas, previous literature has broadly conceptualised the gaps in knowledge with respect to aging and autism, this paper outlines the progress in research that is currently being undertaken around the world and the key issues associated with that and future work. Second, several key questions were identified through these discussions, which need to be addressed in future research. These were:

1 *What questions should be asked to obtain appropriate background information about medical and developmental histories in older autistic adults?*
2 *How do we define the core assessments of basic cognitive function that are appropriate for autistic individuals across the spectrum of ability and across the lifespan?*
3 *Which aspects of co-existing conditions and mental health intervention need to be addressed in ASD?*
4 *What are the effects of psychopharmacology and overuse of medication in autistic adults as they grow older?*

The third outcome was related to convergence about which measures can be easily accessed and administered with high reliability and specificity, particularly associated with diagnosis of older autistic adults, mental health and well-being, and quality of life. Although for measures used to establish a clinical picture of ASD no consensus was reached, the majority of studies include those listed in Table 1. By contrast, clear consensus topics emerged for the background questions, with the important qualification that the exact wording of these questions be formulated in collaboration with autistic adults. Regarding quality of life and well-being, the WHOQOL-BREF is used in so many different studies that a collaborative data-sharing project in this area seems, in the short-term, to be the most feasible.

A fourth outcome extended the discussions from the SIG meetings to further research workshops and symposia on aging and autism. These include a one-day research seminar, titled *'Ageing and Autism Spectrum Disorder: Life course changes, well-being and service needs in later life.'*, which was held at City, University of London, in July 2017. The seminar brought together autistic adults, professionals, clinicians, support services, researchers and charitable organisations (N = 70) to discuss quality of life, mental health and cognitive changes in later life and the strategies for supporting the most pressing needs of autistic adults as they grow older. A related meeting was held at Newcastle University, in September 2017, which set out to develop research priorities for aging and autism in relation to specific areas of physical and mental health and well-being (Warner et al., 2018). In addition, in Canada, in October 2017 there was an international meeting 'Aging in later life: A Think Tank on the Effects of Aging on the Autism Spectrum, which focused on similar topics as in the SIGs (i.e. understanding aging, supporting autistic adults, research methodologies and outcome measures; see Autism Canada, 2017).

Finally, through the networks established from this SIG we identified the cross-sectional and longitudinal work that is ongoing on aging and autism (Braden et al., 2017; Lever & Geurts, 2015; Powell et al., 2017; Roestorf, Howlin et al., 2018) and the potential for multi-site collaborations to take this work forward.

4.1. Implications and future directions

The topics raised in this SIG propose important directions for future research on aging and autism, through engagement with the autism community and collaborative research efforts. An important step, which is already undertaken in some countries, is to include representatives of the autistic community who contribute to research design and interpretation and dissemination of findings. A key aim for research partnerships is better to understand the challenges associated with assessment of older adults. Future work should include a systematic review of the measures that are being used in aging ASD research. This knowledge would inform the development of better diagnostic approaches to later life assessments, earlier referral for diagnosis, and establishing post-diagnostic support pathways for autistic adults across the adult life course. Indeed, some of these issues have been captured as priorities for aging and autism research in a recent report by Autistica (2018), whilst the focus of these topics seems aligned with emerging research from recent studies on gender-differences in cognitive measures (Mandy & Lai, 2017), diagnostic differences in older age (Lever & Geurts, 2018; Powell et al., 2017; Roestorf, Gaigg et al., 2018), and ASD-relevant measures of quality of life (Mason et al.,

2018; McConachie et al., 2017; Moss et al., 2017).

Future research efforts encompassing multi-site studies that use a combination of cross-sectional and longitudinal methods would enhance research knowledge in: (a) our understanding of typical and atypical aging in ASD; and (b) the relative effectiveness of intervention approaches for different sub-groups of older autistic adults. Longitudinal follow-up studies of autistic adults across the lifespan and programmatic research that involves large scale data collections and analysis would drive more rapid progress in our understanding of the issues raised in this paper. Furthermore, combined research efforts and improved methodological approaches would potentially inform the supports and interventions that enable autistic adults to lead fulfilling and rewarding lives.

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The Author(s) declare(s) that there is no conflict of interest with respect to the research, authorship, and/or publication of this article.

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