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## **UNCERTAIN FUTURES: REPORTING THE EXPERIENCES AND WORRIES OF AUTISTIC ADULTS AND POSSIBLE IMPLICATIONS FOR SOCIAL WORK PRACTICE**

### **Abstract**

Little research has focused on autism in adulthood. Little is *known* about the concerns autistic adults may have, particularly about their futures, to inform support and social work practice. The objective of this study was to explore the nature of the worries autistic adults have about their futures. Four focus groups were conducted with autistic adults (n=23), where worries about the next 5 years and next 20 years were discussed. Participants also discussed what might be helpful and unhelpful to support them in preparing for the future. Transcripts were analysed using thematic analysis. The overarching theme emerging from the study concerned worries relating to *uncertainty* about what the future may hold. The main elements of this were *worries relating to support needs, the impact of an autism diagnosis and knowledge of autism from others*. Subordinate themes included *worries about relationships with others, living circumstances and health*. These data demonstrate that current support is perceived as insufficient. The implications for social work practice include autism awareness and focused practice-based support for autistic adults. The lack of autism specific knowledge amongst professionals and the general public was identified by research participants as a barrier in terms of accessing employment and healthcare.

### **Key Words**

Adults, autism, concerns, personalisation social work.

## Background

This article is a collaboration between two English universities to report the findings of a study which explored the experiences and worries of autistic adults, and consider implications for social work practice. To date research on autism has focused predominantly on children, and the paucity of adult-focussed research means that little is known about the experience of autistic adults. Internationally, Kamio *et al.* (2013) in their Japanese study compared the psychosocial quality of life of autistic adults with the typically developing population and found it to be poorer. Specific to employment, Graetz (2010) found evidence of poor employment opportunities for young autistic adults and Roux *et al.* (2013) identify the need for further research to determine strategies to improve employment outcomes for young adults with different disabilities. Services for autistic adults are fewer than those available for children (Graetz, 2010; Shattuck *et al.*, 2012) while Howlin *et al.* (2004) suggest that many autistic people may still be heavily dependent on familial support once they reach adulthood. The small, existing body of research investigating autistic adults' experiences identifies specific, on-going needs which may require social work support and access to adult care services throughout the life course. In reality, social work can assume to interact with autistic adults through both specialist services, which focus on supporting autistic adults and children, and through general adult and child care services as both service users and parents / carers, where normative discourses of parenting and caring may adversely affect autistic adults (Wade *et al.*, 2008).

Society assumes that as children progress towards adulthood, they become more autonomous and less vulnerable (Heslop and Meredith, 2019); however for some autistic people, this is not the case. For many young autistic people, their educational institution will

have been central to meeting their needs and providing support, but beyond school age, the level and immediacy of support changes significantly. The transition from child to adult social care services brings an increasing emphasis on independence and autonomy which can result in autistic people experiencing variable and reduced support. Perceptions of declining access to services and support as autistic people reach adulthood is a worry for many families (Blacher *et al.*, 2010). Preece and Jordan (2007), in their English study of social work with disabled children, identified practice confusion about key characteristics of autism, inaccuracy about intervention approaches and generally a too positive attitude about the ability for generic services to support families with an autistic child. In a study by Little and Clark (2006), parents of autistic children stated that their biggest concerns related to uncertainty regarding their child's adult life, while Browning *et al.* (2009) found autistic adults reported significant worries about their own futures. Social work is concerned with relationships, those practice-based ones with the people worked with as well as understanding clients' own social, support and familial networks (Heslop *et al.*, 2018 in press). Given the proliferation of published material by autistic authors (see for example Jackson, 2002; Mitchell, 2005; Healey, 2011; Grandin, 2015), the emerging critical autism studies (Wood *et al.*, 2018) and the wealth of internet blogs by autistic adults, it seems incongruous that to date the majority of research that has been undertaken has focused on the perspectives of parents and carers. Writing as an autistic adult, Michael (2016) discusses the unease about an uncertain future experienced by all too many autistic adults, asking:

“Who will look after me if I need care? How will I survive a long stay in a hospital? Will a care home pressure me to join in social activities because that is what neurotypical people want? How will I be judged by my peer residents, if I don't make small-talk or

gossip? If sensory overload or anxiety leads to a meltdown, will I be shunted straight to the dementia ward?"

The impression is that autistic people experience uncertainty about their future concerning any health, care and social needs. The National Autistic Society (2016) report "Getting on? Growing older with autism" illustrates the importance of providing information on autism and ageing, particularly in relation to changes in health, preparing for the future, support and services for autistic adults. The Autistica (2016) research strategy 2015-20 ("Autism: Top 10 Research Priorities") identifies the need for future research to focus on adulthood and ageing, with a priority being to find "effective ways to support or provide social care for autistic adults". Atkin and Tozer (2014) suggest that professionals can learn to work more effectively with autistic people by appreciating how family obligations are (re)negotiated through the life course, concluding that practitioners can engage with complex and dynamic family life through personalised approaches, which recognise the role of siblings in the lives of autistic people.

Whilst the focus of contemporary UK social work is generally on safeguarding, adult care focus also incorporates policies of personalisation, choice and independence (Stevens *et al.*, 2018). Since 2007, successive UK governments have pursued a social care policy of personalisation, ostensibly premised on principles of choice and autonomy (Atkin and Tozer, 2014). There are positive examples of the influence of personalisation (see for instance Gollins *et al.*, 2016 on the Think Local, Act Personal initiative). However, a large number of authors suggest that personalisation has been used to facilitate a shift towards marketisation and reduced provision (Ferguson, 2007; Scourfield, 2007; Houston, 2010; Lymberry, 2010) and Mladenov *et al.* (2015) argue that this marketisation has overridden the social justice aspect of

personalisation. Lymberry (2010) identifies that people often need to access social support at the point of crisis, when consumerist models of choice may be overwhelming and challenging to navigate. Needham (2014) argues that pursuing policies of personalisation during a climate of austerity has left people responsible for arranging their own care at a time when local authority services are withdrawn.

In recognition of the specific needs of autistic adults, The Autism Act 2009 placed a statutory duty on the Secretary of State to create and publish a strategy for meeting the needs of autistic adults in England, and to keep this strategy under review. The strategy was most recently reviewed in 2014, and published as *Think autism. Fulfilling and rewarding lives, the strategy for adults with autism in England: an update* (Department of Health, 2014). Alongside the *Autism Strategy*, the Department of Health (2015b) issued *statutory guidance for local authorities and NHS organisations to support implementation of the adult autism strategy* which states that basic autism training should be available for *all* staff working in health and social care, quality autism awareness training should be included in public service's general equality and diversity training programmes and specialist training should be provided to those in roles that have a direct impact on autistic adults' access to services, such as social workers undertaking needs assessments. The Care Act 2014 statutory guidance (Department of Health and Social Care, 2018) directs that assessment of any adult's needs must be personalised, strengths-based and, where appropriate, adopt a whole family approach. It makes reference to autistic adults throughout, emphasising the need for assessors to have appropriate knowledge and skills, and using case studies to highlight how the care and support needs of autistic adults should be assessed and addressed. Supported by Lyn Romero, the Chief Social Worker for adults, the Department of Health (2015a) published a manual for good social work

practice supporting adults with autism. This manual provides guidance and resources for social workers undertaking assessments and emphasises the individual nature of autism, the importance of preparation when working with autistic adults, professional self-awareness, need for clear and effective communication and how uncertainty affects autistic adults. However, Yo Dunn (an autistic adult, writer and trainer) argues, that despite legislation and guidance, social work knowledge of autism must improve. Dunn suggests social work training programmes do not equip social workers with knowledge of autism and many non-specialist social workers may have to rely on their own personal knowledge and experiences of autism (Dunn, 2015).

In the UK, autism and the experiences of autistic people are clearly recognised through legislation, policies and procedures. Specifically to social work, Haney and Cullen (2017) suggest autism is so relevant to practice that specialist teaching should be provided during qualifying training programmes. Investigating the experiences of autistic women in North America, Haney and Cullen identify several considerations for social work practice when working with autistic women, which are: how to help people navigate through social challenges; the need to be mindful that autistic women may also experience other mental health concerns; and to be sensitive about autism when selecting therapeutic approaches. A further study by Haney and Cullen (2018) explored social workers' knowledge and attitudes towards autism in New Jersey, and found the potential for strengths-based approaches to social work practice arising from increasing recognition of neurodiversity:

“The growing movement toward valuing autism as a form of neurodiversity creates opportunities for social workers to help empower individuals on the autism spectrum to advocate for themselves and to develop social and relationship skills that meet their

needs as they define them, rather than as service providers define them.” (Haney and Cullen, 2018:217)

It appears that policies and procedures promote an autism aware environment and social work practice can benefit from understanding autism and autistic individuals. However, Pellicano *et al.* (2014) highlight the need for the autism community to have a greater involvement in research to ensure their experiences and voices are being heard. Notwithstanding positive legal and policy developments, it seems sensible for adult social care services and social work practice to be informed by the perspectives of autistic adults if practitioners are to develop a greater understanding of the issues they face and consider how to construct and provide appropriate support. The study we present below, therefore, aimed to give voice to autistic adults by directly investigating with them the nature of their concerns for their futures, and identifying the type of support and services that they believe would be helpful.

## **Conducting the research**

Our research explored the perspectives of autistic adults on their experiences and worries. Whilst we recognise this is a broad question, we felt it appropriate due to the current lack of available research evidence on the perspectives of autistic adults. A qualitative methodology was employed, using focus groups to facilitate discussion, sharing of themes, group identity and the expression of a multiplicity of views and experiences (Morgan and Kreuger, 1993; Morgan, 1997; Porta, 2014). Porta (2014) concludes that using focus groups as a research methodology is particularly interesting when seeking to identify themes and collective identities. Data were gathered over four focus groups conducted with autistic adults (n=23), two in the North of England (n=11) and two in Scotland (n=12). Participants were recruited

directly through autism charities and support groups (National Autistic Society & Scottish Autism), see Table 1, below, for information on participants. A favourable ethical opinion was provided by Newcastle University, Faculty of Medical Sciences, participants provided written consent to participate, and for us to use quotes for publication, online and in print and in perpetuity, and guidelines were discussed with participants, which included confidentiality and that their participation in the group was voluntary. All sessions were audio recorded to enable transcription, coding and analysis.

Insert Table 1 about here

The focus group sessions included three distinct activities as outlined below in Table 2.

**Insert table 2 about here**

## **Data analysis**

The audio files from the focus groups were fully transcribed and the resulting transcripts were analysed using thematic analysis (Braun and Clarke, 2006). Thematic analysis is very much applicable to research through focus groups, as it is theoretically flexible and can be used to examine conversations and discussions without having to adhere to a particular theory of language, discourse or focus. Thematic analysis has successfully been applied in focus group research (Porta, 2014), on student perceptions of nursing programmes (McDonald *et al.*, 2018), young mothers' experiences of parental support (Mills *et al.*, 2013) and perceptions of professionals involved in child abuse interviews (Powell *et al.*, 2011). Porta (2014) and Stewart (2007) highlight and detail the role of coding in analysing data from focus groups. The process of coding and analysis took time (see Table 3); themes were subjected to rigorous cross-referencing and re-analysis to ascertain context and priority as themes were discussed with co-facilitators to ensure themes were agreed.

Insert table 3 about here

## Research findings

The focus groups presented the research team with rich and in-depth data which were manually coded and analysed. The research team identified and agreed six, broad themes: uncertainty about the future, support, diagnosis, living circumstances, relationships, and health. A thematic map was generated to graphically represent and summarise the research themes (Stewart, 2007) and is a visual representation of the themes relating to the worries and perspectives of autistic adults who took part in the study (see Figure 1).

Insert Fig One about here.

The themes on worries and experiences illustrated in the thematic map are expanded in the next section where each theme is discussed in more detail and illustrated through the words spoken during the focus groups.

### 1. Uncertainty about the future

*Uncertainty* was identified as an overarching theme, which was embedded in more specific themes and played a role throughout discussions during the focus groups. The main concerns related to not knowing, or more general, non-specific worries about what may, or may not happen in the future, for instance: *“You just don’t know what’s in front of you and that alone is quite worrying”* and whether individuals will be able to cope with any change or periods of unpredictability. This *not knowing* was reported as distressing, and uncertainty was related both to participants’ previous negative experiences, and their optimism or pessimism about their future.

## 2. Support

Current research highlights how support reduces in adulthood, with many adults receiving most of their support from family members, rather than external social care agencies (Engström *et al.*, 2003; Minnes and Woodford, 2005). As family members' own circumstances change, the support they are able to provide may change or diminish (Haney and Cullen, 2017). One comment during a focus group was: *"It's the uncertainty of it all, because nobody can see into the future, and it's a fear I think"*. In light of this, it was unsurprising that worries regarding the lack of support in the future was expressed by a number of participants, making it one of the most frequently endorsed themes, for instance: *"The support being there [is a worry]. Will the support still be there for us? And the support actually understanding"* and *"What happens when I'm older and I need more support?"* Familiarity and fears about having to seek a professional's support is exemplified when:

*"It's very hard to share your ASD difficulties with someone else because you don't know where it's going to go"*.

Another concern was about not being believed or treated seriously by professionals, because: *"I'm terrified of not getting believed, and not getting listened to"*. It is concerning, considering all participants were diagnosed on the autism spectrum, that seeking support about autism causes anxiety too:

*"I dread having to come into contact with any sort of medical thing to do with autism...or mental health because they're just a nightmare, they just make you much worse"*.

The research data acutely highlight how support and access to suitable support is a complex, problematic and concerning area for autistic adults.

## 3. Diagnosis

The next most frequently discussed theme was associated with the impact of diagnosis, which included sub-themes related to other people's knowledge of autism and stigma/vulnerability, one person commented:

*"It's very frustrating with the lack of awareness that's out there" and "I was bullied when I was younger and people still bully me... that's my main worry, people taking advantage of me in my life, in jobs and people... but that's just my main worry in life, is just people taking the mickey and advantage of you. It's not nice".*

While a diagnosis may well enable self-awareness, it nevertheless raises the question as to whether or not to share the diagnosis with others, when:

*"I worry about whether to tell people or not [about diagnosis]...So do I explain myself so that explains why I don't want to do these things or will that isolate me even more?"*

This theme related to the impact these difficulties or barriers might have in the future, and how they would influence support received or access to opportunities either personally or professionally.

#### **4. Living circumstances**

The broad theme of living circumstances incorporated several sub-themes involving a range of external factors that could impact on future wellbeing. These included work, finances, residence, independence and government policy. Uncertainty about living arrangements and possible change loomed large. This concern about change in living circumstances and the possible impact on personal and emotional wellbeing is expressed by the fact that:

*"The maintenance [of the house], scares the life out of me. I will do things myself and not to the standard that they need to be done because I can't face getting someone in...I have been demented on a daily basis by the fact of someone coming into my*

*home...I had to get sleeping tablets to cope with it because it wasn't something I could fix myself".*

Financial implications and possible change in income through aging was recognised as a concern. There were concerns about the difficulties of finding and fitting in with or sustaining employment:

*"that always worries me because even if I find a job that's perfect and makes all the adjustments, that's never going to be, that's not set in stone".*

These worries about living circumstances appear to reflect the concerns experienced by the general community, however, uncertainty and concerns about stigma and vulnerability appear to disproportionately affect autistic adults.

## **5. Relationships**

Within this broad theme, sub-themes included concerns relating to a range of relationships - romantic, social, familial and professional - as well as loss and isolation. When involved in a romantic / partnering relationship one respondent explained that:

*"My partner is neurotypical and this is a big problem. He says the thought of living with no plan is fun, I think that is mental. The whole, spontaneity is a virtue, no it's not".*

Partnering relationships are complex, and beyond romantic attraction they involve a wide range of negotiation skills to agree and determine relationship roles. Financial security - or at least a degree of certainty - is important to most people. The difficulties which we have already identified that autistic adults can experience around employment may increase the likelihood of financial dependence on others:

*“My partner is older than me and I’m financially dependent on him – how will we manage as he gets older and winds down?”*

Beyond partnering relationships, participants had concerns about social relationships, and more specifically, personal communication and negotiation skills when meeting new people.

Two participants had the following exchange:

*With friends, I’ve always struggled... I’m okay with my close friends, but bring in someone else and I’ve been called arrogant, aloof, ignorant, you name it.*

***That sounds familiar.***

*And then I don’t want to meet people [in the future], but I do want to meet people but I’m not arrogant, I just don’t know how to start a conversation*

***Yes.***

*And, then I really struggle and isolate myself even more because I don’t want to mix with people because I don’t know what to say*

Family and long-standing friends are understandably very important when:

*“I worry about struggling to maintain a social circle as my parents, family and friends pass away or move on”.*

Invariably family, particularly parental, relationships alter over times as people age, and:

*“what will happen to support for people who are ASD and who are also parents?”*

Relationships take many diverse forms and the concerns expressed by research participants are familiar to many people. However, autism adds another layer of complexity, with

individuals aware of differences in their social abilities which may make it difficult to form new relationships, leaving them concerned about possible future isolation.

## **6. Health**

There were multiple health-related concerns, which included changes in physical and mental health, as well as the health of loved ones and access to healthcare. Mental health was a concern for a number of respondents:

*“I’ve had quite a lot of problems with depression and anxiety disorders, and it’s a big worry, I’m sort of stable at the moment but it’s a big worry about whether I’ll be able to maintain that”.*

Another respondent related mental health problems to autism and bemoaned the lack of timely and accessible support. Participants also recognised the impact supporting mental health needs has on themselves and their loved ones, and worried about the future prospect of deteriorating mental health, for instance: *“How am I going to deal with my autism, anxiety and depression – and my husband’s”?* Another concern is reflected by the comment,

*“I worry a lot about dementia...constantly worrying about how that’s going to impact on the kids and what happens if anything happens to us, then there’s no family”.*

Health concerns related not only to the participants but others in their lives too and alongside health concerns was the expression that there are insufficient accessible services.

## **Suggestions for support services**

The third and final focus group activity was to discuss what was unhelpful and what they felt would be helpful.

## **What wouldn't be helpful?**

The negative impact of change and uncertainty was again highlighted: *“What's not helpful is not having the consistency, as well with support”*. Diagnostic overshadowing (Mason and Scior, 2004), stigma, discriminatory, stereotypical or homogenising attitudes towards autism were clearly unhelpful:

*“Being completely dismissed and dis-acknowledged of everything that you've said because you have autism and you couldn't possibly be right” and “A blanket approach to an individual thing (is not helpful)”*.

A general lack of awareness, or even unknowing ignorance about what autism, in health and social care services is problematic, and may present a barrier which results in support disproportionately falling upon family and friends:

*I think actually a lot of the time it does fall on your personal support, your parents, your partner, it always falls on them, overwhelmingly falls on them because there's huge gaps in service provision and that can cause huge problems in and of itself.*

Participants in this study reported that that they would value support services which are timely and accessible to adults with autism, incorporate practitioners who have knowledge and awareness of autism, and take a personalised approach.

## **What might help?**

In considering what might help to manage some of the worries identified in the earlier part of the focus group discussion, participants suggested that having access to individuals who are knowledgeable about autism would be helpful in allaying concerns about the future:

*Something that I find does help is that sometimes you need somebody a 3<sup>rd</sup> person to objectively sit with you and work things into a structure and break things down into*

*steps, that is impossible to do yourself when you're worrying about something and that support just isn't there largely.*

The notion of practical, as well as knowledgeable, support is important, when:

*"I think practical help, like somebody actually sitting you down with all of the different things in your life, like an advocacy type of thing but more hands on".*

The need for support also extends to emotional-based assistance: *"I find therapy very helpful"*. It appears that the participants valued practical, knowledgeable and emotional support.

## **Discussion and implications for practice**

This is one of the first studies to directly explore with autistic adults the worries and concerns they have about their futures, and hear from them about what might be unhelpful and helpful in addressing those concerns. The findings from this study present specific concerns and implications for social work practice and social care service provision. The *Autism Strategy* (Department of Health, 2014) acknowledges the paucity of attention afforded to older autistic adults. The Strategy recognises the higher levels of need experienced by many autistic adults during the transition from childhood to adulthood and that many autistic adults experience more mental health needs than the general population. Concurrently, autistic people have increased difficulties in trying to access general and social care services due to the way these services are run (Department of Health, 2014).

The dominant, overarching theme which emerged from the data collected was pervasive worry related to *uncertainty*. The findings suggest that the specific uncertainties experienced by autistic people are over and above those that anyone may experience about their future,

and this, coupled with additional difficulties autistic people have in tolerating uncertainty, appears to be a risk factor for the development of further worries. Unfortunately, in a rapidly changing world and despite - perhaps *because of* - the increased availability of information, we cannot always be fully informed about or prepared for every eventuality. An element of uncertainty is an inevitable aspect of the human condition. It is therefore imperative that alongside changes in practice which may minimise uncertainty, such as improved communication and access to services, support is also provided to help autistic people to develop strategies to better tolerate the remaining and unavoidable uncertainty about the future. Research has identified intolerance of uncertainty (IU) as a significant mechanism in the development and maintenance of anxiety in autistic children (Boulter *et al.*, 2014; Wigham *et al.*, 2015; Hodgson *et al.*, 2017) (Authors' own, 2017), and there is a need for further research to explore the role of IU in the development of anxiety in autistic adults. Work with autistic children and adults indicates reductions in IU following Cognitive Behaviour Therapy interventions is feasible (Author's own, 2016; Authors' own, 2018 (in press)).

In addition to pervasive concerns regarding uncertainty, participants identified a number of specific areas of their future lives that were a major source of concern, including worries about their own and their families' health, access to services, employment and changes to relationships. Whilst these are issues that the majority of the population will worry about at some time in their lives, what is compelling about these data is the insights the participants shared about the interaction between these concerns and the presence of an autism diagnosis. These interactions are at two levels: firstly, the ways in which others may respond or react to those who are autistic lead to greater concerns, and secondly, the vulnerabilities

often associated with being autistic may impact on the ability to manage changes in circumstances and negotiate systems that may be relatively more transparent to others. This highlights the additional difficulties an autistic adult might face compared to the general population, which may maintain and enhance concerns about the future and accessibility to social care services.

The most endorsed concerns relating to *uncertainty* were *support* and *autism diagnosis*, which clearly interacted with the additional themes of *living circumstances*, *relationships with others* and *health*. These final three themes encompassed a range of worries experienced by autistic adults. From their discussions it was clear that employment, finances and residence were distinct concerns relating to future security, stability and success. Difficulties in relationships with others, and the security or longevity of these relationships was of concern, particularly in terms of the likelihood that family support would reduce as relatives' health deteriorated in older age. Health of self and others was a concern in relation to access to healthcare and the uncertainty of ill health or death of loved ones. Mental health was a concern particularly in relation to appropriate support for autistic adults when they appear to be confused about the means to access support.

Our findings highlight that the future-related concerns of autistic adults are multi-faceted and complex. Participants emphasised the importance of appropriate, accessible support, and given their anxieties, a relational connection with a practitioner will be an important factor in accessing this support. In particular, they illustrated that this would be best facilitated by individuals who had a good knowledge of autism and for social workers developing a relational connection with an autistic person will help to discover what the person needs. These findings mirror themes identified by Haney and Cullen (2017, 2018) in relation to social

work practice in North America. The indications from this research are that despite legislative support and the availability of practice guidance (Department of Health, 2015a, b; Department of Health and Social Care, 2018) the concerns by autistic adults need to be more fully understood by practitioners. Changes in services and support were seen as necessary to fully address these concerns. On a practical level, changes could include increased understanding of autism amongst social workers, as well as an appreciation of the diversity amongst the autistic community. Methods to increase knowledge could take a number of forms, but would be most valuable if developed and facilitated by autistic adults, in order to accurately explain the difficulties they may face and appropriate ways to structure and provide support.

The frequency of reported worries and concerns related to emotional, physical and mental health have clear implications for adult social work practice. While the data do not reflect in detail on difficulties or worries relating to intimacy/partnering/sexual needs it can be assumed these are as important, and potentially troublesome, for autistic adults as they are for the general population and in particular for younger adults. Given the prevalence of autism, social workers can assume to work with autistic adults even when not working in a specialist autism service. Social isolation, discrimination, and intimidation, may increase vulnerability and give rise to safeguarding concerns. Working collaboratively with autistic adults to identify their concerns both in the present, and for the future, can promote user - rather than provider - led support, based on personal perceptions of need and preferences. At an individual level, relationship-based practice with autistic adults to assess their needs, autism aware support to harness the potential of personal budgets and direct payments can offer creative possibilities of self-directed support. At a service level, involving autistic adults

in designing provision and training social care professionals would facilitate support that is much more suitable to the specific needs and concerns of autistic adults. Participants in our study also identified that a designated support service, able to provide autism aware advice and guidance on a range of issues (from relationships, to finances, health, housing and employment) would be helpful. The provision of timely and accessible support could potentially avoid the sometimes overwhelming challenges of navigating what can be a bewildering myriad of differing procedures and structures amongst various service providers.

## **Limitations**

Some limitations of this research include that the sample of adults who participated represent a small proportion of the autism community. While this sample is relatively small, it does allow an insight into the lived experiences of autistic adults, enabling us to share this knowledge and information in order to better support the adult autism community. Some participants expressed the presence of a learning difficulty, however those with more severe learning disabilities are not represented. Another limitation is that facilitators guided the topics for discussion, based on evidence from previous research. As a possible consequence of using focus groups with strangers, intimacy, partnering and sexuality are not explored in depth. Finally, identified themes were validated by the facilitators of the focus groups, but it was not possible to check these directly with the participants.

## **Conclusion**

We concur with the findings of Pellicano *et al.* (2014), which highlight the need for research focussing on areas which can impact on autistic adults' day-to-day living. Our findings also highlight the need for research relating to social work practice with autistic adults, the

putative reasons for possible lack of engagement of support services, family dynamics and how these relate to social care referrals and social work input. While experiencing legislative and policy advances (for instance due to the *Autism Strategy, 2014* and *The Care Act, 2014*), future research is needed to improve understanding of the support needs of autistic adults, and the extent and nature of basic and specialist autism training needs, and to consider how to increase the suitability and efficacy of responses from social and health care professionals. Within the current political context of funding limitations and austerity, given the prevalence of autism (which may be higher than current official UK statistics suggest), the needs of autistic adults and legislative requirements, this research would help to identify appropriate levels of autism training for practitioners. In the sense that uncertainty cannot be removed from the human experience, its existence can be predicted, if not its specific manifestation. We therefore propose that research with autistic adults needs to be conducted in two, interrelated strands. Firstly, directly exploring options for provision of autism-aware, timely, accessible, practical support (related to issues such as housing, employment, finances and access to social care services etc.) in order to reduce uncertainty to the extent that is possible; and secondly, exploring strategies which may increase tolerance of inevitable uncertainty associated with the future. Concurrently, research with social workers, in both specialist and more general social care services, is needed to explore and understand their awareness of autism and the needs of autistic adults throughout the life course, identifying best practice and considering how this can be extended. The combination of these approaches may go some way towards enabling autistic adults to live life to the fullest, both in the present and in the future, and to ensure that social care services meet both their needs, and legislative and policy requirements.

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