Introduction
Anxiety related to uncertainty about the future is a very real and significant concern for many individuals on the autism spectrum and their families. Many parents and carers will have increased concerns about what the future will hold for the individual on the autism spectrum they support or care for, once they die or are no longer able to provide the level of support previously given.

Difficulty tolerating uncertainty about the future has been identified as a major contributor to the development and maintenance of anxiety disorders. Previous research has found that many family members of adults on the autism spectrum experience mental health difficulties and individuals on the autism spectrum are also more likely to experience difficulties with anxiety. The aims of this research were to find out more about the nature of the worries adults on the autism spectrum and their family members might have about the future in order to identify priorities for future research and inform service provision.

Why is it important to understand the lives of adults on the autism spectrum?
Currently, the majority of autism research focuses on the early years and childhood. There is very little research involving adults on the autism spectrum, while there is an increasing population of ageing adults on the autism spectrum.

It is therefore imperative to find out how we may be able to provide appropriate support to increase wellbeing.

What did we do?
- **Focus Groups**—Four Focus Groups were carried out with 23 adults on the autism spectrum. During the focus groups we discussed concerns they had about their future. Participants also identified things they thought might be helpful and unhelpful to help them prepare for the future.
- **Online Survey**—120 Family members and relatives of adults on the autism spectrum took part in an online survey. The survey explored the nature of concerns those proving support to adults on the spectrum have about their relatives’ future.
Focus Groups - what did we find?

Thematic analysis was carried out on the transcripts from the focus groups, this was completed by two independent researchers to prevent bias. Our analysis identified that uncertainty about the future was the dominant worry for participants. A number of sub themes were also found relating to concerns about ongoing access to appropriate support, future access to an environment that is suitable for autistic adults, ongoing concerns about the impact of diagnosis, the changing nature of health and relationships.

What might help autistic adults to be better prepared for the future?

• Adults on the autism spectrum stated that **APPROPRIATE SUPPORT** was most important in helping them to manage their worries about the future — including support from family, friends and professionals. Adults stated this support was best when it was Autism Specific, and individualized.

• Adults also stated a clear supported structure to help with problem solving in relation to future concerns and challenges would be very helpful. This would include breaking issues down into manageable steps and tackling challenges step-by-step.

• Some adults had previously found participation in therapy extremely helpful and suggested that ongoing access to therapy to deal specifically with future concerns may be useful.

• Having an outlet for concerns such as writing things down or confiding in supportive others was also identified as a process that would be helpful in alleviating future related anxiety.

What is unhelpful?

Adults stated no support or inconsistent support is the most unhelpful thing and that they would want support in place for their future. They related that in their opinion, the following aspects were unhelpful in tackling any future worries or concerns: others stigmatizing autism—being judged, lack of autism awareness and knowledge from others, if support is too rigid this can also be difficult. Adults also related that if their concerns are minimized or not taken seriously this can also be unhelpful.

What would be useful for the future?

Most adults stated that a **DROP-IN service for support in relation to planning for the future** would be useful.

They also stated a better **UNDERSTANDING of autism from others** would be helpful, so that future related concern could be addressed appropriately.

Adults stated that meeting with a social group of peers would also be helpful in providing support and advice.
Online Survey—what did we find?

Information about Respondents:

120 family members, relatives and carer’s responded to the survey.

The average age of respondents was 54 and they were mainly mothers (72%) of adults on the spectrum. The majority were married (78%) and employed full-time (38%).

Information about the autistic adult receiving support:

Most respondents reported the adults they were supporting was male (71%), with an average age of 28, diagnosed with Asperger’s Syndrome (37%) or Autism Spectrum Disorder (30%). 41% also had a learning difficulty and 43% also had challenging behaviours. 83% of adults on the spectrum were reported to have additional anxiety and 37% experienced depression.

Further findings of those supporting adults on the spectrum:

36% of respondents didn’t know who would care for their relative on the autism spectrum in the future., whereas 29% stated this support would come from another family member.

Respondents who reported that the individual they were supporting also had anxiety, scored significantly higher on the worry, anxiety, stress and depression scales themselves.

44% of respondents had begun to plan for their relative’s future, whereas 28% had not started planning for their future due to not knowing where to start.

Mental Wellbeing of Respondents:

We asked those supporting an adults on the autism spectrum to tell us a little but about their own mental health and wellbeing.

Relatives self-reported on average, moderate levels of worry (47%) and anxiety (37%), mild levels of depression (23%) and stress (21%) and high levels of intolerance of uncertainty (28%). Those (64%) who reported their autistic relative was “not at all” prepared for the future had significantly higher levels of worry, anxiety, stress and lower quality of life than those who reported some degree of preparation.

Main Findings from those supporting adults on the spectrum:

1. Whether the adult they support will be happy in the future, 72% worried weekly.

2. Who will look after/ care for the adult they support when they no longer can, 58% worried weekly.

3. Where the adult they support will live, 53% worried weekly.

4. 83% reported that the adult they support has difficulties with anxiety.

5. 64% reported the adult they support was “not at all prepared” for the future.

6. 77% reported they worried at least weekly that needs of the adult they support would not be met and they would have a poor quality of life.
What next?

- This research provides important insight into the lives of adults on the autism spectrum and those supporting them.

- It highlights that concerns relating to the future are a significant cause for concern, and major cause of stress and anxiety for adults on the spectrum and their families.

- It also indicates that the majority of adults do not feel adequately prepared for a future where their current support structures are no longer available.

- It provides clear evidence that mental health difficulties such as anxiety and depression are very common amongst adults on the spectrum and those providing support to them and that feeling unprepared for the future is a major factor which contributes to these mental health difficulties and impacts negatively on quality of life.

Implications for service providers

The adults on the spectrum we have worked with and their supporters have provided us with some clear advice about the ways in which services could be structured to alleviate some of the concerns and worries experience about the future. This includes:

- Consistent access to ‘drop-in’ services which can provide information and advice about future planning

- Access to support from peers on the spectrum who have similar experiences, in the form of support groups

- For some access to therapeutic services to specifically address future related anxiety

- Timely and structured planning for adults on the spectrum and family members to increase feelings of preparedness

- Financial Support to ensure future stability

- Thorough knowledge of autism and ability to provide person-centred support from staff in support services

Future Research

Future research should investigate whether there are strategies or support that can be implemented which will better support adults on the autism spectrum and their families across the lifespan.