



## **Investigating optometric and orthoptic conditions in autistic adults: Part 1** **Summary of our findings**

### **Rationale and aims**

Visual sensory symptoms and eye conditions in autistic adults are poorly documented in the research literature. Some research suggests a greater need for spectacles (refractive errors) and a higher number of eye-coordination (binocular vision) problems in autistic individuals, but this research has been conducted on autistic children and mostly those with co-existing learning disabilities; little is known about the vision of autistic adults who do not have learning disabilities.

The aim of this study was to describe the visual sensory symptoms (e.g. hypersensitivity, sensory overload) and eye conditions (e.g. poor vision, requirement for spectacles, lazy eyes) in autistic adults who do not have learning disabilities. We also wanted to determine the impact of these on quality of life.

In addition, we wanted to understand the experience of autistic adults when visiting an optometrist. It is possible that if an optometrist has limited understanding around autism, an eye test could be a stressful experience for autistic people, leading to incorrect test results and future avoidance of visits. We would like to develop guidelines for optometrists in order to improve the experience and accuracy of eye tests for autistic adults.

### **What we did**

A total of 18 autistic adults, without learning disabilities, took part in this study, of which 6 were female and 12 were male, and age range was 25-67 years. Most of the participants wore spectacles, and there were some who had certain eye conditions, but not all. A total of four focus group sessions were conducted, and each had between four and six participants.

We asked four key questions during the focus group sessions, which were then discussed by the participants. These were:

- 1) Does anybody feel they experience any visual symptoms or unusual visual experiences?
- 2) Do you feel you can do anything to improve these symptoms?
- 3) How do your visual issues impact your daily routine?
- 4) What are your experiences of eye examinations?

The discussions were securely audio-recorded, and then transcribed. The transcripts were then thematically analysed, which is a qualitative research technique, resulting in a total ten theme (key ideas) emerging from the discussion data.

### What we found

We gathered a lot of useful information from the focus group discussions. A total of 10 themes were assigned to the responses to 4 key questions.

#### **Question 1: Does anybody feel they experience any visual problems or unusual visual**

The first theme from this question was “visual experiences”. The participants expressed a range of visual sensitivity issues, such as with light and patterns etc. However, these vary from person to person. There was also discussion about issues surrounding eye movements, that being tracking, visual location and preventing double vision.

The next theme was related to “autistic individuals’ vision-related knowledge”, which varied amongst our participants. This correlated with an emotional response. For example, those participants who understood normal ageing processes of the eye or the presence of floaters were relaxed and less stressed about their vision. The opposite was true for participants who did not have such a level of understanding about their eyes.

#### **Question 2: Do you feel you can do anything to improve these symptoms?**

A range of “coping strategies” were suggested by our participants. They explained that visual symptoms usually occur as part of the larger multisensory experience. However, to cope with visual symptoms in particular they described avoiding visually cluttered environments, preferring certain types of spectacle frames and lenses, the advantages and disadvantages of tinted lenses, alterations to lights, and finally just having to cope with certain visual experiences.

#### **Question 3: How do your visual issues impact your daily routine?**

Firstly, the participants described negative impacts of their visual experiences on their “personal wellbeing”; this was physical, mental, and emotional wellbeing.

Next, in terms of the “impact on personal life”, visual experiences were described to impact the participants’ home life, ability to visit public places, social life, and travel. Although most participants saw the disadvantages of their vision on these aspects, some participants did describe how their visual experiences were of benefit. For example, sensitivity to find detail was beneficial when completing fine arts.

Thirdly, the participants were generally disappointed with the level of “public understanding of autism”. Therefore, they were anxious about discussing sensory issues with potential employers or service providers.

#### **Question 4: What are your experiences of eye examinations?**

The discussion on this question revolved around four key themes. Firstly, related to “the practice”, the participants described the impact of the layout of an optometric practice and changes to this. They expressed that practice staff need to be met and made more aware of the issues faced by autistic individuals than a provide I’m more accessible service. In terms of booking appointments, autistic individuals prefer booking appointments online.

In regard to “testing techniques”, participants pointed out that tests requiring them to respond or judge visual images required the optometrist to provide very clear information and have a robust questioning technique. Whilst some participant said they enjoyed the structure of an eye examination, others expressed that they felt quite stressed and anxious about the whole experience.

Next, the “patient-practitioner relationship” was seen as utmost important by the participants. It is important that the practitioner is attentive, compassionate, and understanding by which he can build a good rapport. As it takes time for autistic individuals to get used to a new person and comfortable with them, they prefer practitioner continuity. Finally, it is important that the practitioner communicates well each aspect of the eye examination and the key outcomes.

The final theme was “patient education”. Providing autistic patients with “what to expect information” about the eye examination prior to their visit would be a great advantage. This is because they would come prepared, fully expecting each stage of the visit. Similarly, practitioners should ensure they address all presenting queries of their patients to ensure they go away stress-free.

#### What we concluded

Autistic adults are largely dissatisfied with their vision, and experience a range of visual symptoms, but these vary from person to person. Visual symptoms can occur alone or as part of a larger multisensory response, nevertheless, vision contributes to sensory overload and emotional responses. These symptoms or experiences can have both positive and negative impacts on the lives of autistic adults.

Autistic adults employ a variety of strategies to overcome their visual symptoms, but the last resort is to endure these. In terms of eye examinations, it is evident that for many autistic individuals these are currently not very accessible; improvements can be made in terms of the practice, the manner of the staff, the testing procedure and information provision to make these more “autism-friendly”.

#### Our next steps

We now plan to submit our results to a journal for publication. From the participants’ opinions about eye examinations, we will be producing a set of guidelines for optometrists which they can follow to make their services more autism-friendly. Together with this we would also like to produce a training program which optometrist can go through with the aim to equip them with skills to provide more effective eye examination for their autistic patients.

This study has formed the ground work for the next part of this project. The next study will be looking at exploring the types of eye conditions present in an autistic adult population and how treating these may impact vision, visual symptoms and quality of life. We are planning to provide eye examinations for autistic adults at the University of Manchester for this. This study is still in the process of being designed and ethically approved.

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