

Adapting the orthoptic investigation for children with autism spectrum disorders: how can research from other healthcare areas be applied to orthoptic practice? A literature review

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Abstract

Background and aim: The symptoms of autism spectrum disorders can have an impact on the orthoptic investigation; however, no gold standard of treatment of children with autism spectrum disorders has been established. There is a paucity of research on autism spectrum disorders in ophthalmology. Hence this work aimed to evaluate strategies used in other areas of healthcare, and establish their applicability to orthoptics.

Methods: A literature search was conducted using PubMed, Web of Knowledge and Scopus. Only English language papers were considered for inclusion. The papers were collated by topic, and their references searched for further information.

Results: Childhood diagnoses of autism spectrum disorders are increasing, and a higher incidence of ocular anomalies is found in the autistic population. A number of strategies have potential to be useful in the orthoptic investigation, based upon limited research.

Conclusion: Further research is required to establish a gold standard for orthoptic treatment of children with autism spectrum disorders. Early indications suggest that fear reduction strategies used in other areas of healthcare could be applied to orthoptic care.

Key words: Adaptation, Autism, Desensitisation, Paediatric, Pre-teaching

Introduction

Autism spectrum disorder (ASD) is a developmental disorder, classified on a spectrum which includes Asperger syndrome. This disorder affects how sufferers communicate and relate to other people, as well as how they are able to understand their environment. Though symptoms may vary in severity between individuals, all sufferers experience problems in three fundamental areas: social communication, social interaction and social imagination. Individuals with ASD may therefore experience difficulty in interpretation of facial expres-

sions, tone of voice and of the feelings or actions of other people, as well as struggling to cope in new situations, all of which affect their lives in many ways.

The National Autism Society (NAS) reports that approximately 700 000 people in the UK have ASD, equivalent to over 1% of the UK population,^{1–3} with a male:female diagnosis ratio of 4.3:1.⁴ Childhood diagnoses of ASD increased fivefold in the UK during the 1990s, and continued increasing into the early 2000s. In more recent years, the incidence rates have plateaued, but have not decreased.^{5,6} Within this population, a range of associated ocular anomalies have been reported,⁷ including increased incidence of strabismus, and abnormalities of saccadic and smooth pursuit eye movement systems.^{7–15} Strabismus is one of the most common ophthalmic deficits, with a wide range of incidence rates reported (19.7–60%). Milne and Griffiths⁷ concluded that the true figure is likely to be approximately 21%,⁸ as only one study in their review reported a 60% incidence, from a small sample of ophthalmology patients ($n = 10$). Though 21% is at the lower end of the reported range,^{14,15} it is significantly higher than the 2–5% incidence found in the general population,^{16,17} resulting in high rates of children with ASD attending the orthoptic clinic.

The increased rates of strabismus suggest an impairment of oculomotor control in ASD patients, with research on anomalies of saccadic and smooth pursuit eye movement systems driven by proposed abnormalities of cerebellar systems. It is, however, unclear whether the abnormality is one of generation or inhibition of saccades.^{11,12} It has also been reported that only 14% of children with ASD were able to generate voluntary smooth pursuit, and 92% gave abnormal OKN responses;⁸ however, there is currently insufficient evidence to determine the significance of these isolated findings.

Recent suggestions that eye tracking measures may be a useful diagnostic tool for ASD^{18–22} highlight the importance of an orthoptic examination. Without an orthoptic examination, the results of the test may be confounded by an eye movement disorder, and hence affect diagnosis for the subject.

Due to the symptoms of ASD, the orthoptic clinic and investigation can be particularly challenging for the clinician, patient and parent. Adaptations of the investigation are therefore necessary, and while some departments have devised their own protocols there is

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no standardisation of protocols throughout ophthalmology settings, due to limited research within this area. The NAS provides a document on their website entitled 'Guidance for eyecare professionals' which gives an overview of the condition, and a variety of tips for interacting with and examining an autistic child.²³ While this document is relevant, it does not focus on the orthoptic investigation.

This review aims to evaluate strategies researched, and used, with ASD patients in a range of healthcare and special provision settings, their successes and their applicability to the orthoptic clinic.

Reducing fear

Anxiety levels can be high for children with ASD meeting strangers in unfamiliar surroundings, due to their social imagination difficulties, which impacts on the clinical assessment. Therefore strategies to reduce fear could be beneficial to the patient and clinician. A research survey of parents of ASD children²⁴ reported that just 26% ($n=6$) described visits to a doctor as 'not difficult', and 18% ($n=4$) reported their doctor was not 'always patient' with their child.

One proposed strategy is through controlled exposure to medical instruments away from the traditional hospital setting.²⁴ Children attended desensitisation sessions with the school nurse, with positive behaviour reinforced with access to a favourite item. This strategy would be easily replicable in the orthoptic clinic, with the caregiver of the child able to provide appropriate positive reinforcers. Escape behaviour was permitted, with the success of the study (83%, $n=15$, of children able to complete the examination; comparable to the success rates of other methods considered in this work) suggesting that allowing escape behaviour does not have an overall detrimental impact on fear reduction outcomes. This suggests that, in the eye clinic, allowing the child to leave and rescheduling another appointment may result in a better long-term outcome.

Of the 18 children in the study diagnosed with ASD,²⁴ 15 were able to complete the full examination with the feared instruments at the end of the study. When followed up, however, 3 patients who had previously completed the examination had lapsed into fearful behaviour. Children exhibiting fearful behaviour on the first visit to the orthoptic department may therefore require a shorter follow-up period, or use of an alternative strategy, to maintain gains made in fear reduction and compliance.

Tackling the fear barrier has been found to be successful in the dental environment in facilitating the full examination of children with ASD. This examination is arguably more intrusive than the orthoptic examination, and this therefore suggests that strategies which successfully reduced fear in this environment could also be successful in the orthoptic clinic.

A study that used systematic desensitisation (gradual exposure to the environment, in this case combined with distraction by television), peer modelling (a video of a non-ASD child submitting to the dental examination),

reinforcement techniques and a mock dental clinic,²⁵ reported that 3 boys with profound ASD and dental fears were then able to submit to a dental examination in a real dental clinic.

Video peer modelling has, however, also been reported to be an ineffective tool compared with distraction techniques.²⁶ These conflicting results may partly be attributable to small sample sizes, which limit the comparative analysis possible, but also due to natural variation in the ASD population affecting the conclusions of studies.

Pre-teaching

It is arguable that the fear reduction methods examined previously relied upon pre-teaching as part of their approach. It is therefore important to consider pre-teaching as a standalone method to aid orthoptic examination of children with ASD.

Bachman *et al.*²⁷ used pre-teaching to aid a vision screening programme for developmentally delayed pre-school children. Pre-teaching consisted of an interactive group session where children touched and played with equipment, and also practised visual acuity tests. Children were tested in the school environment, as recommended by other studies;^{24,25} however, not all participants had a diagnosis of ASD. There was also no control group with which to compare the success rate, due to ethical concerns over withholding pre-teaching from any child. While this means the findings cannot be purely attributed to the intervention, 97% ($n=102$) of the children were able to complete the screening programme following the intervention. As failure to complete the screening tests would result in referral, if the intervention had been unsuccessful a high referral rate would be expected. However, the referral rate of 13% is comparable to the referral rate of 11.4% from orthoptist-led screening of mainstream reception-age children.²⁸

Pre-teaching also met with success in the cases of 3 boys who scored 'could not test' on a vision-only screening programme.²⁹ Two were diagnosed with developmental delay, the third with ASD and a chromosomal abnormality. Training sessions consisted of repetition of the screening behaviours required; matching at 1.5 m and 3 m, and wearing of occlusive glasses.

The children required a minimum of 30 sessions to learn the matching behaviour at 1.5 m whilst wearing occlusive glasses, with additional sessions required to achieve matching at 3 m. This type of repetition training would be difficult to conduct for the orthoptic assessment, due to the variability and amount of training time required. It can also be considered to be a reactive, rather than a proactive technique. This reactive treatment only investigated visual acuity testing and required a considerably longer treatment time, compared with the one session given by Bachman *et al.*¹⁰ in their proactive study.

Of course some ASD children may be able to cope with the investigation without intervention; for example, of the 6 participants considered for inclusion as part of the reactive vision screening pre-teaching programme,²⁹

3 were subsequently excluded as they passed the pre-assessment. The cost of the formulation and implementation of an intervention strategy must therefore be low, to ensure cost-effectiveness across the ASD population.

Utilising caregivers as therapists

An orthoptist may interact with a patient only briefly, whereas the extensive knowledge caregivers have of these special needs children means they are best placed to understand how the child will react to a given situation. A combined approach to the investigation, involving the caregiver and orthoptist, may produce the best result; so long as the caregiver is informed of the test purpose and can therefore act accordingly.

Love *et al.*,³⁰ however, investigated the possibility of using the mothers of ASD children as their therapists for fear reduction. The study involved only 2 boys, one with mild-moderate ASD, the other with severe ASD. Their mothers received an hour of explanation and practise of the role play required in the therapist role by way of training, using earlier described techniques of modelling and positive reinforcers to help their children overcome phobias. After the cessation of treatment the child diagnosed with severe ASD was still able to complete the feared tasks when followed up at 5 months, and again at 1 year.

The training given to these mothers was very brief, but they were nevertheless able to achieve reductions in their children's fear. Orthoptists may be able to make use of parental therapy, for example to achieve toleration of occlusion of one eye. This parental strategy would enable a much longer period of fear reduction therapy, unrestricted by busy clinic timetables, but still have a positive impact on the orthoptic assessment.

Use of parents as therapists is not without obstacles. In a study of parental compliance in giving therapy to their ASD children,³¹ no parent was found to be 100% compliant. Therapy recommended by the orthoptic department to be completed at home may therefore have a low compliance rate. In amblyopia studies, however, average compliance with duration of occlusion treatments has been reported to be between 33% and 54%.³²⁻³⁵ Despite this less than ideal compliance rate, children still achieve improvements in visual acuity, and hence low parental compliance with fear reduction therapy may not be a barrier to positive outcomes for the orthoptic investigation.

Altering the investigative procedure

Pre-teaching has been demonstrated to be a successful technique for achieving ophthalmological examination in patients with ASD;²⁷ however, it is not always a practicable strategy. Altering the investigation is therefore particularly applicable to the first visit, and to patients who struggle with pre-teaching.

In the standard visual acuity examination, the child is asked to name, or match, optotypes. However, children with ASD often have delayed language development,³⁶ with approximately 25% of affected individuals not developing functional language.³⁷ This test of comprehension, as well as of visual acuity, is therefore challenging or even impossible in these cases. An

Table 1. Teller acuity card age norms

Age (months)	Study no. ^a	Test distance (cm)	Mean acuity (cycles/deg)	Standard deviation (octaves)
Newborn	1 (n = 17)	38	0.66	
	3 (n = 20)	38	0.9	0.5
	4 (n = 40)		0.7	0.5
	5 (n = 30)		1.0	0.5
1	2 (n = 8)	36 ± 3	1.1	
	3 (n = 20)	38	1.1	
	6 (n = 6)	33 ± 3	0.8	0.7
	7 (n not given)		1.3	1.0
	10 (n = 32)	38	0.94	
3	1 (n = 21)	38	3.89	
	3 (n = 20)	55	2.6	0.6
	7 (n not given)		4.1	0.6
6	1 (n = 30)	38	7.44	
	2 (n = 8)	36 ± 3	4.7	0.8
	3 (n = 20)	55	5.9	0.6
	6 (n = 6)	33 ± 3	5.3	0.5
	7 (n not given)		7.8	0.5
	10 (n = 40)	55	5.65	0.47
12	1 (n = 40)	55	11.08	
	3 (n = 20)	55	9.6	0.3
	6 (n = 6)	33 ± 3	6.3	0.7
	7 (n not given)		10.2	0.5
	8 (n = 18)		6.4	0.4
	10 (n = 40)	55	6.42	0.29
18	1 (n = 35)	55	12.39	
	10 (n = 40)	55	8.59	0.37
24	1 (n = 44)	55	14.64	
	3 (n = 20)	55	13.2	0.5
	8 (n = 18)		20.9	0.4
	9 (n = 9)		14.9	0.6
	10 (n = 40)	55	9.57	0.27
36	1 (n = 32)	55	17.82	
	3 (n = 20)	55	18.6	0.5
	9 (n = 9)		27.7	0.5
	10 (n = 40)	84	21.81	0.36
48	10 (n = 32)	84	24.81	0.31

^aStudies: 1, Salomao and Ventura (1995)⁴²; 2, McDonald *et al.* (1985)⁴³; 3, Courage and Adams (1990)⁴⁴; 4, Dobson *et al.* (1987)⁴⁵; 5, Brown and Yamamoto (1986)⁴⁶; 6, McDonald *et al.* (1986)⁴⁷; 7, van Hof-van Duin and Mohn (1986)⁴⁸; 8, Kohl and Samek (1988)⁴⁹; 9, McDonald *et al.* (1986)⁵⁰; 10, Lim *et al.* (2005).⁵¹

alternative is to use the preferential-looking Teller acuity cards (TAC) originally developed for infants but also used in patients unable to take an optotype test.³⁸⁻⁴⁰ To enable interpretation of results, normative data sets are available for this test. However, the data are variable and only available up to the age of 48 months, as shown in Table 1. Though myelination of the visual system may be complete at 48 months, research has suggested that grating acuity continues to improve even beyond the age of 78 months,⁴¹ meaning that using the normative data for older children may result in a lack of sensitivity for detection of some milder degrees of visual impairment.

The use of TAC in children with ASD has been demonstrated to be feasible in the vast majority of patients by Scharre and Credon,⁸ who used Teller acuity grating cards under binocular conditions to assess the visual acuity of 34 ASD children. Of these, 33 were able to complete an assessment of visual acuity in this objective way.

Research assessing the impact of testing visual acuity with TAC has found that the results can be used to provide information for childhood intervention pro-

Table 2. Sensitivity and specificity values of Teller acuity cards when examining for an inter-ocular acuity difference (IOD) of greater than 1 octave^{53,54,56}

Study authors	Sensitivity	Specificity
Drover <i>et al.</i> ⁵³ (<i>n</i> = 126)	80%	74%
Kushner ⁵⁴ (<i>n</i> = 69)	50%	91%
Katz and Sireteanu ⁵⁵ (<i>n</i> unknown) (data re-examined by Drover <i>et al.</i> ⁵³)	30%	98%

grammes, schools and social agencies. Ophthalmologists report the results to be useful in diagnosis and clinical management, while visual acuity testing was also associated with a reduction in parental stress.⁵² TAC have therefore been demonstrated to provide useful data not only to orthoptists and ophthalmologists, but also to multi-disciplinary professionals involved in the care of special needs children.

While the testability with TAC is high, a potential issue in their use is the variability in the sensitivity values when examining for an inter-ocular acuity difference (IOD) of greater than 1 octave. Specificity rates are consistently high; however, there is the possibility of a high false negative rate when using TAC to find an IOD of greater than 1 octave, as demonstrated in Table 2.

The study by Drover *et al.*⁵³ is the most recent, and examined the sensitivity and specificity of TAC in different subtypes of amblyopia. The well-designed methodology of the study, and participant selection, would suggest that the values given by Drover *et al.* are the most likely to resemble the true sensitivity and specificity values for TAC.

An alternative to TAC is the adaptation of subjective tests, as was performed by Newsom and Simon,⁵⁶ who developed a procedure for measurement of distance acuity in non-verbal children. The children were trained to be able to discriminate left- and right-facing Snellen letter Es in an upper time limit of 4 hours. Of 11 children studied, 8 successfully learnt the behaviour. The children were seated 6.1 m from the display board, which is reflective of a child's functional distance vision. It is, however, an uncrowded test of visual acuity, but provided this is considered during interpreting the results will maintain their validity. Though the acuity was measured under binocular conditions in the study, this method could be combined with parental home therapy as a way of measuring the unocular acuity of children with severe ASD. While this is a very simplified method of measuring optotype acuity, only 73% of children were able to learn the simplified subjective method,⁴⁴ whereas 97% were able to complete a TAC assessment.⁸ This supports the argument that orthoptic assessment should not seek to assess these children by 'age-appropriate' tests but by developmentally-appropriate tests.

These studies suggest that altering the testing procedure, and altering the test performed, are both viable options for investigation of visual acuity in children with ASD. The level of alteration necessary is of course dependent upon the individual child, with both options having limitations.

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Conclusions

The research discussed from a variety of settings has been shown to be potentially applicable to orthoptics, and could therefore form the basis of an orthoptics-specific intervention strategy for the assessment of children with ASD. Of the strategies examined, studies on pre-teaching and the use of TAC both report the highest success rates of 97%.^{8,27} The use of TAC would be the simplest approach to use, while pre-teaching could be used in small groups at special schools, as was done in the research.²⁶ Alternatively therapies could be combined, with parents performing repetition training²⁹ with their child at home. This method of repetition training would allow sufficient time for the behaviour to be learnt, and may result in the child being able to perform a gold standard optotype test; this would overcome the limitation of low sensitivity values from TAC.⁵³⁻⁵⁵

Though this work has demonstrated the possible application of research from one area of healthcare to another, it has highlighted a lack of original research on ASD. This paucity of research is not specific to orthoptics, but in ophthalmology overall. While over 30 years of research has been examined in the scope of this work, no ophthalmological testing protocol has been established to date; though professionals should familiarise themselves with the advice given by the NAS.

An overarching strategy on ASD for orthoptics would be beneficial to improving outcomes for this group of patients. This field of research is, however, rapidly growing. At one centre alone there are currently more than 20 studies ongoing into various aspects of ASD, which can be found on the Autism Research Centre website (http://www.autismresearchcentre.com/all_projects); further research is ongoing worldwide. It is to be hoped that providing healthcare professionals with a better understanding of ASD from the results of this research will enable improved care, and positive outcomes, for affected patients.

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