Improving vision awareness in autism services: Evaluation of a dedicated education programme for support practitioners

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The project reported here was funded by the Scottish Government through the Scottish Strategy for Autism.

Background: The research reported here sought to evaluate whether a dedicated education programme in vision awareness improved the knowledge and skills of autism support practitioners in identifying visual impairment in autistic people with intellectual disabilities and providing better support to those individuals identified as visually impaired.

Methods: Researchers undertook a mixed methods evaluation. A survey questionnaire was devised and administered before and after training and focus groups were undertaken in order to gain qualitative data relating how practitioners implemented their learning in practice.

Results: Knowledge confidence and practice confidence scores of participants were significantly improved by the programme, which maintained its impact one year on. Practitioners reported increased access to optometry, changes to support practice and improvements to service environments as a result of the training.

Conclusion: Autism support practitioners’ skills in identifying and supporting people with visual impairments were demonstrably enhanced through dedicated vision training.

KEYWORDS  
autism spectrum disorder, intellectual disability, optometry, sight loss, social care, visual impairment

1 | INTRODUCTION

This article reports on a project to undertake and evaluate a training programme for autism support practitioners. The programme aimed to increase practitioners’ awareness of possible ophthalmic visual impairments among autistic people, particularly individuals with complex needs that include intellectual disabilities and/or limited verbal communication.

The project comprised a partnership between a specialist vision support organization (RNIB), a specialist autism service provider in whose services the programme was carried out (Scottish Autism), and academic partners (Edinburgh Napier University) who advised on the evaluation process. The mixed methods evaluation employed a questionnaire to ascertain practitioners’ confidence in their knowledge and practice in supporting autistic people with visual impairments before and after participating in the education programme. Focus groups were used to investigate reported changes to practice as a result of the education programme.

2 | BACKGROUND

There is a small but evolving evidence base of the association between autism and visual impairment and on the similarities in behavioural presentation found in both conditions. Research suggests that congenitally blind children, otherwise typically developing, share many common behaviours noted in sighted autistic children. These include echolalia, pronominal reversal, delay in development of symbolic play and stereotypical mannerisms such as eye-poking, rubbing and rocking (Hoevenaars-van den Boom, Antonissen, Knoors, & Vervoel, 2009; Johansson et al., 2006; Parr, Dale, Shaffer, & Salt, 2010; Smith, Nichols, Issekutz, & Blake, 2005; Williams, Fink, Zamora, & Borchert, 2014). Moreover, visual processing difficulties associated with the neurological bases of autism such as difficulties with spatial awareness, light and contrast sensitivity or facial recognition (Coulter, 2009; Simmons et al., 2009) may share behavioural presentations with ophthalmic visual impairment such as turning the head to look
through the corner of the eye, difficulty with motor coordination or problems navigating spaces with intense light sources (see Coulter, 2009). Ophthalmic conditions are frequently undetected among children, adults and older people with intellectual disabilities (Emerson & Robertson, 2011) and this population includes people with intellectual disabilities and autism. This situation has been highlighted by research in special education schools that include autistic students within their populations. In one such study, Das, Spowart, Crossley, and Dutton (2010) found 46% of pupils needing visual correction but with less than half this number already using adequate visual correction. Woodhouse, Davies, McAvinchey, and Ryan (2013) record a similarly a high level of undiagnosed visual impairment in special schools without screening programmes, while Little and Saunders (2015) note the need for adequate visual information in support and education plans, a need that was often unfulfilled in their sample of children with special educational needs. Under-diagnosis is therefore likely in a significant proportion of the adult autistic population also. This may, in part, be due to the similar behavioural presentations of autistic traits and visual impairment noted above.

It is therefore imperative that social care and education practitioners supporting autistic people, particularly individuals with complex needs or limited verbal communication, are aware of the signs that might indicate visual impairment and the need for regular sight tests. Practitioners also need the skills to respond to the environmental and individual support needs of people with autism and visual impairments once an ophthalmic condition is diagnosed.

The “Bridge to Vision” training programme described here focused on increasing awareness of sight loss issues among autism support practitioners and embedding vision knowledge in support practice. Autism support practitioners included in the programme were social care workers and classroom assistants drawn from a range of autism services that included community residential care with round-the-clock support to adult day placements and the organization’s school. Increased vision awareness among practitioners was achieved through training, mentoring and advice from RNIB. Increased understanding and knowledge of sight loss among autism practitioners stands to aid the prevention of avoidable sight loss, and also to better detect visual difficulties in autistic people, particularly those with intellectual disabilities and/or limited verbal communication. Through developing vision awareness among autism practitioners, it is anticipated that support practice and environments for visually impaired service users will also be improved.

3 | THE EDUCATION PROGRAMME

RNIB’s “Bridge to Vision” training programme involves two stages: vision awareness training for a large number of autism support practitioners, and the recruitment of a smaller number of “Vision Champions” who receive further training and lead practice teams in addressing vision support needs.

The Vision Awareness training is a 1-day course aimed at increasing support practitioners’ understanding of the impact of sight loss and to highlight the importance of regular access to eye care. The course covers common sight problems, and how these problems can impact upon daily living. The course highlights the possible similarities of some signs and behaviours associated with sight loss and those associated with autism. Part of the education programme involves a practical interactive exercise wherein participants were given glasses which simulate common eye conditions and carry out simple everyday tasks. These practical exercises provide participants with an insight into the difficulties faced by people with visual impairments.

The Vision Champion role was developed to provide selected practitioners with the skills and tools to detect possible sight loss in people with autism. Vision Champions at Scottish Autism attended a 2-day training course where they received training on common indicators of sight loss. The course also highlighted some of the challenges in the environment for people with sight loss, pointing out hazards and difficulties in daily activities such as eating and drinking, moving between environments, and coping with changes in light. The Vision Champion training provides advice on how to adapt the home environment to meet the needs of visually impaired individuals such as avoiding problematic patterning, ensuring a contrast between doors and walls, and identifying light sources that may cause distractions. Furthermore, the training offered information on how to provide appropriate support to improve mobility and reduce the risk of falling with advice on keeping pace with person being supported and orientation awareness to identify potential hazards.

The Vision Champion training provides a toolkit to identify sight loss by undertaking systematic observations, make informed referrals to eye care professionals and to ensure that appropriate practical information concerning a person’s vision needs is available to practitioners. The toolkit contains a series of cards that help the Vision Champion to conduct natural observations (see Figure 1). A traffic light system enables the Vision Champion to make informed decisions about the need to referral for an optometry assessment.

The toolkit also contains a pre-optometry form onto which Vision Champions enter information gathered from the observations. This can then be passed to the optometrist conducting the sight test to provide important background information. The ongoing role of the Vision Champion is to proactively embed visual awareness, understanding and response to visual impairment into their team’s practices with further mentoring and information provided by RNIB.

4 | EVALUATION METHODOLOGY

The research team adopted a mixed methods approach to evaluate the Bridge to Vision programme. Quantitative assessment comprised of a survey questionnaire designed to assess practitioners’ reporting of their knowledge and practice, which was completed before and after training and at 1-year follow-up. Qualitative evaluation consisted of a
series of focus groups with the Vision Champions reflecting on their learning process, the impact of their training and facilitators and barriers to effecting changes in practice.

4.1 | Ethics

The study was independently ethically reviewed by Edinburgh Napier University Research Ethics Committee and approval-granted. All participants provided informed written consent. All research ethics and governance procedures were adhered to throughout.

4.2 | Quantitative methodology: questionnaire development and design

A review of current health measures revealed no validated questionnaires that assessed practitioner knowledge and confidence on the subject of visual impairment in people with autism. The *autism and Sight Loss Questionnaire* was developed by the project partners to assess four constructs: (i) knowledge confidence, (ii) recognition of vision issues, (iii) practice confidence and (iv) perceived barriers to eye care. The first construct included four items which explored participants’ knowledge confidence in detecting visual impairment. The second construct included six items which addressed the recognition of vision issues. The third construct had five items which assessed practice confidence in recognizing vision issues. The final construct had six items which assessed perceived barriers to eye care. The questionnaire used a five-point Likert scale, which is frequently employed to assess attitudes (Rattray & Jones, 2007). Items included in the final analysis are detailed in Figures 2–4 below. The items were reviewed and assessed to ensure there were no double-barrelled or double-negative (Rattray & Jones, 2007). This constant review process ensured the content (face) validity of the questionnaire (Bowling, 1997). The questionnaire was tested on a small sample of autism support practitioners outside the main study sites. The piloted questionnaires were assessed for readability and comprehension, and changes were made accordingly (Oppenheim, 1992).

4.3 | Procedure

Vision Awareness Training was delivered to 57 autism support practitioners employed within three of a Scottish Autism’s service areas. Practitioners undertaking the vision awareness training completed the questionnaire before and after training to measure the impact of the course. The questionnaire was administered a third time in December 2014 to measure the lasting impact of vision awareness training.
4.4 | Quantitative data analysis

The survey data were analysed by two researchers (Butchart and Karatzias) using SPSS version 18.0. A five-point Likert scale was initially used and later collapsed to three categories: disagree; neither agree or disagree; and agree. The collapsing of categories from five to three was done to minimize the effect of outliers (Field, 2005). The Autism & Sight Loss Questionnaire was tested for reliability using Cronbach’s alpha, a test aimed at determining whether scores correlate in a way that allows researchers to reliably determine a coherent trend. The questionnaire achieved an overall Cronbach’s alpha score of 0.67, suggesting that the overall scoring scale attributed to the questionnaire is reliable (Kline, 1999). However, further reliability testing on the subscales revealed that one – recognition of vision issues – did not achieve the required standard of >0.6. This means that while each individual question in this subset can give us basic descriptive statistics on the answer scores, the six questions together did not register a coherent enough correlation in scores to treat “recognition of vision issues” as a single category for scoring.

Pre-training and post-training questionnaires were analysed using paired-samples t-test to evaluate changes in time in relation to the awareness training. Further analysis to assess the impact of the training was conducted using repeated measures process known as Friedman’s ANOVA. The test aimed to assess whether there was a significant difference between scores at the three different points in time. By comparing mean scores at pre-training, post-training and follow-up, the authors were able to assess whether the training had an impact and whether that impact was lasting.

4.5 | Qualitative methodology: focus groups

Following the vision awareness training, eight practitioners came forward to take on the role of Vision Champion. As the work here represents evaluation of a “real-world” service context rather than scientific intervention, selection of Vision Champions was undertaken in dialogue between trained practitioners and line managers. As such, selection constitutes purposive rather than random sampling. Vision Champions were invited to participate in focus groups at 3-month intervals on the same day as meeting with their RNIB mentor. Two Vision Champions left the organization immediately after training, leaving six to undertake the Vision Champion role and report on their progress in this way. Focus groups were facilitated by a researcher who was not involved in organizational or training issues. Mentors and organizational representatives were not present, thus assuring a level of anonymity for comments given and independence from the training and implementation processes. Given the wide range of support and interventions continuously undertaken in social care contexts, it would be difficult to apply any single comparable outcome measure.
in service users to improved visual support; the authors therefore relied on practitioner reporting to determine where the education programme had most impacted practice.

4.6 | Qualitative data analysis

The focus group data were transcribed for analysis and coded by two members of the research team (Butchart and Long). The data were analysed using a thematic analysis (Braun & Clarke, 2006). The researchers used NVivo qualitative data analysis software to undertake and compare coding.

5 | RESULTS

5.1 | Knowledge confidence

To assess knowledge confidence, participants were asked to agree or disagree with four statements. Figure 2 shows the statements and the ways in which participants rated their response before and after training.

There was a statistically significant difference before and after for all four statements ($p < .05$). Participants’ knowledge confidence increased after training. Practitioners felt more aware of the main causes of sight loss and how the eye and visual systems work. They were more confident in recognizing the signs of sight loss in general as well as in people whom they supported.

5.2 | Practice confidence

There were five items assessing participants’ practice confidence. Participants agreed or disagreed with five statements detailed in Figure 3 before and after training again showing an overall increase.

There was a statistically significant difference before and after training in practice confidence ($p < .05$). Participants were confident in suggesting referrals for eye tests, and supporting someone with dual diagnosis. They knew how often their service users should have an eye test and why and when their service users should wear glasses.

5.3 | Recognition of vision issues

The survey featured six questions that sought recognition of topics included in the Bridge to Vision training to assess whether participants were better able to recognize these issues after training. This subscale did not achieve statistical reliability. The authors also recognize a limitation in questionnaire design by providing statements that were likely to prompt participants to agree rather than undertake an objective test of knowledge that either included open-ended questions or false positives, hence the exclusion of this category from further analysis.

5.4 | Barriers to eye care

Participants’ were asked to consider whether they agreed that given factors would be a barrier to eye care for people with autism. There were six items listed: service user behaviour, service user communication, physical access to the opticians, appointment times, eye test process and outcome of the eye test (e.g. getting a service user to wear glasses).

The results showed that factors relating to a service user’s communication or behaviour were considered less of a barrier after training, suggesting that practitioners were more aware of alternative sight test methods used for people with complex communication needs or felt more skilled at supporting someone through the process. However, physical access to optometry and appointment times were seen as more of a difficulty, perhaps suggesting that practitioners were becoming more aware of the practicalities of accessing a more involved sight test. These conflicting trends rendered the overall differences as not statistically significant.

5.5 | Practitioner comments on the impact of vision awareness training

Before undertaking the Vision Champion stage of the training, those practitioners that had come forward as Vision Champions took part in a focus group where they were asked to reflect on what they had gained from the vision awareness training. A thematic analysis of their discussion identifies the following key points as identified lessons from the training (Table 1):

These points help to identify how the training influenced knowledge and practice confidence. Points four, five and six highlight the value of practice-oriented learning. Particularly insightful for practitioners were the practical tasks using spectacles which simulated visual impairment. Wearing these spectacles and trying to complete everyday tasks were quite revelatory for participants, who reported feeling nauseous or tired just from short spells of usage. Equally helpful was the information on the environmental impact for someone with poor vision and ways of ameliorating the effects. These included creating contrasting colours in doors and walls, and awareness of the positioning of furniture and the effect of light sources. Practitioners’ enthusiasm for all these elements of the training was clear throughout the focus group discussion.

6 | REPORTED CHANGES TO PRACTICE

From their initial training in February 2013 through to November 2013, Scottish Autism’s Vision Champions met three times with mentors from RNIB and before each mentoring meeting participated in a focus group to discuss their experiences of the role and the impact on services that Vision Champions felt that they had made.

Focus group data were again transcribed and thematically analysed. The points given below represent experiences described with more than one reference in the focus groups (Table 2). The significance of the points and contextual information is given in the commentary, where the authors also highlight some examples of practice that were
**6.1 | Changes to service environments**

Paying attention to problematic patterning, a lack of contrast between doors and walls, or light sources that may cause distractions were all part of the RNIB training programme, and directly influenced environmental changes in services. For example, one Vision Champion reported installing a balustrade to aid navigation into a building for a service user with impaired lower vision; a Senior Autism Practitioner who was also a Vision Champion disclosed that the training influenced her choice of carpet and decoration in a new service location; and the support worker quoted above directly influenced repainting a service location.

**6.2 | Increased number of sight tests**

The Vision Champions reported a number of service users attending sight tests as a result of the Bridge to Vision programme. A number of these were initiated by practitioners who had attended the Vision Awareness training without the direct involvement of Vision Champions. Vision Champions appeared to be taking a more active role in those cases that required some detailed observation and recording before referral, as the programme structure envisages.

**6.3 | Improved documentation of sight loss issues**

Vision Champions each undertook an audit of support plans within their service areas to assess the quality of vision information. The
audit left Vision Champions feeling that greater detail was needed in service documents. The Champions reported that in many instances support plans either stated what vision impairment a service user had, without further explanation of needs, or that visual information was lacking. This led to several team members initiating change within their service areas, either through including the RNIB’s “Vision Passport” within service plans, or working to improve the sensory needs section of individual support plans using the Vision Passport as a basis.

6.4 | Closer attention to vision issues

Wider cultural change and changes to practice within Scottish Autism are difficult to quantify, but the Vision Champions reported far greater awareness within their everyday work. There is evidence from individual comments and examples given in the focus groups that did not warrant a unique code but together indicate impact on practice. These individual and context-specific changes included: changing the swimming pool accessed by a service user so that the individual could enter the pool through gradual steps; positioning service users with impaired vision carefully in relation to light during art sessions; and approaching a service user directly rather than from the side so that they could better see who was approaching.

7 | THE SUSTAINED IMPACT OF VISION TRAINING

The pilot sites were surveyed again 1 year on from the training to ascertain whether the training had an ongoing impact on practice. A comparison between scores over the three time points (pre-training, post-training and 1-year follow-up) allows us to assess whether the improvements reported between pre-training and post-training were sustainable.

The process involved grouping questionnaires from the three time points in order to ensure that learning was benchmarked in the same individual practitioners. Returned questionnaires were matched, where possible, with previous surveys which resulted in 25 matched pre-training, post-training and follow-up questionnaires. The total scores for each category were then summed resulting in an overall score for pre-training, post-training and follow-up. The new groupings were tested to assess whether there was a difference across the three time points using Friedman’s ANOVA. Figures 5–7 illustrate the impact of the training over time for the three subscales.

The first subscale of knowledge confidence (possible score range of 4–12) demonstrated a significant difference (p ≤ .05) between the three time points. Post hoc tests revealed that the difference lay between pre-training and post-training/follow-up. Pre-training scores (7.36) were significantly lower than post-training (11.44 ± 1.04, p < .05) and follow-up (10.96 ± 1.88, p < .05). There was no significant difference between post-training and follow-up scores (p > .05), which would suggest knowledge confidence was maintained over time.

The same process was followed to assess the statements on practice confidence (possible score range of 5–15) and again there was a significant difference (p ≤ .05) over time. Post hoc tests revealed that the difference lay between pre-training and post-training/follow-up. Pre-training scores (12.96) were significantly lower than post-training scores (14.48 ± .96, p < .05) and follow-up (14.40 ± 1.15, p < .05). Again there was no significant difference between post-training and follow-up scores (p > .05), suggesting that practice confidence was also maintained over time.

There was a small reduction in perceived barriers to eye care (possible overall score of 18), but the differences between pre-training
(14.76), post-training (13.84) and follow-up (13.12) were not statistically significant.

8 | DISCUSSION

In the United Kingdom, the Public Sector Equality Duty requires that people with autism have the legal right to access universal services such as healthcare, education and leisure services in the same way as any other citizen (Equality Act, 2010). The Public Sector Equality Duty also requires that all public services make reasonable adjustments to their services to ensure equality of access for the whole population (Turner & Robinson, 2011). Ensuring reasonable adjustments extends beyond physical access to services and includes providing a skilled and knowledgeable workforce that is able to meet the distinct and individual needs of people that require support. There is, however, evidence that some public services do not possess the knowledge and skills necessary to effectively support people with complex needs (NHS Scotland, 2009; NHS Quality Improvement Scotland, 2009). A common theme that has emerged from these investigations relates to the knowledge and confidence of practitioners across support services in understanding the distinct and specific care needs of people with intellectual disabilities, including those with autism. Recommendations arising from these reports highlight the importance of ensuring that there is appropriate education and access to specialist support for practitioners working in this sector.

Autism-specific support organizations increasingly provide specialist training to ensure that services respond to the core features of autism such as difficulties in communication and social interactions, rigidity of thought and behaviour, or sensory sensitivities (see American Psychiatric Association (DSM V) 2013). Yet while support practitioners may be sensitive to difficulties stemming from a person’s autism, practitioners also need to take account of wider health needs. Within autism-specific services, there is a need to be aware of “diagnostic overshadowing” whereby behavioural presentations and stress reactions are assumed to be related to autism and other possible causes are overlooked (Hepburn et al., 2014). Diagnostic overshadowing is a particular risk in relation to visual impairments given the evidence that autism and visual impairment can have similar behavioural presentations during development and in adulthood. As documented above, researchers have shown that traits such as echolalia and nominal reversal; delay in the development of symbolic play, and repetitive behaviours such as eye-poking, rubbing and rocking are common in the development of both vision impaired and autistic individuals (Hoenevaars-van den Boom et al., 2009; Johanssen et al., 2006; Parr et al., 2010; Smith et al., 2005; Williams et al., 2014). Differences in the central nervous system of autistic individuals may also lead to visual processing difficulties such as spatial and visual-motor processing, and extreme sensitivity to colour and light (Coulter, 2009: Simmons et al., 2009). However, while associated presentations such as turning the head and looking from the corner of the eye, aversion to light in certain environments, apparently poor attention to someone’s surroundings, contrast sensitivity or distorted posture are just a few examples of traits associated with visual processing (Coulter, 2009: 166), these presentations may equally be a symptom of ophthalmic conditions. In some cases, poor social attention or eye contact may be interpreted as autistic traits (See Simmons et al., 2009), but may in fact stem from undiagnosed visual impairment.

While there is insufficient research data available to make a definitive estimate of the general prevalence of ophthalmic conditions among the autistic population (Butchart et al., 2017), Emerson and Robertson (2011) argue that visual impairment is under-diagnosed in people with intellectual disabilities more generally. This needs to be taken seriously as a problem that is likely to seriously impact quality of life for individuals whose visual difficulties are missed. For this reason, access to eye care via optometry or ophthalmology services is important as a means of ruling in or out ophthalmic conditions that may be causing or exacerbating impairment in functioning.

In this context, partnership work such as the education programme described here can play a vital role in facilitating awareness of specific health needs among autism support practitioners. The data presented here demonstrate that partnership working and effective knowledge-sharing between a vision support organization and an autism support provider has the power to educate and enthuse autism practitioners about the need for eye care and vision support. Practitioners’ self-scoring of practice knowledge and practice confidence on the Autism and Sight Loss Questionnaire showed significant improvements after undertaking vision awareness training and in the qualitative data gathered through focus groups practitioners reported a number of changes to practice, service documentation, service environments and access to eye care.

The authors note, however, that educating support practitioners about the need for regular eye care is only part of the process of ensuring equal access to optometry services for people on the autism spectrum. Many eye care practitioners are likely to require education in understanding autism in order to provide autism-friendly environments and practices. If properly embedded into service provision, current work developing autism awareness among eye care professionals as well as effective eye care protocols for people with autism (e.g. Coulter, 2009, 2013) has the potential to enable vision-aware support practitioners and autism-aware eye care professionals to work together and ensure that eye care and vision support are available for all people with autism, including those with intellectual disabilities.

9 | CONCLUSIONS

The Autism and Sight Loss Questionnaire assessed support practitioners’ knowledge confidence and practice confidence in detecting sight loss issues in people with autism. Overall, these figures show practitioners’ confidence in recognizing and supporting people with visual impairment was improved by the Bridge to Vision training. Although barriers to eye care were also perceived as being reduced, the difference was not statistically significant. Further analyses examined the impact of the training over time and found the training maintained its impact 1 year on.
The focus group data demonstrate the ways in which practitioners were more aware and responsive to the visual needs of people with autism and complex needs following training. Practitioners were able to clearly identify changes in their practice and environmental adjustments made in their services. These included changing the way that service users were physically approached, changing amenities accessed by service users, awareness of light sources, and adjustments to decor and furnishings to minimize patterned fabrics and accentuate contrasts. Practitioners also reported improvements to the documentation of vision issues in services and increased access to eye care services. Practitioner reporting therefore suggests that dedicated vision awareness training and the presence of Vision Champions in autism services can make a difference to identification and support for autistic individuals with visual impairment.

10 | LIMITATIONS

The survey findings are based on practitioners self-reporting of knowledge and practice confidence rather than an objective test of vision knowledge. Similarly, the scope of the present study was limited to practitioner reporting of changes to practice rather than outcome measures for supported individuals. Questions on recognizing vision issues had to be excluded from results given the lack of reliability for the subscale.

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