

The role of lived experience eye care champions in improving awareness and access to eye care services for people with learning disabilities and/or autism

Marek Karas^{1,2}  | Donna O'Brien¹ | Lance Campbell³ | Rebecca Lunness³ |
Joanne Kennedy³ | Grace McGill³ | Stephen Kill¹ | Lisa Donaldson^{1,4} 

¹Eye Care and Vision Team, SeeAbility, Leatherhead, UK

²School of Optometry and Vision Sciences, Cardiff University, Cardiff, South Glamorgan, UK

³Eye Care Champions Team, SeeAbility, Leatherhead, UK

⁴Department of Optometry and Visual Sciences, School of Health and Psychological Sciences, City University of London, London, UK

Correspondence

Marek Karas, School of Optometry and Vision Sciences, Cardiff University, Cardiff, South Glamorgan, UK.

Email: karasm@cardiff.ac.uk

Abstract

Background: Documented inequalities in access to eye care for people with learning disabilities and/or autism are caused by poor uptake of primary eye care services, poor identification of eye problems, lack of signposting and reasonable adjustments of existing services, concerns about costs of care and the low priority historically given to these issues in eye care policy at a regional and national level. In 2019, the charity SeeAbility employed four eye care champions (ECCs) with lived experience of learning disability and/or autism to work in local communities in London and the Northwest of England. They provided peer-to-peer support on understanding the need for good eye health and engaged with policy makers, and learning disability, autism and eye care professionals at the local, regional and national levels to influence both the clinical practice of individual practitioners (within existing service/pathway models) and more widely to influence the commissioning of the Easy Eye Care pathway. This study explores the experiences of these ECCs.

Methods: The study was conducted in April and May 2023. A case study approach was used to describe the experiences of the ECCs from March 2019 to March 2023. Data from structured interviews with the four ECCs and workload analysis were triangulated to provide a multifaceted understanding of this novel health promotion project.

Findings: The ECCs found the role useful and reported that confidence in their practice and impact grew with time but they required ongoing support in the role. A good understanding of the promotional messages was reported. Developing a good network of contacts at an early stage, both people with learning disabilities and healthcare professionals, was key. Relationships with professionals were supportive and positive and a positive emotive response to their lived experience was reported in these interactions.

Conclusions: From the perspective of the ECCs, the role is useful and beneficial. The work suggests some key recommendations for future development which include planning to build networks, support in presentation and communications skills and

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defining key messages and knowledge. Confidence of the ECCs builds with time in the role but also needs support the emotive impact of their lived experiences on audiences is highlighted. There is a need to evaluate how the programme is perceived by those who interact with it and how it changes behaviours which leads to better health outcomes.

KEYWORDS

eye care champions, eye health, eye test, health advocacy, lived experience, optician, optometry, vision

Accessible Summaries

- People with learning disabilities are 10 times more likely than other people to have a problem with their eyes but less likely to get the eye care they need.
- This paper explains how people with a learning disability and/or autism are employed to tell other people with learning disabilities and/or autism, their supporters, health and care professionals and people who plan services about how important it is to get regular eye care. This job is an 'Eye Care Champion'.
- We share what the eye care champions did in their role, what worked well and what did not.
- We discuss how what we have learnt can help other people with learning disabilities and/or autism work as eye care champions and perhaps as champions for other areas of healthcare.

1 | INTRODUCTION

People with learning disabilities are known to be 10 times more likely to have serious sight problems than the general population (Emerson & Robertson, 2011). Vision problems are present in 47%–50% of the learning-disabled population (Donaldson et al., 2019; Kinnear et al., 2018) with the incidence rising with the severity of learning disability (Warburg, 2001). At least 60% of adults with learning disability need spectacles, 44% have strabismus and cataracts, optic nerve pathology and cerebral visual impairment are more prevalent than in the general population (van Isterdael et al., 2006; van Splunder et al., 2006). Studies suggest there are similar increased prevalences in the autistic population (Butchart et al., 2017).

There is considerable overlap between the populations of people with a learning disability and those with autism. The prevalence of autism in the population of people with a learning disability has been reported as between 8% and 39.3% (Brugha et al., 2016; Dunn et al., 2019) and estimates of the prevalence of a learning disability in the autistic population range between 7% and 70% (Emerson & Baines, 2010; Fombonne, 2003). NHS organisational policy is to address the needs of people with learning disability, autism or both (National Health Service, 2019) and the pathway that the eye care champions (ECCs) work to implement aims to address unmet need in both populations.

Li et al. (2015) highlighted that problems with communication, inadequate health history and lack of specialist training and assessment skills were all challenges to delivering better care to these populations. In common with all health conditions, underreporting of ocular problems or

symptoms can occur due to difficulties in communicating symptoms by people with learning disabilities and autism, or because those signs or symptoms are often overlooked or attributed to the person's learning disability (Blair, 2017). This means that a targeted eye examination is of greater importance as symptoms are less likely to result in self-referral for an examination.

Along with the wider population, people with a learning disability and/or autism access primary eye care by attending a community optometry practice (opticians) or being referred to secondary care hospital ophthalmology services. If the person is eligible, the cost of a primary care appointment is met by the NHS, if not they have to pay a fee for both clinical assessment and spectacle provision. People with a learning disability and/or autism are not in themselves eligible for NHS provision, unlike children, older adults, people in receipt of certain means-tested benefits and high-risk groups such as those with a family history of glaucoma or with a diagnosis of glaucoma or diabetes (NHS, 2023). This places the burden on the person with a learning disability or autism to work out if they are eligible for NHS care. Even if the person is eligible, the NHS fee does not take into account the extra time often needed in providing the assessment.

Additionally, evidence shows that accessing these services is a problem for people with learning disabilities, with half of people with a learning disability reporting they had not had an eye test for over 2 years (Help and Care, 2020). Research in special schools shows that 44% of children with learning disabilities or autism reported no eye care history (Donaldson et al., 2019). There may be a reluctance to attend a practice because of the commonly held belief that you have

to be able to read or speak or that the process will be rushed without adequate time for preparation and suitable adjustments (Help and Care, 2020; Wilson et al., 2023). These documented barriers to eye care constitute a health inequality and they have been acknowledged by the government with recommendations for adjustments at an individual and service planning level (National Health Service, 2019; Public Health England, 2020).

SeeAbility has been working at a national and Integrated Care System (ICS) level to influence the commissioning of a specialist learning disability and autism eye care pathway—the 'Easy Eye Care' pathway (LOCSU, 2020) for primary eye care provision aimed at addressing these barriers. The ECC role was initially created as a peer-to-peer health awareness-raising project. It has evolved to educate eye care and social care providers of the importance of routine eye care as well as bringing the lived experience of people with learning disabilities and/or autism into the discussion and planning process for specialist eye care pathways at a local and national level.

This paper details the role of the ECC as a model for lived experience health promotion and explores the experiences of the champions after 4 years in the role, placing it in the context of other similar documented interventions. We believe this information will help inform the future

activity of eye care champions and the development of other 'health champion' lived experience public health promotion roles in future contributing to the existing understanding of how this type of intervention can be used to address health inequalities.

2 | METHOD

2.1 | Description of the ECC service

In 2019, SeeAbility employed four ECCs to work in local communities in London and the North West of England. These paid posts were open to people with lived experience of learning disability and/or autism. The original aim of the role was to provide peer-to-peer support for people with learning disabilities and/or autism to build an understanding of the need for good eye health. The role evolved to include engagement with learning disability, autism and eye care professionals and policymakers at the local, regional and national levels to influence, respectively, the clinical practice of individual practitioners (within existing service/pathway models), and more widely service and pathway design. Table 1 details the elements of the ECC job role.

TABLE 1 The role of the eye care champion's job as set out in the job description and interviewees' opinions on how useful each function of the role is in their work ($n = 4$).

Elements of the role	Is this element of the role useful	
	Yes	No
<i>Making people eye care aware</i>		
People with learning disabilities	100%	0%
Professionals	100%	0%
Planners	100%	0%
<i>The role</i>		
Being a spokesperson	100%	0%
Giving advice, face to face, Email and phone	100%	0%
Find out about events/groups locally	100%	0%
Presenting to groups	100%	0%
Attending exhibitions	100%	0%
Help share messages on different media	0%	Social media is of little use to people with learning disability 100%
Help make training material and activities	100%	0%
Share personal experiences	100%	0%
Contributing ideas	100%	0%
<i>Knowledge</i>		
Know about people with learning disabilities	100%	0%
Understand barriers	100%	0%
Know about reasonable adjustments	100%	0%
Know what services people can access	100%	0%
Government policies	100%	0%

TABLE 2 Levels of activity by region and type of contact.

NHS region	Type of contact				Totals
	Face to face		Online		
	People with a learning disability	Professionals	People with a learning disability	Professionals	
London	146	150	44	1012	1352
Northwest	530	388	211	570	1699
Totals	676	538	255	1582	3051

The ECCs work alongside an eye care pathway co-ordinator (who does not have a learning disability or autism) and a wider SeeAbility team towards the same above aims. The ECCs have support and access technology provided as required under the Access to Work scheme (a UK government scheme which supports those with a physical or mental health condition or disability to work). A training programme was provided over the first 2 months of the role that included face-to-face training on eye care and learning disabilities and autism from SeeAbility specialists (eye care and vision rehabilitation professionals). The ECCs underwent the SeeAbility standard staff induction, completed a workbook which structured information and visits to eye care and social care services. Some changes to the role were enforced by the COVID-19 pandemic. There was a shift from local face-to-face 'eye care awareness training' events and presentations to online activity both nationally and in other regions. This included creating opportunities to present to national organisations such as the General Optical Council (the UK optical regulator that sets standards of practice for optometrists and dispensing opticians), NHS England national and regional learning disability teams as well as other industry and professional organisations and groups.

2.2 | Activity data

Activity data for the period April 2022 to March 2023 were analysed. Service data were collected on the number of people with learning disabilities and/or autism and the number of health and social care professionals that attended events either online or in person.

2.3 | Structured interviews

The ECCs were invited to participate in a 45-min one-on-one online structured interview with the same researcher (M. K.) to explore their experiences providing the ECC role. This researcher has no day-to-day involvement with the ECCs and no managerial responsibility over them. After consenting to participate, interviews took place on the same day in June 2023. An interview schedule (Supporting Information: Appendix S1) was devised based on the ECC job description which guided discussion of the role under three headings: making people and services eye care aware, functions of the role and knowledge needed to conduct the role.

The interviews were recorded in Microsoft Teams and the automatic transcription facility was used as the basis of a transcribed data file. This was then edited by M. K. to form the final text file used in the thematic analysis and formed Step 1 of the analysis.

2.4 | Thematic analysis

The thematic analysis of the individual transcripts used Nvivo 12. We worked to a definition of thematic analysis as '... a method for identifying and reporting patterns (themes) with data' (Braun & Clarke, 2006). We approached this analysis from a realist perspective in that the interviews represented the views of the participants, and we were not seeking to explore their deeper motivations or understanding of the role. We developed themes from an inductive 'bottom up' approach, which develops themes closely linked to the data; our interest was to describe the ECCs' views and experiences of the role at an explicit level, that is not looking beyond the data to develop an understanding of why the participants responded in the way they did (Braun & Clarke, 2006). As researchers, we acknowledge our own biases in being invested in trying to improve eye care services for people with learning disabilities and the potential biases inherent in the ECCs talking about their role to members of their own organisation. We feel that using the researcher M. K., who had no day-to-day contact with the team, to conduct the interviews mitigated this to some extent.

We followed a recognised six-stage process (Braun & Clarke, 2006; Kiger & Varpio, 2020) in conducting the thematic analysis with the initial transcribing of the data being stage 1. The researchers M. K. and L. D. independently reviewed the transcripts and then came together to agree on a coding framework (stage 2). The data were coded by both researchers independently and then reviewed to produce a thematic map (Figure 1) (stages 3 and 4).

We used the Standards for Reporting Qualitative Research reporting guidelines (O'Brien et al., 2014) as a checklist for writing this report.

2.5 | Ethics

We regard this to be a service evaluation and, therefore, we did not seek formal ethics approval. We did conduct an evaluation of the

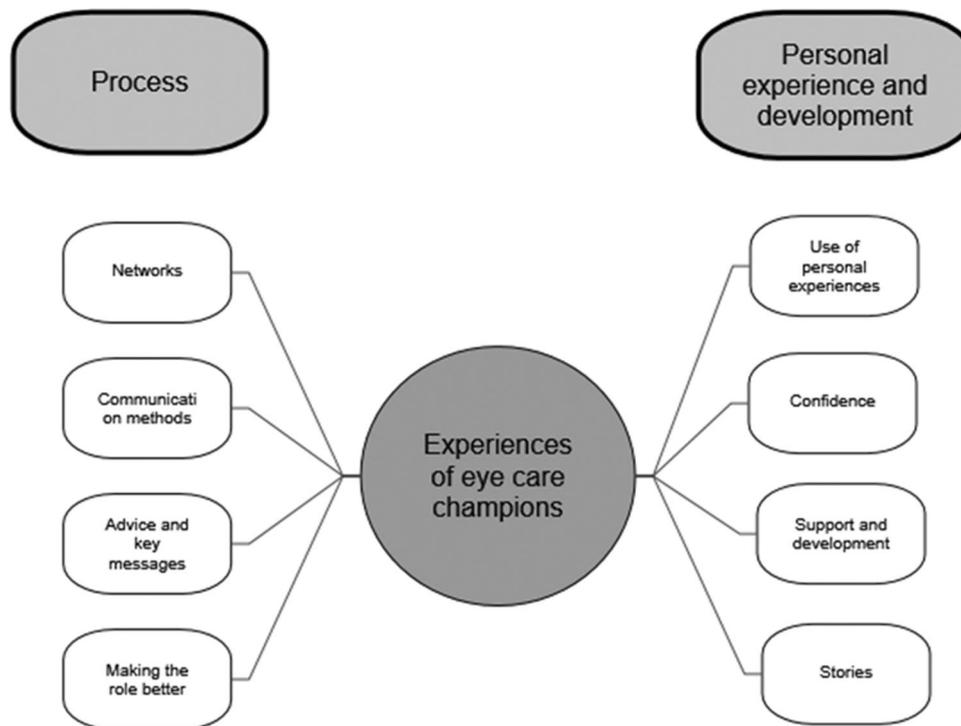


FIGURE 1 Thematic framework.

ethical considerations which is reported on in Supporting Information: Appendix S1.

3 | RESULTS

3.1 | Description of service

Between May 2019 and July 2023, SeeAbility employed four people with learning disabilities and/or autism as 'Eye Care Champions' (ECCs) under paid employment contracts. Two of the ECCs, based in Wigan and Bury, were originally employed to operate in the NHS North West region and two are based in Maidstone and London covering the NHS London region. The roles are part time ranging between 0.28 and 0.6 full-time equivalent (mean 0.46, Full Time taken as 37.5 h). The roles were advertised via SeeAbility's website and social media presence and through networks of people and organisations in the learning disability and autism sector. All four ECCs are still in post at the time of publication. Three of the ECCs are female and one is male.

3.2 | Activity

In total, across both London and Northwest teams, the ECCs had contact with 3051 individuals from April 2022 to March 2023. Of the total, 2120 (69.5%) were with professionals (health, social care and health planners) and 931 (30.5%) were with people with a learning

disability or autism. A total of 1214 (39.8%) were face-to-face contacts and 1877 (60.2%) were online. The Northwest team saw marginally more contacts (1699, 55.7%) than the London team (1352, 44.3%). The Northwest team had a much more even spread of contacts across the two modalities while the London team was heavily skewed to professional contacts online. Table 2 details these levels of activity.

3.3 | The job role of the ECC

Participants were asked during their interviews about the usefulness of each element of their role as set out in their job descriptions. The results set out in Table 1 are unanimous in agreement that all functions were useful except for the use of social media to contact people with learning disability. This was not considered useful because of safeguarding reasons.

3.4 | Thematic analysis

Two broad themes of 'process' and 'personal experiences and development' emerged from the data with a set of four subthemes under each. These are illustrated in Figure 1, the thematic map. We have chosen to include the frequency of each subtheme (Table 3) as it occurred in the data not to draw conclusions about the relative importance of each theme but more to inform the reader as to how often themes were mentioned. Communication methods were

TABLE 3 Frequency of themes and subthemes.

Themes and subthemes	Frequency
<i>Process</i>	
Networks	22
Communication methods	(41)
Face to face	23
Email	3
Social media	10
Phone	1
Leaflets	2
MS Teams	2
Advice and key messages	33
Making the role better	27
<i>Personal experience and development</i>	
Use of personal experience	13
Confidence	10
Support and development	21
Stories	11

mentioned most (41 times) and stories (11 times) the least. The four ECCs are identified as ECC 1-4 for the purposes of direct quotes used.

3.5 | Process theme

The overarching theme of 'process' emerged from experiences that were defined by their relevance to the process of carrying out the role, namely: networks, communication, advice and key messages and making the role better.

The importance of building networks emerged as a crucial step to gaining access to the target audiences of people with a learning disability or autism and professionals. Each contact is linked to another set of contacts.

I contacted learning disability teams and learning disability nurses ..., so I was emailing them telling them all about what we do and got quite a lot of them so we went to their groups, did more presentations from that (ECC3)

The importance of organising this information from the start was noted as was the need to support the ECC in a very structured way to build these networks from Day 1 of their role.

'I would advise [an eye care champion] to try and get contacts as soon as possible when they start' (ECC3). And 'It's about finding out where the groups are,

where we're missing out on the groups and who have not had what, who's had the training and who's not,... then avoid repeating the ones we've done' (ECC2)

In-person meetings were seen as a particularly important communication method with most comments made under the subtheme of communication aimed at face-to-face encounters. The ending of lockdown restrictions was welcomed.

It's been easier since we've been allowed to go back to face-to-face activity (ECC3)

Even though online activity made up a significant proportion of contacts, very few comments on the use of Microsoft Teams were made other than to highlight how the participants had become more skilled at using this method of communication. The same was true for email and phone contacts. All the ECCs expressed a strong view that social media was applicable to professional networks but due to safeguarding concerns was of limited use in contacting people with a learning disability.

I'll be surprised if they read those tweets. I think it's more the people that organise it (ECC1)

Comments on advice and key messages given were split between the type of information given to professionals and that given to people with a learning disability. ECCs felt confident in giving individual advice, which was centred on encouraging people to seek an eye examination and dispelling fears.

everyone should have an eye test once a year (ECC1)

you are 10 timesmore likely to have an eye problem if you have a learning disability (ECC4)

I had an individual once who was scared about going to an eye test during COVID because of all the extra PPE that everyone had to wear (ECC3)

A lot of people always say it's the pressure test, what's what puts people off. The Puffer [non-contact tonometry] (ECC2)

They were also clear about when to signpost onwards for clinical issues.

Many of the suggestions around making the role better crossed over into the development theme but organisationally the need for good planning was highlighted as was the need to actively build contacts through direct meetings. A structured system of support, starting with the induction into the role, was highlighted as being important; this would cover building networks, building knowledge and teaching presentation skills.

3.6 | Personal experience and development theme

This overarching theme emerged from experiences that were defined by their relevance to the individual themselves, namely: the use of personal experiences, confidence, support and development and stories.

Personal confidence in carrying out the role came out as an important factor in delivering training and information and comments were framed in terms of the ECCs growing confidence in the role.

I think it is learning how to build confidence. I think when you have that confidence, it makes it, it makes it easier to just come out when you're doing presenting (ECC4)

I now start conversations before [colleague name] could even get his mouth open. I just wish I'd done that before because I was always the second one to answer any question (ECC3)

ECCs highlighted how their confidence had grown through carrying out the role and that some elements such as presenting skills, use of Microsoft Teams and communicating at conferences could be practised beforehand.

The subthemes of support and development overlapped with many of the other subthemes as improvements to the role were often identified as ways of ensuring personal support to develop skills, knowledge and confidence. The ECCs felt that they had all developed in the role and were more able to carry out their role with less support over time.

... but COVID taught everyone a lot of things that you can work online to do certain things (ECC3)

Being pushed a bit more to start the conversation (ECC3)

... making a guide for new starters so that it says right, you need to find about this.

...this is what happens and this is how it works and it's like a framework, isn't it? (ECC3)

.... Because we built that confidence to do it and then eventually in the future I hope at one point we should be able to build confidence so that if [colleague name] can't make it or if I can't make it then the other can do it on their own (ECC4)

The theme also revealed some specific information gaps.

so it's useful to have more understanding of the formal sort of what social services are available or health services are available (ECC4)

Personal lived experience of eye care, or problems accessing it, came out as a key factor in getting across the messages of the ECCs to professionals and health planners.

so now I explain about when I got headaches. my eyes were getting a little bit worser. So my friend said just go make an appointment at the optician. So I talked about my own story. Because I never wore glasses in my life. And I explain about how you can get headaches. It can affect your eyes quickly (ECC3)

... I never knew that she had a lazy eye and I think people take notice (ECC1)

Because when people hear my story they sit back and go Wow (ECC1)

One champion (ECC3) has a complex eye care history and sight impairment. She talked about sharing her 'loads of experience in eye clinics' with healthcare professionals, explaining that her experiences often make a big impression. 'I made everyone cry [at 100% Optical]' (a conference for eye care professionals) where she told her story of not always getting the right eye care to a large audience. She also referenced feedback from an NHS Big Conversation online conference delegate: 'you were an inspiration to so many, including myself. You have overcome personal set backs to successfully change the world for the better and had the courage to tell your story'.

3.7 | Stories of supporting others

The ECCs were asked for stories of supporting individuals to access eye care. They were all confident that their role was to encourage people to seek a professional eye test but not to advise on an individual's circumstances.

One ECC talked about encouraging someone to attend an eye test when they were worried about their vision but scared because of COVID and PPE. Another successfully pushed for a visiting optometrist eye care appointment for someone she was helping who was living in an assessment and treatment unit and the optometrist came out to him and gave 2 pairs of glasses and drops which were a huge help.

4 | DISCUSSION

Community engagement is used in the planning and implementation of health and wellbeing initiatives as a method to address health inequalities (National Institute for Health and Care Excellence, 2016). Within this umbrella term of community engagement are found both the roles of the health champion and peer/lay advocate (Bagnall et al., 2015; O'Mara-Eves et al., 2013), definitions that can be used to describe the ECCs. Vision awareness training and the creation of

vision champions within professional health and social care staff working in 'intellectual disability' and community services have been described (Dick et al., 2015; Finlayson et al., 2017) with the aim of improving the identification and signposting of vision problems and to help adapt practice to a person's specific visual needs. To our knowledge, the model of a nonprofessional lived experience ECC described in this paper is novel to the eye care sector.

When peer and nonpeer healthcare champions are reported on, the overwhelming majority are in roles of health advocacy and promotion to their target groups (Bagnall et al., 2015) and not advocating health professionals, health planners and commissioners. In contrast to this, almost 70% of the ECCs' contacts were with professionals, planners and commissioners.

In their interviews, the ECCs agreed on the importance of every element of their role (as defined by their job description) except for the use of social media for communicating with people with a learning disability. In its peer-to-peer function, the ECC role is not dissimilar to other reported health champion projects (Hargreaves et al., 2022; Woodall et al., 2013) composing a mix of one-to-one, group and large event interactions but focus on influencing the clinical practice of individual practitioners and shaping service and pathway design and commissioning seems to be unique. Hargreaves et al. (2022) set out a role description for peer alcohol health champions which included the wider aim of working with other members of the community and professionals to influence alcohol policy but the ECCs had the more defined aim to influence the commissioning of a specific pathway.

In common with peer healthcare champion programmes described by Woodall et al. (2013) and Hargreaves et al. (2022), the ECC underwent training for the role and the need for good preparation was highlighted at numerous points which suggests a thorough and well-designed induction at the start of employment is beneficial. Because this is a paid role, it offers the chance to fully utilise the governmental support for anyone with a learning disability or autism within the workplace via the Access to Work scheme.

In contrast to Hargreaves et al. (2022) who reported on the training being too intensive, the ECCs suggested additions to the core training programme. Comments suggested that presentation/communication technology skills were important which would entail training in the use of PowerPoint to create presentations, the use of Microsoft Teams and other video meeting/webinar platforms as well as practice in public speaking. In addition to these practical skills, comments suggest that an induction needed to include key knowledge areas: facts about access to health and social care, eye care epidemiology, key messages, the role of health and social care for people with a learning disability or autism and the policy environment being addressed. The ECCs all agreed that engaging with all stakeholder groups: peers with learning disability, health professionals and service planners was useful. Engaging with a wider range of stakeholders may be useful in planning other similar roles and talks to a wider definition of health advocacy as the promotion of the interests of a defined community and not just the specific needs of an individual (Cohen & Marshall, 2017; Loue, 2006). Work focused

on the peer supporter role in mental health (Kilpatrick et al., 2017) has reported a lack of understanding and support for the role amongst professionals working alongside the peer supporter. In contrast, the ECCs in this study reported experiences with professionals that were successful and supportive. The experience of working with multiple stakeholders was also linked to reports of increasing confidence, knowledge and skills for all the ECCs with time in their roles.

The mix of communication methods by the ECCs was common to other nonprofessional health champion programmes (Hargreaves et al., 2022; Wallace & May, 2016; Woodall et al., 2013) with the exception of the use of social media. Even though social media is increasingly reported in health promotion activities (Wallace et al., 2021), our study found that a strong view was expressed by the ECCs that social media was applicable to professional networks but due to safeguarding concerns was of limited use in contacting people with a learning disability or autism.

After four years in the role, the ECCs were confident in sharing key statistics and messages such as '10 times more likely' and 'everyone should be able to access an eye test'. There was no concern around the ECCs providing, or being expected to provide, individual clinical eye care advice and they were all clear that their role was to promote eye care and signpost to eye care professionals. When considering transferring this model to other areas of health, it is suggested that clear calls to action (in the case of ECCs, the need to have an eye test) and effective clear messaging (here around the incidence of eye problems and how to access eye care) are established at the outset. Hargreaves et al. (2022) reported the successful use of similar clear unambiguous messaging on alcohol limits and legislative alcohol controls in delivering the alcohol health champion intervention. Because the eye care sector focuses promotional activity on retail (sale of glasses and contact lenses), which can be a barrier for people with learning disabilities who often have a lower income (Emerson, 2007) signposting a clear healthcare message is vital to improving uptake of services.

The results suggest the ECCs were successful in exploring and developing a network of contacts both peer and professional. Some comments from the ECCs suggest that at the outset, the building of a network could be more systematic and planned. Work has shown that experiencing social support and connectedness in health advocacy programmes is critical (Agarwal & Brydges, 2018) so it can therefore be hypothesised that receiving messages from peers and/or people with lived experience to make messaging relatable and 'personal' is impactful and this is borne out by the reports of the ECCs. Reports of positive impact following engagement with people with learning disabilities and eye care professionals indicate this model has a positive, emotive impact on eye care professionals. The lived experience championing of an unmet need was reported to have a direct impact in terms of encouraging individuals and their supporters to seek eye care and this is a common finding in peer health champion interventions (Woodall et al., 2013). The positive and, in some cases, emotive response of professional audiences is worthy of note and an area for potential future evaluation.

All the ECCs talked about how their confidence improved with time and there was a strong theme of personal development and becoming 'experts' as they grew in their role. Woodall et al. (2013) noted this positive effect on personal development across a range of other similar projects, with improving self-esteem and confidence in the role being personally transformational, leading in some cases to further education and employment. They also reported on positive health benefits which the ECCs did not mention. With only 5% of working-age adults with a learning disability being in paid employment (NHS England, 2022) employing people with lived experience as health champions addresses an employment need, aids personal development and most importantly allows the system to benefit from that lived experience. The retention of all of the ECCs over the 4-year project suggests that the role offers a sustainable opportunity.

Well-planned and accessible eye care services enable everyone to make the most of their vision through the use of optical correction such as glasses or contact lenses. When vision is impaired the level of impairment needs to be understood by everyone involved so that effective adaptations can be put in place. When eye disease needs to be treated or managed eye care services need to make reasonable adjustments in delivering care. Lack of access to services or poorly designed services that do not meet the needs of people with learning disabilities or autism constitutes a health inequality.

Barriers faced by people with a learning disability and/or autism in accessing eye care are common to those found in other health areas, namely, difficulties with communication, poorly adapted clinical environment and a lack of staff training and confidence. (Black et al., 2020; Turner et al., 2013). In this model, the ECCs work at an ICS level to influence the commissioning of specialist learning disability and autism eye care pathways (LOCSU, 2020) for primary eye care provision. Such planned services with additional staff training, adequately funded clinical time and service auditing and support offer the opportunity to address this health inequality at a system level beyond the reliance on reasonable adjustments of existing provision. The work of the ECCs in the NHS London region has led to the launch of just such a specialist service, the South East London Easy Eyecare Pathway in 2023. (Miller, 2023).

4.1 | Limitations

This study set out to explore the experiences of this novel intervention and by doing so it builds our understanding of one, narrow, but important aspect of the programme, how it was perceived by those working as ECCs. It suffers from the potential bias of the researchers being part of the same organisation as the subjects, all working towards better access to eye care for this population. The group studied is small but the service is the only one of its kind. The wider picture that now needs to be addressed is how the programme is perceived by those it interacts with. Does it influence behaviours and result in positive changes? Do people with learning disability and autism go on to access eye care as a result of their engagement with the ECCs? Do health and social care professionals

change their practice? And most importantly, do health planners address the needs of this group by putting in place tailored pathways?

5 | CONCLUSIONS

The paper presents an innovative model of eye health promotion which takes a multifaceted approach to awareness raising by sharing key eye care messages with people with learning disabilities and/or autism, their supporters, healthcare professionals and health commissioners. The model and experiences reported share many common features with other similar projects outside of eye care. The ECCs found the role useful and reported confidence in their practice and impact grew with time but required support. A good understanding of the promotional messages was reported. Developing a good network of contacts, both people with learning disabilities and/or autism and healthcare professionals at an early stage was key. Both face-to-face and online communication methods were reported as successful, but a strong view was expressed that social media was applicable to professional networks but due to safeguarding concerns, it was of limited use in contacting people with a learning disability and/or autism.

Relationships with professionals were supportive and positive and a positive emotive response to their lived experience was reported in these interactions. The findings suggest the role of lived experience ECCs as described is seen positively by those working within it.

CONFLICT OF INTEREST STATEMENT

The authors are employees of SeeAbility.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Marek Karas  <http://orcid.org/0000-0001-9939-6604>

Lisa Donaldson  <http://orcid.org/0000-0003-0486-5952>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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