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Developing awareness of deafblindness in health and social care provision for older people.

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Introduction

Deafblindness is most prevalent in later life, with 87% of those with more severe dual sensory impairment aged 60 or over (Robertson & Emerson, 2010). The difficulties with communication and mobility caused by deafblindness are particularly profound for those in later life, where acquired communication disorders often coexist with difficulties in independent living, access to support and social isolation (Pavey, et al., 2009). Social isolation, which is a negative outcome in its own right, also means that people with dual sensory impairment may not be known to those health and social care services which could provide support for them. When deafblindness is under-recorded, it is likely that there will also be under-provision of appropriate services for people who are deafblind. Therefore, identifying people who are deafblind within the community is crucial to both deliver necessary support and appropriately assess the level of support needed across a community.

Recognising and assessing deafblindness

Recognising deafblindness for service providers such as social and health services and care homes can be difficult. Frontline staff require training to be aware of dual sensory impairment and how this affects the provision of advice and signposting to services. While health and service providers may be aware of their duty to identify, contact and keep a record of individuals with deafblindness, there is likely to be less awareness of the impact of other disabilities in masking dual sensory impairment, something which may be more critical to older people who may have other physical or mental impairments due to a stroke, dementia, Parkinson's, learning difficulties, which could reduce the likelihood of a diagnosis of deafblindness.

Local authorities in the UK have a duty to assess any adult who appears to have a need for social care or support, such as people who are deafblind. This issue has important implications for training – not only for those staff involved in assessment, but also for those who have a client-facing role who would be able to make an initial basic assessment of deafblindness and then refer for appropriate specialist assessment. Knowledge of deafblindness is needed to correctly assess individuals, and social care professionals with such specialist knowledge are more likely to identify the impacts of dual sensory loss (Sense, 2013).

In Good Hands

Preventative services delivering social care to support people to live independently can help reduce social isolation and improve quality of life. Furthermore, such provision can decrease the burden on the existing health and social care system (Goodwin et al., 2012). In Good Hands (Scene, 2013) is a project run by Scene Enterprises and funded by the UK Big Lottery Fund (www.biglotteryfund.org.uk) to both build capacity of organisations and services to support people with deafblindness, and to increase the number of older people identified with age-acquired deafblindness.

In Good Hands is a programme of awareness raising, training, qualifications and opportunities devised and developed by Scene Enterprises CIC and utilised by In Good Hands to support older people with deafblindness. In Good Hands also delivers support and training around age-acquired communication disorders to local authorities, care homes and other stakeholders.

The intended outcomes of In Good Hands are:

- Effective communication between volunteers, care givers and older deafblind people
- Improved mental health and physical wellbeing of older deafblind people
- Increased confidence and knowledge of how to access services and specialist equipment available to support people who are deafblind
- Support older deafblind people to maintain their independence and to re-engage in social and community activities.

These outcomes were approached through raising awareness of deafblind issues and providing specialist training to health and social care staff, volunteers and families to ensure they were better equipped to identify, assess and support older deafblind people and ensuring that community organisations with volunteers are better placed to reduce the social isolation often faced by deafblind people.

Methods

Design

An action research approach (Minkler & Wallerstein, 2008) was chosen as it offered an evaluation framework which emphasised the need to work closely with those developing and delivering In Good Hands as well as the service users who are likely to benefit from the project. As a result, a range of data were collected from multiple sources, including dialogue with the project team in order to understand and identify new developments, a review of existing literature, training for volunteers to take an active research role, interviews with people who have completed one or more of the training packages provided to inform content of questionnaire, an online questionnaire for people who have completed training and interviews with deafblind people.

Participants

A total of 16 people were interviewed about their experiences and impact of the training. A further 17 interviews were carried out with deafblind people. Although in this paper we focus on the impact of the training on policy and practice. We also analysed monitoring data to find out how many people were trained, as well as the sector they came from.

Ethics

Ethical approval for this evaluation was provided by the Teesside University School of Health & Social Care Research Ethics and Governance Committee prior to the start of this evaluation.

Data Analysis

A thematic analysis was conducted (Braun & Clarke 2006) using NVivo10, a qualitative data analysis programme, to manage the data and aid analysis.

Results

Uptake of training

Training was provided free of charge and was open to all sectors that had some contact with deafblind people. This includes the public, voluntary and independent care sector, voluntary organisations and individuals e.g. families and voluntary carers. All 12 local authorities in the North East of England participated in the training.

Monitoring data collected by IGH shows that over an 18-month period 1443 people successfully completed some form of accredited training through the programme. This included 355 social workers trained as specialist deafblind assessors. Some people completed more than one course. Just over half (52%) of completions were for the foundation course, with the remainder evenly split between specialist deafblind assessor, communicator guide and acquired communication disorder training. This was expected given the aim of raising awareness and this also provided a basis for people to move on to the other more advanced courses.

A further breakdown of course by sector shows that the voluntary sector (509 people completing training), independent (245) and public sectors (633) engaged well with the training, along with 56 who were not affiliated with any organisation. The voluntary and independent sectors (primarily social housing organisations and the care sector) engaged well with the foundation training. The majority of public sector involvement was around the Specialist Deafblind Assessor Training.

Interviews

Awareness raising

Participants reported that their awareness of deafblindness and its effects on people had increased as a direct result of the training. The foundation level training provided good insight on identifying signs that a person has a dual sensory impairment. The training had an impact from raised awareness at operational and individual levels, with some changes beginning to be instituted at strategic/policy level. Individuals completing the training reported benefits of increased awareness in both their work

I learned so much that I hadn't even thought of before and feel more able to help people who can't see and are deaf.

and personal lives

It has even made a difference for me with my family. I find I am passing on information to other members of my family.

There was a general view that the training raised awareness of deafblindness, provided reassurance and reinforced prior learning. Given the numbers who have completed the training and the geographical spread, this was a good step towards informing support and services further in the future.

Improving confidence, knowledge and understanding

Participants reported that prior to the training, they felt providing care and support for deafblind people could be complex and that they lacked the confidence to do this. However, participants felt that the training increased their confidence in engaging, communicating and supporting deafblind people.

Some of our staff who haven't done the training panic if they come up against someone who is deaf and blind. I would say that all of the staff who have done the training are a lot more confident to be able to support them much better.

The majority of interviewees reported improved confidence which helped them to work more effectively with deafblind people. They reported a link between increased knowledge and understanding which resulted in increased awareness and confidence but also the ability to be more effective in their work with deafblind people.

The training gave most of our care home workers a better insight into how day-to-day life was for one particular client. It helped us to be able to focus better on his needs.

Improved communication skills

Communication was identified by participants as a major problem when working with people who are

deaf and/or blind, and they reported communication was more problematic for people who are deafblind. For those who are providing care, adequate communication with deafblind people is essential if their needs are to be met. Communication skills were covered to varying degrees within each of the courses but responses focused on personal development and improved communication with clients:

Knowing even a little bit about talking to them [people who are deafblind] properly has made a difference to me.

Participants also reported using the skills learned to communicate with clients:

One lady I work with, I do finger spelling [Deafblind Manual] with her. I showed her how it works and she does it back to me. We are still learning and I've got to do it slowly because she struggles with it a bit but it's working. She can now tell me what it is she wants.

The communication elements of the training were viewed very positively. The practical elements also helped in terms of putting learning into practice.

Changes in working practices

Those who had been through training reported changing their working practices, primarily in relation to improved ways of communicating, assessing needs and supporting clients. Training was reported by many as leading to changes in their working practices.

At an individual level, people recognised the need to change the way they work with some clients in order to better meet their needs. Comments included:

It [the training] really makes you think a bit more. I used to put their plate of food down without actually telling them where it is or what it is. Now I go in and say you've got this and then tell them whereabouts on their plate it is. I just hadn't realised what I was doing was so clearly wrong.

Changes in practice were also reported at an organisational level in terms of checking whether deafblind people are present in groups, making support aids such as magnifiers and plate guards more widely available and ensuring hearing aids are well maintained. Some are in the early stages but serve to highlight the potential impacts the IGH training can have on organisations working with and/or supporting older people meaning those with a high likelihood to include older people with age related dual sensory impairment or loss. These changes are unlikely to have happened without their participating in the training and that these changes do ultimately impact on the quality of service client receive.

Organisational changes

Training affected operational working within organisations. For example, a voluntary organisation that had adopted a telephone contact system for all referrals recognised this would not work for deafblind people and offered face-to-face contact to clients. Other organisations committed to getting as many of their staff trained as is possible and where possible, to cascade training down to all staff to facilitate changes in practice. One participant stated:

Quite a few of us did the training and then we fed that down to all of the leads across the area so every centre had a lead. Then each of the leads arranged meetings with their staff to disseminate the training [...] especially the practical exercises.

There is some evidence to suggest that the learning and tools available within the training resulted in some changes to handbooks and care planning:

We have made some amendments to our handbooks and added some questions to our assessments to make sure we find out if a person has hearing and sight problems. Now all the staff are doing this whether they have done the training or not.

As a result of the training, a voluntary sector organisation recognised that “touch” is a key aspect of communication for deafblind people and so amended its “No Touch” policy so that those with hearing and sight loss may consent to include touch as a communication aid providing it is appropriate and culturally acceptable. Another organisation providing support to elderly and vulnerable adults ensure they identify people with hearing and/or sight problems seat them close to the group facilitator.

Improved services to clients

Overall, participants felt that training had resulted in improved services to clients. Those who had completed training reported making changes to their everyday practice to improve their communication with clients, such as “letting them know I have arrived by touching their shoulder”, explaining what is on their plate and where it is placed and “writing notes in very large bold print”. Such changes contributed to improving the quality of life of clients.

Many participants reported that the training sessions provided an opportunity for them to meet others working with these clients, learn from each other and better understand about other services available. Examples are beginning to emerge of some partnership working as a result of these developing networks. The awareness of other available services and useful equipment has also resulted in referrals for new services being made and the use of additional aids to support those with a sensory impairment.

Access to services such as hearing aid maintenance resulted in improved hearing for some people. For many elderly people with hearing aids, maintenance can be a problem as batteries and tubes need changing regularly. Finding there are services available to do this resulted in fewer problems with hearing aids, fewer visits to audiology departments for repairs and reduced frustration from service providers and clients alike:

It makes a real difference to me when my hearing aid is working properly. It opens everything up for me.

Much of the training was aimed at improving support for clients. Improved communication skills and relevant services and equipment have a role in clients retaining their independence. Those living in residential care were keen to maintain some independence. One care home resident stated:

I like it here and they do look after me well but I like to be able to do things on my own. Now my hearing aid is working properly, I can join in some of the things they do here, talk to my family on the phone and get on the bus and pop into town if I want to and I really love that feeling.

While clients may not realise that improvements in their care or services are linked to the training, they did recognise changes in practice and reflected on the benefits. People who completed the training continue to confirm that such improvements are the result of the training and unlikely to have occurred without it.

Increase in numbers of deafblind people identified and registered

There was evidence that organisations were identifying increased numbers of deafblind clients. There was a perception that as staff begin to know what to look for, they were more likely to identify deafblindness. Dual sensory awareness and communication skills were embedded in a range of workshops aimed at older people including healthy nutrition, good hydration, money management and wellbeing and safeguarding workshops. “Talk & Try” events were designed as a way of identifying elderly people with sight and hearing problems and providing support, through advice/information, referrals to relevant services or an opportunity to test equipment. These events were positively viewed by those who attended.

Discussion

The In Good Hands project’s key aims were to raise the profile of dual sensory impairment and provide training to improve the skills of people providing care and support to older people. The widespread uptake of this project across sectors indicates the need for dual sensory impairment training. Prior to the project, such training was not readily available. The practical nature of much of the training promoted identification and communication skills, and helped participants to see clearly how to put that learning into practice.

IGH provided new skills to the health and social care workforce to facilitate the identification of deafblind people. Existing literature is clear that while the numbers of deafblind people are increasing they do not truly reflect the full extent of the problem which means many do not receive the services they need. Raising awareness and improving communication are important steps in supporting those who are deafblind, and this work is starting to influence policy making at a local level. Training was

cascaded to other staff and practices were changed at an operational level by staff in client-facing roles.

The In Good Hands project has also led to policy change as a result of the raised awareness and better understanding of the issues of communicating with people with dual sensory impairment, such as reconsidering “no touch” policies and having face-to-face meetings. Changes to policy, even at organisational level do not happen quickly. The fact that these changes have been made in such a short time indicates that the training has been beneficial and raised institutional, as well as individual, awareness of deafblindness.

Conclusion

Older people who are deafblind are likely to be missed by providers of health and social care. This project has demonstrated that delivering training to frontline care staff can lead to real gains in terms of both the support and the identification of people who are deafblind.

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