

CONSULTATION QUESTIONS

1. The strategy outlines a care pathway (page 10).

(a) If you are a service user and/or carer, please tell us what difference you believe the implementation of the pathway will make to the services you experience.

(b) How can we best ensure that services and support meet your needs?

(c) If you are a care provider, what changes will you need to make to implement the pathway?

(d) How will you make these changes?

2. The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7).

(a) Which of the key factors are most important for a successful pathway?

Given:

1. the broad range of (a) people with single / dual sensory impairment or sensory loss, and (b) those who are congenitally deaf, blind or deafblind
2. that the strategy considers the full life / age spectrum
3. the significant differences in presentation and need as well as associated service response for this diverse demographic

effective and relevant training to include awareness raising, CPD, post-qualifying specialisation, and at all levels of service delivery and formation, will be critical if the care pathway is to be successful.

(b) Which are the most challenging to put in place?

A significant portion of workers and professionals at all levels who come into direct contact with this range of people lack basic practical awareness of the key ways in which sensory loss and impairment / congenital deafness, blindness or deafblindness can impact on individuals' ability to interact with and negotiate their world.

This complexity is compounded when the members of these groups also have additional disability/ies or conditions(s) (for example learning or physical disability, mental illness, autism).

Given the prevalence of deafblindness/dual sensory loss in the aging population and what we know about:

- its non-diagnosis;
- misdiagnosis as single sensory loss or impairment, or as the onset of dementia (“they get very confused when I am speaking with them”: see example 3 below) or other condition;
- the compounding interaction with other conditions;

investing in appropriate expertise in order to provide quality awareness training, basic diagnostic skills and higher level professional skills will be critical and is likely to be one of the most challenging factors in ensuring successful care pathways.

(c) Do you think that any key factors have been missed?

3. The strategy identifies areas for action that should be addressed going forward (Page 13-16)

(a) Which of the areas for action will be the most challenging to implement?

It is difficult to identify which will be most challenging to implement as many (if not all) are significantly inter-related.

Person-centred and cost-efficiency seem to be key drivers within the strategy. However, cost-effective can only happen if needs are correctly and clearly recognised. For example: all too often third sector organisations work with people who have a mis-diagnosis of single sensory impairment/loss and receive mis-appropriated professional support and services that (in effect) represent, in financial terms, budgetary waste. Such financial waste can only happen in a work setting where staff at all levels lack the expertise to recognise the indicators of dual sensory loss/impairment and the mechanisms by which appropriate referral and assessment can happen.

The three examples which follow are commonplace and demonstrate the difference that even basic awareness and training can make.

Example (1) .– many outpatients and doctors’ appointments take place in a room where the doctor sits with their back to the windows effectively exacerbating the visual difficulties a number of their patients may have. When combined with a hearing loss that too is exacerbated as the visual clues the person may use to support their hearing are not available due to the position of the speaker. As noted in the consultation document, many older people acquiring a sensory or dual sensory loss don’t self diagnose and may be unaware that (for example) deteriorating hearing is often unconsciously compensated for by their use of visual clues and by (untrained) lip reading. If their vision is also deteriorating then factors which limit their ability to pick up on those visual clues will also impact on their functional hearing.

Example (2) – within a home care setting - low level awareness training about the impact of environment, lighting and acoustics might lead a level 2 worker to report to their supervisor that the person they support appears to be struggling in certain settings or certain environmental conditions. With adequate training, the supervisor will be aware of the indicators of deafblindness / dual sensory impairment or loss and of the correct referral routes.

Example (3) “behaviours associated with severe vision or hearing disorders are often attributed to reductions associated with age related cognitive decline and dementia” Lyng K, (2005) **Deafblindness in the future: acquired and age related**

In relation to being ‘suitably qualified’, the reality is that there is a dearth of appropriately trained care workers and professionals. This submission is being made by the director of the Deafblind Studies programmes, a professional level course which resulted from a cooperative partnership of cross UK agencies including Deafblind Scotland and Sense Scotland, each with different but complimentary interests in deafblindness. The project was initiated to:

1. address the frustration felt by deafblind people, practitioners and voluntary agencies (working in the field of deafblindness) which resulted from the poor standards of knowledge and expertise that were evident in the care sector; the sector charged with delivering services to deafblind people. The direct result of these issues was a continual catalogue of omissions and mistakes in the type and level of service offered to deafblind people of all ages, both in the community and in care environments.
2. ensure that this highly skilled and specialist area of work was supported by a recognisable professional qualification. The partners had felt that the opportunities to learn and gain qualifications in this area was limited and did not reflect the complexity of issues faced by deafblind people and those who support them.

With only one local authority worker in Scotland having undertaken the course and evidence from the partners that this complex condition is still not being picked up this reiterates that the most challenging area for action lies in understanding and awareness brought about by training.

Following on from this challenge will be the availability of funds to extend the reach of existing training and also funding to facilitate the undertaking of appropriate training.

(b) Which of the areas for action will make the biggest difference and why?

Training – for all the reasons noted already.

(c) Are there any other areas for action that you would like to see included within the strategy?

Anecdotal evidence suggests that the deficit in critical understanding of the true nature and impact of sensory loss generally, and dual sensory loss or sensory loss combined with other disabilities and/or conditions specifically, exists at all levels. This seems to be true not only across the workforce (hands-on to senior management) but also, more significantly, at strategic planning levels. Inevitably, this has the potential to result in misinformed discussion about what is thought to be needed and a consequential cascade of misinformation, misunderstanding and poorly directed funding to address what should be done.

Anyone involved in the decision making process that results from this consultation - ministers and policy makers, strategic thinkers etc – must make themselves aware of the issues about which they are making decisions.

4. Please comment on the current provision of sensory impairment services as either a service provider or service user. If you have any experience of sensory impairment services, please let us know what you think of them: this should include any experience of one-stop shops.

If services include training and development for those staff tasked with responsibility for supporting people in relation to needs which result from their sensory status then adequate training and associated funding needs to be made available to support its implementation.

Mandatory qualifications meet that need in part. However, specialist workers need specialist training. Greater emphasis and improved status for existing programmes of specialist training alongside investment in the development of specialist units which integrate into the SVQ structure, and at all levels, will be essential in equipping the workforce to both meet statutory requirements and to deliver economical appropriately targeted services.

A number of pertinent quotes from a recent survey of past students from the Deafblind Studies programme are included below by way of underlining the importance that must be placed on appropriate training development and implementation:

“The learning from the [Deafblind Studies] course is unique and gave me a perspective of both Congenital and Acquired Deafblindness. In my role as a manager of [organisation’s name removed to maintain confidentiality] learning disability services I am involved in a number of strategy groups. As learning disability and sensory loss both sit within 2 separate strategy groups, I am a member of both groups. The learning from Deafblind Studies has enabled me to raise awareness amongst others on these groups and given me the broader knowledge to be more effective in my input in the broader sense of deafblindness.”

“I had never actually learnt about deafblindness in depth before only basic so it was vital in making a positive impact on my practice and the service I work in.”

“In both the areas of congenital and acquired deafblindness I found that I became more confident and knowledgeable and, as a result, was able to advocate more professionally, effectively and in evidence based ways, with and for the deafblind people I supported. There were times when the arguments I was able to construct or the information I was able to refer to, which were the direct result of my learning from the diploma, became hugely significant.”

“I would like to see this course return to Scotland, particularly as the "See Hear" Sensory Strategy is up for consultation. I would strongly recommend that specialists, local authority "champions", social workers in the sensory field and assessors for the Welfare Reform -SDS, take this course to ensure that there is a far better understanding of what is actually involved with their client groups.”

5. What difference will the implementation of the strategy make to your life?

6. Does this strategy properly reflect the current climate and developments in policy and practice for children and young people particularly in relation to the Getting it Right for Every Child approach and the Doran Review?

7. Do you have anything you wish to add to the Sensory Impairment Strategy or any other general comments that have not been covered by the questions?