

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.

N/A

Deafblind Scotland supports the principles within the strategy, however, would want to draw attention to areas where additional consideration should be given both before and/or during implementation. DBS would also endorse as one of the partner organisations the submission from Deafblind Studies.

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

By ensuring that services and standards are set in a manner which is not a 'race to the bottom' but which reflect the outcomes as identified in documents such as 'Seeing it My Way' and the principles of Co-production in achieving citizen outcomes putting individuals at the core of all within the strategy.

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

At this stage and in light of the recent report published this week where MSP's on the Scottish Parliament's local government committee called for urgent action to address the sluggish pace of reform two years on from the Christie Commission, which recommended wholesale changes to the way services are delivered.

DBS would have grave concerns around how pathways are going to be developed locally (recommendation 4) as the strategy calls for these but does not provide them. Further as the lower incidence disability of severe dual sensory loss/deafblindness at its highest estimated numbers (even in our ageing population) of 5000 or so citizens this would equate to a very small number within each locality and therefore high risk of this group and the services required being lowest on the priorities for inclusion in pathways locally.

(d) How will you make these changes?

See answer C however in any changes Workforce development should be central to any strategic developments and implementation.

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?

Having a hierarchy of key factors is not helpful in as much as the priority of importance for individuals who live with deafblindness/dual sensory loss will perhaps

differ from those with a single sensory loss and across the generations. However this said for DBS the most important factors are;

Bullet 1, simplicity around referral routes and accessible information for patients/users

Bullet 3, not only consideration to sensory impairment within generic assessment consideration requires to be given to the significant differences in presentation and diverse demographic with which deafblindness/severe dual sensory loss will present this will include; within the ageing population, those living with physical disabilities, those living with congenital conditions, to name a few, and, will require specialist training to ensure appropriate assessment and therefore 'journeys' on any pathways developed.

Bullet 7, equivalence of practice across Scotland

Bullet 8, a commitment to awareness raising training for front line staff although DBS would also like to see effective and appropriate training to include, CPD, post-qualifying specialisation, and at all levels across all partner agencies.

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

Bullet 6 & 7, Consistency of approach across Scotland as identified earlier if the Scottish parliament committee has no confidence that this has been occurring across Scotland post Christie report why would there be confidence that this strategy would experience a different reality.

Bullet 2, Gathering information – until there is an agreed national 'portal' for information gathering across all the partner agencies with relevant data sets agreed this exercise will be fragmented at least and cost prohibitive at best.

Bullet 3, implementing across Health and Social care whether it be acute, primary or social service would be sensible at a very basic level, however, the implication of ensuring that all staff across all levels of assessment processes are suitable aware of and can assess to refer in sensory impairment may prove to be the greatest challenge, although this DBS believes would be a step change and is the correct direction of travel.

Bullet 4, Screening as with bullet 3 is a culture change and an addition into screening 'regimes' already in place, time and patience will be required to ensure implementation.

Bullet's 1, 3, 4, 5, Ensuing deafblind/dual sensory impaired individuals have appropriate communication support to engage when any of these key recommendations are in place will be challenging due to the shortage of skilled workers and a lack of funding to finance the specialist communication support.

In the current financial background here is a need to achieve as much as possible without taking resources away from service provision.

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

As with concerns raised earlier around the lack of or slow progress of reforms concerns within DBS and our membership is that this strategy could be ignored almost in its entirety as the term 'commitment to' rather than any kind of requirement with measurable outcomes is prevalent throughout the strategy and the key factors.

Missing is also any supporting evidence that single points of access actually deliver good outcomes for individuals, although they may deliver on efficiencies within fiscal considerations does this translate in to positive outcomes and/or experiences for citizens

There needs to be tangible key factors identified in respect to information gathering and sharing in the drive to shape services and supports for the future, this may for example include the identification of actual data management systems to be used across the sectors or actual portals for information 'pulling'.

Post diagnosis support and sign posting for those newly diagnosed with sensory impairment appear to be a vital but missing aspect of the strategy.

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?

At the risk of being overly simplistic all of the areas for action which require 'new' streams of financial support will be hard to argue for in terms of local priorities and local planning especially as the strategy articulates commitment to but not requirement from.

The audit in **recommendation 1** will require robust arrangement for the parameters of the exercise and DBS would ask if this will include costs from Acute services including surgery, through to optometry on the high street? And all the areas of spend in between which may include research grants, third sector provision which is not public funded, specialist educational support etc.

The who, what, why and how of any audit requires careful consideration and a view on how to include the costs across the sectors and across the co-morbidity of conditions within which sensory impairment costs may be hidden or indeed appropriate sensory impairment action may reduce costs ie in falls prevention where if appropriate support for someone with dual sensory loss is provided falls may be reduced therefore reducing costs in this area. A very challenging and potentially costly recommendation, however, has the potential to yield returns for planning of best value, person centred, sensory impairment strategy across all areas.

Recommendation 2 will probably not be implemented as it requires only a consideration but has no measurable outcomes to be achieved at local partnership levels. This is a recommendation where audit information could inform how this recommendation can be realised. Getting all to agree that rather than looking at the Sensory screening as additional but as something which can inform and support within generic and specialist provision will be the challenge. For example inclusion within assessment for dementia may change the assessment outcome as often (from research findings) dementia is misdiagnosed when sensory impairment, in particular dual sensory loss are overlooked. ("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)

Recommendation 3 A challenge will be in agreeing what this looks like and in how this will be funded, however, if there is no measurable outcome then it is unlikely to be addressed across Scotland in any standardised way and therefore will not mirror any of the requirements of current ‘mandatory’ training.

Recommendation 4 provides a challenge, not least because in order to reflect the needs in a local area the information on what these needs are is required, as is evidenced from recommendation 1 and from other areas of this strategy need in respect to sensory impairment is not clearly identified and/or understood and in particular, as stated earlier, for individuals who live with deafblindness/dual sensory loss this is even less so. If local partnerships are not performing, as highlighted earlier, in that they either do not exist or the pace at which they are effecting change is sluggish at best then to have budgets devolved for this recommendation on top of budgets from other sources to effect change, and evidence without tangible outcomes seems premature.

Further the lack of GP involvement as often a first and only point of contact in the sensory impairment ‘journey’ seems to be remiss within the strategy.

Recommendation 5 - As stated earlier, Gathering information – until there is an agreed national ‘portal’ for information gathering across all the partner agencies with relevant data sets agreed this exercise will be fragmented at least and cost prohibitive at best. There are several challenges here in that individual personal information around diagnosis from birth onwards is confidential and requires a shift in respect to our understanding and access to confidential information and data protection. There is also the exercise of mapping local resources may be done using models such as that hosted by The ALLIANCE, a project called ALISS which asset maps local resources and offers a resource rich information environment at a local level.

Recommendation 6 the challenge here is that the onus is on the individual to take forward a challenge under the Equality Act, this can be a barrier for people with dual sensory impairment/ deafblindness and as a result no one seems to be enforcing the Act.

DBS feels that underpinning all the challenges to implementing the recommendations within the strategy is a recognition that there are interrelated recommendations which have fiscal implications in a national and local environment where there are and have been and will be competing priorities such as the introduction of the Self Directed Support Bill, the implementation of the Doran Review, The Public Bodies (Joint Working(Scotland) Bill 2013 to name a few, however, DBS also feels that with the implementation of a See Hear strategy over 10 years and with some ‘teeth’ within the strategy it should and could sit within the landscape of other changes and be incorporated into the change programmes and activity already underway.

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

Recommendation 3. The other recommendations are the most challenging is so much as they will only impact with considerable injections and redirection of resources, which will possibly take the time scale of the strategy to achieve.

Recommendation 3. If carried out successfully its impact will be far reaching and benefit individuals living with deafblindness/dual sensory loss and indeed anyone living with a sensory impairment. Not least because accessibility to support and services and by extension equal citizenship will be achieved.

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

Specific, Measurable, Achievable, Realistic, Timed targets for all partners involved in this 10 year strategy

Workforce development is a gap.

More tangible links or inclusion with other strategies in Scotland where it appears there is duplication of effort where common goals are trying to be achieved. For example the dementia strategy, the falls strategy, stroke strategy, diabetes strategy to name but a few. There needs to be a strategic overview of strategy within Scotland with respect to health and wellbeing in its broadest sense and some way of linking or pulling resources where there is common ground.

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.

In DBS's experience the current provision is patchy across Scotland when it comes to recognising the specific needs of deafblind/dual sensory impaired individuals. There is little awareness of the individual communication and support needs in particular the lived experience of DBS members is that in the main services try to support the single sensory loss with the addition of the second sensory loss and underestimate the impact and changes a combined loss brings.

There is no preparatory intervention when it is known that dual sensory loss is inevitable for example the training in alternative communication methods, counselling support for the loss of both senses etc.

Provision in the main for deafblind/dual sensory impaired individuals living in their own home is often following some type of community care assessment. Where support may be identified there seems to be a drive to 'pigeon hole' this support into housing support or care at home support, and no actual recognition that an individual can require guiding and communication support, as a unique form of support, requiring specialist skills to perform as the 'eyes' and 'ears' of an individual and not particularly in a 'care' role. This type of support is separate from the interpreting support a Deaf person who communicates using BSL requires, which is recognised as interpreting support. However it is the experience of DBS that where an individual is a Deaf BSL user and they lose their vision and require to change to a Guide Communicator for support as they can no longer see the BSL this is 'downgraded' to

a form of care support.

When facilitating at recent consultation events, was evident that the more articulate views of individuals capable of advocating for themselves was prevalent however as the research informs the higher numbers of those living with dual sensory loss/deafblindness are those in older age groups and are far less likely to attend these events or reply to consultations.

Current services within One stop shops include specialist organisations in single sensory impairment no dedicated provision is available to support those living with deafblindness/ dual sensory impairment within these settings.

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

For DBS it will make our role as a membership charity representing Deafblind People in Scotland far more challenging with 32 local authorities and potentially 32 partnerships to engage with it will be difficult to support those hardest to reach and make meaningful contributions to partnerships.

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?

DBS do not work with children under 16 years of age, however, our opinion at this point in time is that the strategy can do no more than acknowledge the need to develop a cradle to the grave approach in Scotland and perhaps should be clearer that 'joined up' services and strategies are not mature enough in their development for it to be more than an intention for the future.

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?

Deafblind and Dual Sensory Loss are one in the same disability and interchangeable terms and should not be separated within the body of the strategy for fear of creating the impression that they are being considered as two separate and distinct disabilities when in fact they are degrees of the same.

DBS would want as with the (Deafblind Studies submission) the term deafblindness to include all degrees of dual sensory and not just those who are fully deaf and blind
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

Although there may be a need for a joined up sensory impairment strategy in Scotland and DBS would support this in principle. There is a need within the strategy

to provide supporting evidence/rationale for this and perhaps the evidence/rationale for why what is currently in place requires changed at a time when change and fiscal challenges are so prevalent.

The strategy states that “different types of sensory impairment require different responses” hence requirement for a rationale that directs to a shared framework?

DBS recognises that the Scottish environment is forever changing, is dynamic and as such needs to develop a strategy which is not a panacea to meet all needs but is fit for the future.

This is an aspirational and inspirational task which will never have a ‘right time’. This said, it is perhaps an aspiration - a step too far at this juncture in the current Scottish context and development, and as such the timetable for implementation would require a rethink.