

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.

Comments from Service Users in Midlothian focussed on:

- The idea of a Sensory Impairment care pathway is a good one, if slightly difficult to fully understand as a service user.
- It was voiced that the word 'care' was not necessary before 'pathway' as the inference is that all people with a sensory impairment require care when in fact, many do not.
- A single point of contact would be very helpful as there is a distinct lack of integrated provision between services currently.
- Any such point of contact would be best kept at a local level.
- As many people have other health or social care issues in addition to sensory impairment, a clear care pathway should mean the sensory impairment is not overlooked.

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

Service users commented:

- Make information easily accessible to all, to ensure people are aware of the full range of services that are available to them, both through statutory and voluntary provision. This is of particular importance at the point of diagnosis.
- The profile of Sensory Impairment has to be raised with a cultural shift achieved through awareness raising and compulsory training programmes at **all levels** throughout public services, but especially in Health and Social Care. This would ultimately help to facilitate a culture shift within the general public. This should contribute towards the alleviation of the ignorance which can lead to the discrimination often currently experienced by people with sensory impairment. One service user stated "Just because I am blind, I am not stupid", yet this is how he had been made to feel.
- Require the additional needs of people with a sensory impairment to be addressed in all service provision e.g. additional communication needs/ additional time requirements.
- Ensure services such as provision of specialist equipment or hearing aids is consistent in all areas and that the cost of these is not prohibitive.
- Speed up the process of assessment and provision of hearing aids and make sure follow up services are easily and quickly available locally e.g. any adjustment required/ user advice/ battery changes.
- Fund/encourage research and development to improve things like hearing aids. One contributor commented, "I can hear everyone at the back of the bus but I cannot hear people in front of me. If my hearing aid was attached to my glasses, that would be better"
- Take full account of people who are working – that their requirements are properly accommodated in their place of work. Also that they are not excluded from available support services just because they are working.
- Support and promote the concept of peer support across all ages, for carers

as well as service users. This will help address the emotional needs which can be associated with sensory impairment as well as assist with the sharing of very practical information.

- Make sure that the individual is treated as such and that they are at the centre of any support/ service provided for them.

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

- We would hope to contribute to the design of the care pathway to ensure that it meets the local needs identified in Midlothian. Work is already underway in conjunction with East Lothian Council in particular, but also pan-Lothian through the Joint Physical Disability and Complex Care Programme Board, to identify more clearly exactly what these are.
- Midlothian is committed to the principle of an integrated Health and Social Care provision and will utilise the development of this to support the implementation of the care pathway. This will then facilitate more easily, the required commitment from all the necessary partners/stakeholders.
- We hope to develop a rolling programme of sensory impairment awareness raising training for **all** front line Midlothian Council staff. This will be done by utilising the procured services of RNIB and Deaf Action to train trainers. Building in this capacity will ensure sustainability.
- Build on existing links to the sensory impaired community through the ongoing work of our Physical Disability Action Plan to facilitate service user input and feedback.
- Continue to work on the availability of information, in particular through Midlothian Council Website.
- Make maximum use of available and future technology to support the needs of those with sensory impairment through further development of our Midcare Service (Telecare/ Telehealth).
- Consider the needs of people with sensory impairment on a more person centred basis, not as per dictated by their age group i.e. children, adults and older people. This recognises that intervention as a child will have a knock on affect to the individual's requirements as an adult and thereafter as an older person.

(d) How will you make these changes?

- Planning for implementation of the care pathway requires to be based on a clear view of the needs of the community as well as the partners who will deliver it. Future demands therefore need to be quantified.
- Work is currently being undertaken to review the functions of the commissioned services from RNIB and Deaf Action, which will contribute to delivering the pathway.
- Engagement across the Health and Social Care Partnership will work towards ensuring clear understanding, commitment and contribution from all associated providers, service users and carers.
- Through the implementation of the Midlothian Joint Physical Disability Action Plan, ongoing work around communication will assist in awareness raising and access to information.

- Provision of training needs around the implementation of the pathway will be reviewed.
- Through our participation in the Scottish Community Care Benchmarking Network we will seek to identify best practice associated with sensory impairment service provision as a basis for consideration.

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?

- Awareness raising and training was highlighted by service users, carers and staff members as key. This was seen as necessary to provide the backbone for the culture shift required to allow any chance of success for the strategy.
- In terms of planning for any changes, it was recognised that gathering meaningful data and understanding the true prevalence of sensory impairment is a prerequisite.
- A single point of access was viewed very positively by all in principle, given the significant confusion, lack of knowledge/understanding around the various services/agencies involved.
- Basic screening was also highlighted as being a very worthwhile intervention with the potential to have a very positive preventative outcome and long term gain, both for the individual and service providers.

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

- Sharing of data continues to be an issue between agencies both in principle but also technically. Even on an individual basis people have quite differing views on their willingness to share information. This will therefore require a great deal of careful management.
- Consistency of service provision across Scotland will continue to be difficult to achieve given differing financial/political priorities at a local level.
- Effective communication between all stakeholders. While this is certainly achievable, it can take a lot of work, time, effort and commitment to fully realise.

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

- Lip Reading training was highlighted as being of high significance but that there are large inconsistencies in its provision.
- Staff members wondered if it might be appropriate to review speech therapy services as part of this strategy?
- Transitions from children's to adult services in particular and from adult to older people's services was felt requires more recognition and focus.
- Audiology Departments were seen as being central to a successful care pathway but currently require significant restructuring to fulfil this potential. The existing focus is on meeting targets and does not produce a person centred experience for service users.
- 'Access to Work' appears not to be providing a particularly well thought of service. It favours the private sector and it was felt resources could be better used e.g. provision of this service by local Audiology Departments.
- Transport issues can create particular barriers for people with visual impairment, restricting their ability to travel independently. This area has not been covered at all in 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?

- One contributor commented that the essential recommendation is no. 6. If this recommendation to ensure compliance with the Equality Act 2010 was successfully implemented (which does not seem to be the case at the moment) the ability to implement all the other recommendations would follow.
- The data collection element of recommendation 4 and in turn required for recommendation 5, involves a considerable shift in attitudes across the spectrum of stakeholders. Personal choice will also have to be taken into account.

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

- Again, the principle that Recommendation 6, Compliance with the Equality Act 2010 was highlighted as being the most influential as its principles underlie successful outcomes for all of the other 5.
- Recommendations 1(Audit), 2(Screening) and 3(Mandatory Training) were seen to be essential to set the foundations to facilitate 4(Promote effective local care pathways) and 5(Effective information sharing between agencies) while achieving recommendation 6(Compliance).
- Overall, the combined effect of all recommendations was recognised.

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

- Promotion of independent living is key and this is as much to do with confidence and emotional wellbeing as with health and practical support. Promotion of self help and peer support is therefore crucial.
- Focus on prevention through adequate support and service provision within children's services and education provision. The needs of carers/parents cannot be overlooked either, given their input to this process.
- The use of technology is of particular benefit to those with hearing loss. Developments in this field and its application to the support of people with sensory impairment should be encouraged/ incentivised.

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 Midlothian, we commission RNIB and Deaf Action to provide our primary sensory impairment services.

RNIB provide specialist services to meet the needs of people in Midlothian who are blind or partially sighted. This includes :

- Rehabilitation and mobility service
- Social work assessments
- Registration and certification
- Core equipment item provision

DEAF ACTION provide specialist to meet the needs of those with a hearing impairment. This includes:

- Social work assessment
- Specialist equipment
- Communication support.

MALANI (Midlothian Adult Literacy and Numeracy Initiative) provides free Lipreading Courses for people with an acquired hearing loss.

FORWARDMID A voluntary organisation supported in part by Midlothian Council, providing a forum for people with physical disability (includes sensory impairment). A very active forum involved in the co-production of the Midlothian Physical Disability Action Plan. Provides training and is involved in a wide range of associated partnership initiatives.

VOCAL (Voices of Carers across Lothian) Provides support for those providing a caring role including those with sensory impairment.

MIDLOTHIAN ACCESS PANEL A voluntary group which includes service users with sensory impairment who provide feedback to Midlothian Council on planning and design issues relating to physical disability/impairment.

MIDCARE (Midlothian Telecare Service) Midlothian Council Social Work service providing appropriate Telecare equipment following assessment of need which includes sensory impairment.

Some service users commented that they had little knowledge of existing services within Midlothian.

There was also considerable confusion around the fact that services from RNIB and Deaf Action are in fact procured by Midlothian Council.

Confusion was also evident around the provision of equipment and the responsibilities of Health versus Social Work versus RNIB/Deaf Action.

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

In general the proposed strategy was received very positively by service users, carers and staff alike. Just to see sensory impairment being given this level of consideration was regarded as a step up.

Fully implemented, the proposed strategy will improve the lives of people living with sensory impairment and set the stage for continuous dialogue and more appropriate ongoing service development.

Service users/carers voiced a sense of empowerment through being consulted. Concern was however raised over the lack of available resources and the potential impact this may have on full implementation.

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?

The fundamental principles incorporated in GIRFEC would appear to be exactly what is required to facilitate a successful implementation of this proposed sensory impairment strategy. Given the proven success of these principles within children's services, sensory impairment services can only be improved and strengthened by mirroring accordingly.

At one focus group, two parents of children with visual impairment had had very different experiences and the significance was the time difference between them. One was very negative but was of a child who is currently of university age. An obvious struggle with service provision had led to the parent having to withdraw the child from Local Authority education and self fund private education to enable the achievement required to take them onto further education. This parent obviously felt very let down by the system and this has taken a considerable financial toll on the whole family, not to mention the very practical and emotional strain it caused. The other parent currently has a child in Local Authority primary education and was full of praise for the support they are currently receiving. There are obviously still issues but this seemed to be more focussed in areas such as lack of understanding leading to exclusion around social activities outwith the education system.

Hopefully these two experiences demonstrate GIRFEC principles working successfully to improve the experiences of children with sensory impairment and their parents as they go through the education system.

Successful transition into adult life, whether into further education or work is key in everyone's lives. As with most processes, the added difficulties for people with sensory impairment accentuates this. The GIRFEC principle of putting the individual at the centre should be at the heart of any adult service provision for those with sensory impairment. Planning of services/support should ensure the focus remains on what makes a positive difference to the person's life and that this is what is provided. Equality of access is necessary to allow independent, productive lives for all.

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?

- The principle of a sensory impairment strategy was welcomed. Slight concern was voiced by service users/carers that the needs of those with hearing and visual loss can be very different in a lot of ways and this has to be kept in mind. The issue of acquired versus congenital conditions was also highlighted as requiring significant consideration.
- A perception of hearing impairment being less well supported than visual impairment was suggested by a few contributors with one service user stating they “would rather be blind than deaf”. This appeared to stem also from the fact that blindness was perhaps ironically more visually obvious than deafness.
- It was acknowledged that the strategy would improve awareness and understanding of sensory impairment amongst both professionals and the general public. This would hopefully raise standards of service provision but more than one contributor felt there was a need for stipulation of standards within the strategy.
- The impact of Welfare Reform is of significant importance given the degree of anxiety being felt by people whose life is affected by sensory impairment. A sense of great injustice was described by service users who feel their access to opportunities afforded by non-impaired people has been restricted, leaving them dependent on the benefit system. They now feel targeted and punished as a result.
- On the document itself, it was felt to be lengthy and contained language not particularly easily understood by all. In general however, it was well received.

Consultation activity

Feedback was gathered in Midlothian through two consultation events in Dalkeith with service users, carers and professionals, facilitated by Deaf Action and RNIB. Staff were also given the opportunity to comment as were members of the Midlothian Physical Disability Planning Group.