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.

Not applicable-Service provider.

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

The pathway set out very broadly represents all sensory impairments and it does recognise that the needs are very different across the spectrum of vision and hearing impairment. The pathway is to be inclusive of children and young people and recognises that the support and input required for this group is different from that of adults with acquired sensory loss. It would be beneficial to have clearer individual pathways for different sensory impairments.

Children to not generally experience a loss but have an impairment that has been present from birth/early life. These visual impairments are life long conditions. Children with VI, vision does not correct to a normal level with any aid. Around 70% of children with visual impairment also have complex needs and this should be reflected in the document and pathways, with particular reference to education, communication and social skills. There is a need for early intervention and support for children and families should be emphasised and included within the report.

It should also be recognised that orthoptist have a significant role in the assessment, monitoring and planning for children with VI. The orthoptist may be the first eye care professional to carry out any formal visual assessment on child and consequently braking bad news with regards to possible diagnosis. In regions where multi-agency assessments for children with VI are already in place the orthoptist is one of the key members of the team. Approximately 70% of the orthoptic case load is centred on paediatric eye care, around 5000 appointments a year within Tayside alone. There is a comprehensive Orthoptic led pre-school visual screening programme in place across Scotland, in response to Hall 4 report.

Currently 20% of those over the age of 75 are living with a visual impairment. With the demographic forecast showing that by 2021 40% of the population will be over the age of 50 we have to consider the implication this will have on service provision for the future. Anti-VEGF can be used effectively in the treatment of wet age-related macular degeneration (wet AMD) and has recently been licensed for use with diabetic eye disease. Consequently from the shift in population demographics and the increase in diabetes in children and young people eye disease will become more prolific increasing demand on ophthalmology.

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

The pathway for children and young people need to be more clearly defined.

Within Tayside the “Childrens’ Visual Impairment Services Tayside Agencies” (CVISTA) is an inter-agency group with professionals (health, education, visual impairment societies, Guide Dogs for the Blind Association, RNIB Scotland, SENSE Scotland, PAMIS, Parent to Parent and Barnados) working in a co-ordinated way to provide services for children with visual impairment and their families and is led by the Community Paediatricians. Similar services exist across the country and should be highlighted by this review. It should be noted that national pathways of care for children with VI will be further developed through the

national managed clinical network for children and young people with visual impairment (VINCYP)

In NHS Tayside for adults with visual impairment we have a “one-stop” service which is staffed by an RNIB support worker five sessions per week. The development of the RNIB service within the Eye Clinic was a joint project between NHS Tayside and RNIB and has been extremely successful in increasing the pace of access to suitable support. We also have a close connection to the Visual Impairment Services in the community, including those in Dundee, Perth, Angus and Fife. Our Perth Ophthalmology Out-Patient Clinic is supported by a Visual Support Information Officer from Perth and Kinross Visual Impairment Service, particularly when the Low Visual Aid Clinic is running.

There is provision of Low Visual Aid throughout Tayside. Referrals to this service are received from Ophthalmologists or direct referrals from community optometrists, visual impairment societies, education and GP’s. Low vision individuals are assessed within the Low Visual Aid Clinic to provide support during visual loss and to maximise the usage of low visual aids to maintain independence.

(d) How will you make these changes?

With in NHS Tayside good links exist currently for children and adults with visual impairment with a broad spectrum of other agencies.

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?

For all with a visual impairment it is important that:

- The pathway should be clear and easily available
- Clear referral routes to appropriate specialist. Eyecare Integration and Implementation Project will allow community optometry electronic referral to ophthalmology, as GP’s do at present, insuring improved patient pathway from referral to diagnosis.
- The correct diagnosis should be made by the appropriate professional
- There should be a consistent response from agencies within the pathway with quality assurance and audit
- There should be equity of service across the country
- There should be an understanding of partnership roles and responsibilities
- Training and competency to a minimum standard is developed and maintained across all professions which are involved with children and adults with VI

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

The Strategy is currently too generic to be meaningful and therefore unlikely to effect change.

Differing boundaries for local authorities and health present a challenge in co-ordination and communication of service provision e.g. NHS Tayside covers 3 local authorities and borders more all delivering different quality and types of services. Education support for children with VI varies greatly from teaching knowledge and skills to equipment provision to allow independent learning. Habilitation services for children are inconsistent and may be provided by an adult worker or not provided at all.

Equity of integrated service for adults e.g. “one-stop” vision support service developed with RNIB, allowing the delivery of timeous and effective offers of support for patients.

The measurement of outcomes is difficult but necessary to ensure that provision is most effectively targeted.

Training of all professionals involved with sensory to a minimum level.

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

- The child and adult population with VI, HI and DSI are not homogenous and their needs and services required are different. This should be acknowledged in order that the needs of both populations are best served.
- The need for provision of support for development of independence , social skills training, social communication and family support should be included for children as this is what brings benefit in terms of attainment, independence and employment
- Little is included regarding employment which is important to children and young people who need to develop skills in order to become employable and not join the 70% of adults with VI who are unemployed
- Screening programmes are referred to mainly in terms of proposals for old age screen being incorporated with other assessments. It is important to emphasise the need to continue screening programmes already in place within children and adult services e.g. diabetic eye screening programme, new born baby cataract screening, ROP screening of premature babies
- Assessment of VI in children could not be undertaken by non-specialist staff.

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?

- Identification of current spend – this will be challenging in context of children with VI and complex needs given the number of services involved with each child.
- Effective and equitable local provision following pathway development. Development of good practice standards is essential or monitoring this will not be possible.
- Data collection, in children with VI and complex needs there is not a single measure e.g. acuity which identifies VI so accurate data collection is currently difficult, however this should be improved with the development of the national MCN.

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

Effective and equitable local provision of VI services for all age groups.

Currently there is wide variation in priority, spend and provision of service. Recognition of the need for these services within a planning framework should lead to an improvement in quality of service provision.

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

- Greater importance should be given to the need for a clear transition plan, in relation to the move from child to adult services. The needs of the child with a sensory impairment moving into adult services are very different to those of an adult developing a sensory impairment. There should be guidance on planning for this step.

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 NHS Tayside we are delighted to have a “one-stop” service which is staffed by a vision support worker, from RNIB. The development of the RNIB service within the Eye Clinic was a joint project between NHS Tayside and RNIB and has been extremely successful in increasing the pace of access to suitable support. We also have a close connection to the Visual Impairment Services in the community, including those in Dundee, Perth, Angus and Fife. Our Perth Ophthalmology Out-Patient Clinic is supported by a Visual Support Information Officer from Perth and Kinross Visual Impairment Service, particularly when the Low Visual Aid Clinic is running

Due to the nature of children’s visual impairments a one-stop service would be more challenging to provide. A service such as CVISTA (see 1(c)) in Tayside, would be more appropriate. This service has two clearly defined pathways, one for an infant or young child with newly diagnosed visual impairment and no associated disability. The other is for such an infant or young child with visual impairment associated with complex health needs. This service allows communication and planning around the visual requirements for a child to meet their full potential in all parts of life including education.

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

n/a

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?

GIRFEC specifies a lead professional should be named for every child, whether they be in health or education, this could be reflected in the pathway. There is little mention of the need for early intervention and educational support which is the main focus of others current policy documents.

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?

- Any funding for development of children's pathways/services should be separated from adult funding as otherwise , due to small numbers there will be no advancement in children's services
- The document concentrates on maintaining skills rather than acquiring them which for children is key to their development, learning, independence and ultimately employment.
- The use of advancing technology for those with VI has not been considered