

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.

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

The pathway set out is broadly applicable to children and young people, but there are significant differences from adults which require to be noted and addressed. The pathway suggested is not specific enough as it appears to be trying to cover too much and a more specific plan requires to be developed to ensure services deliver appropriate and equitable support for children and young people. This could lie alongside and underpin the overall strategy , but is required for any impact on care.

It should be recognised that children in the main do not experience 'loss' but that they have an impairment which has been present from birth/early life and that the significant majority of children, around 70% , with visual impairment (VI) have additional disabilities. This needs reflected in the document and pathways due to the developmental impact particularly relating to social communication, learning and self-esteem.

The need therefore for early intervention and support for children and families should be emphasised and specifically included.

It may be more helpful for a parallel pathway to be documented for children and young people given the different services and strategies required for them as opposed to adults/older people.

It should also be noted that there is a very significant difference between the child VI and HI population as HI includes all children with a reduction in hearing fully correctable with aiding however VI does not include any child whose vision corrects to within the normal range by use of aids. The needs of a child with functionally normal hearing who wears hearing aids and those of the child with a life-long uncorrectable visual impairment are very different as are the supports. Services require to be specific and tailored rather than generic and it should be recognised that ,for children, skills particularly in health, education and habilitation are not transferable between HI and VI. Professionals offering services require to be specifically trained in regard to the needs of children with VI etc..

There is mention throughout of the need for provision of information but the accuracy and quality of this is key. There is a need to set out standards of service provision in order that providers are clear on their responsibilities and that service users are clear on what they should expect . This should apply across all health boards and local authorities . The national MCN for children and young people which will formally commence in April 2014 will aim to lead on this.

The need for sharing of appropriate information between services is rightly given prominence, however , it is also important to note that there is a need to respect individuals personal information, which is not always apparent in some services. All services require to respect this in order for families to trust and work with them.

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

Although the pathway is not entirely applicable to children and young people , the main steps have already been set out in previous reviews and are in place in some health boards and local authorities within children's VI services. Clear pathways to multiagency services through a central single access point is already recommended and again in place in some , but not all areas. There is a need for the pathways already in existence to be used consistently, and for services to be available, particularly within local authorities , when identified as required through these agreed pathways.

There is a significant issue with availability of services particularly trained teachers of visual impairment and trained habilitation specialists . In order to implement a pathway for children local authorities in particular require to be explicit in their service provision and seek arrangements with other authorities or agencies to provide services.

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)

(d) How will you make these changes?

Nationally this work for children with VI will be led by the managed clinical network which aims to set service standards and pathways for children and young people with visual impairment initially within health ,which is the starting point ,and then moving into education ,social work and third sector services who should provide the majority of support and life skills for these young people

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 children with VI these have already been identified through the Community Eyecare Review and the national MCN plan.

- The correct diagnosis should be made by the appropriate professional
- There should be a single point of access for services once identification of a significant impairment is made
- The pathway should be clear and easily available
- There should be a consistent response from agencies within the pathway with

- quality assurance and audit
- There should be a written understanding of partnership roles and responsibilities
- Training and competency to a minimum standard should be developed and maintained across all professions which are involved with children with VI.
- Multi-agency planning which specifically involves those with specialist knowledge of childhood VI

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

The Strategy in its current format is too generic to be meaningful and therefore unlikely to effect change

The consistency of response is particularly problematic. The provision of services across different local authorities is extremely variable . This is particularly true of habilitation services for children which are not provided in several local authorities at all and in others by adult workers with no training in the developmental needs of children and young people. Also the provision of educational support varies greatly in quality both in terms of teaching support and provision of appropriate equipment for independent learning. There is great variation in skill and knowledge

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

Differing boundaries for local authorities and health present a challenge in co-ordination and leadership-e.g one health board can cover and border 10 or more local authorities with all delivering different quality and types of services – delivering minimum standards across all local authorities will be a significant challenge.

© 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. It is important to note that children with reduced hearing who aid to within normal limits are currently regarded as being hearing impaired, while those with reduced vision which is correctable to within normal limits by use of aids are not regarded as visually impaired – this is one of the reasons that the populations are significantly different. Were the same criteria as HI applied to VI in children the numbers affected would be increased more than ten fold, with approximately 20% of the population being aided by 16 years.
- Education is not mentioned in the document and provision of good quality educational support is essential for children and young people. This should include higher education as well as preschool and school.
- The need for provision of support for development of independence, mobility , 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 for continuance of screening programmes already in place within children's services .The initial starting point in the pathway does not account for screening programmes in childhood where the majority of significant VI is detected.
- GPs are mentioned as a point of diagnosis but this is not their role, and they do not have the requisite skills to provide this for children with VI – they are a point of referral to specialist services for diagnosis

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?

- Ensuring maximum sustainability once funding has ceased – previous short-term funding exercises have provided improvement initially but are not always embedded into long-term practice/commitment.
- Identification of current spend – separating out spend accurately for children in particular will be difficult given the number and complexity of services involved
- Ensuring effective and equitable local provision following pathway development. Without any central monitoring or standards this will not be possible
- Data collection: In children with VI there is not a single measure e.g. acuity which identifies VI so accurate data collection is currently difficult. There is an absence of a single reliable database at present, 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?

Local service planning reflecting the need in order that there is effective local provision or clear access to regional/national provision. Currently there is wide variation in priority , spend and provision with for example, in some local authorities , no specifically trained educational input to children with VI in preschool years, teachers providing input despite having no specialist qualification/training, and absence of any provision of habilitation assessment or training . A 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?

- The high incidence of SI is mentioned in relation to adults with LD, however the incidence of VI within children and young people with LD is at least as high if not higher. The strategy , if it does not acknowledge this, and make recommendations to address these needs, would miss an opportunity to reduce the impact of a child's disability particularly as there is evidence that a large number of these children have a correctable or partly correctable visual defect rather than an irreversible impairment . This has implications for the level of independence gained not only for the individual but in relation to the level of future support required and quality of life, educational achievement , employment prospects and costs of care longterm
- Greater importance should be given to the need for a clear transition plan , particularly in relation to the move from child to adult services. Transition only appears to be mentioned in the pathway, not the text. The needs of the child moving into adult services are very different to those of an adult developing a sensory impairment and this requires recognition. Clarity around responsibility for planning is required.
- Inclusion of education and habilitation specifically is required along with early intervention for children with VI

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.

Service provision is extremely variable, excellent in some areas and poor or absent in others.

In children, due to the low incidence, services are often person dependent. Often professionals are isolated and have limited support within their local area. This has been helped by development of wider networks across local authority and health boundaries.

For children with VI the provision of joint assessment and review systems involving health education and social work has improved service provision and been widely welcomed by parents, children and professionals in those Health Board's where it has been implemented.

There are recommended structures for service provision for children with VI , which will be further clarified through the national MCN , but there are still difficulties in individual service provision. There is a need for ongoing training and introduction of practice standards in some areas to ensure service improvement and equity.

Quality assurance and audit of service provision is required

Due to the nature of children's visual impairments and the high incidence of additional difficulty the concept of a one-stop shop for children's sensory impairment is not appropriate or workable. However these children's needs should be supported through a child development centre with additional input from specialist VI services which should be multidisciplinary and may well be multiagency.

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?

It may be helpful to have an adapted pathway for children and young people which specifically reflects the role of the lead professional within it

An emphasis on the need for early intervention , habilitation, and appropriate educational support for children is not present within the strategy which is not reflective of the importance placed on these in other policy documents.

There requires also to be a greater emphasis on transition.

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 funding requires to have conditions attached , otherwise outcomes will be poor. Progress and outputs require to be monitored robustly
- Funding would be best distributed through identified leads within health boards. This would help to avoid the difficulties of division amongst 32 local authorities making funding too small to be usable or being diverted by individual groups for isolated projects which would not benefit the whole SI population.
- Funding for development of childrens pathways/services should be separated from adult funding as otherwise , due to small numbers there will be no advancement in childrens services
- Important to recognise that sensory loss is not usually the situation in children therefore the use of this term throughout does not reflect the child population
- The document concentrates on maintenance of skills rather than acquisition which for children is key to their development, learning, independence and ultimately employment
- The use of technology to assist with VI has been missed in the strategy.
- There is a need for ongoing responsibility to monitor developments and outcomes in order that developments which do take place do not disappear once the spotlight is turned on another area of interest .