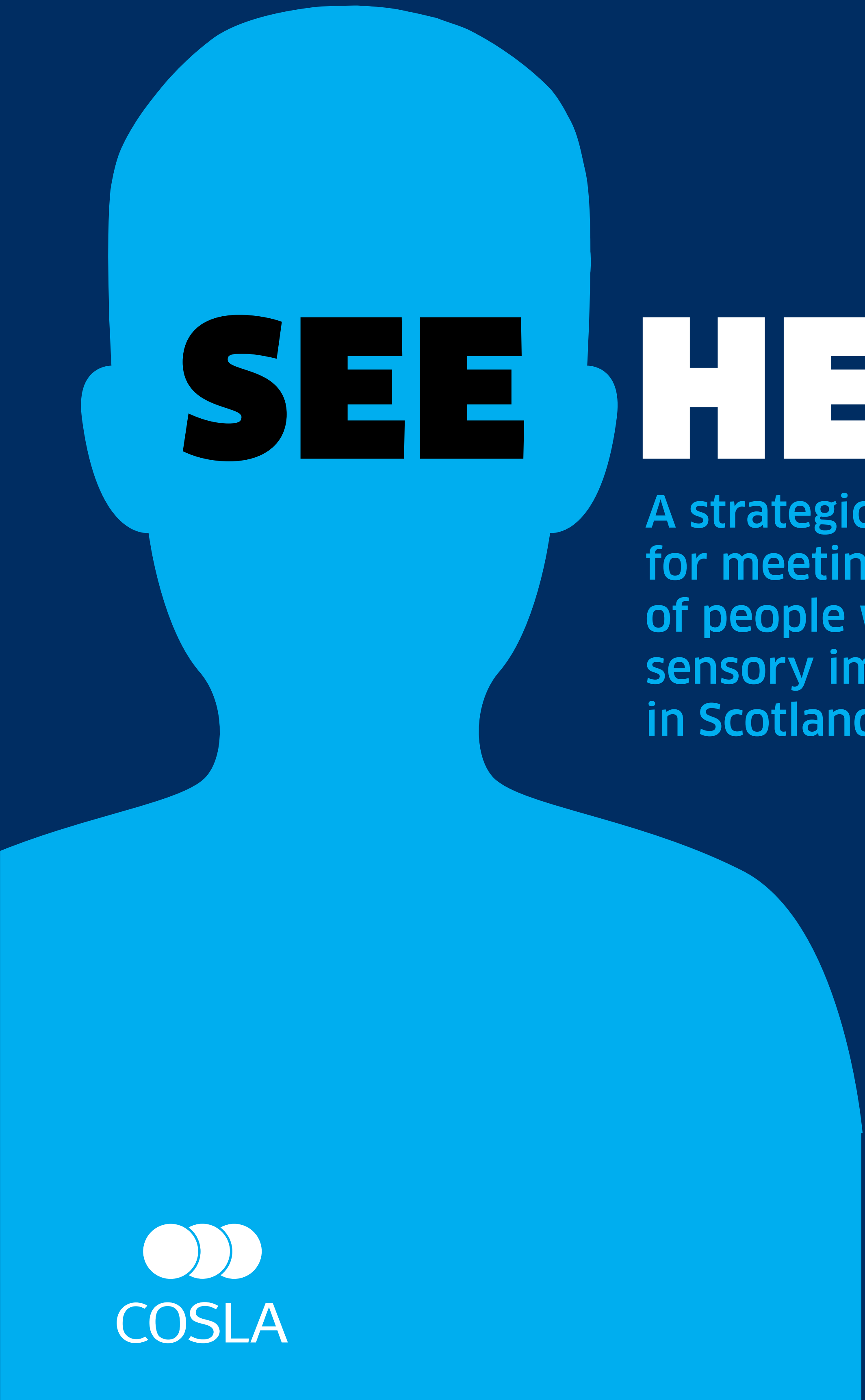

SEE HEAR

A strategic framework for meeting the needs of people with a sensory impairment in Scotland

COSLA

healthier scotland
SCOTTISH GOVERNMENT

SEE HEAR

A strategic framework for meeting the needs of people with a sensory impairment in Scotland

The Scottish Government, Edinburgh 2014

First published by the Scottish Government, April 2014
ISBN: 978-1-78412-306-2 (web only)

eBook first published by the Scottish Government, April 2014
ISBN: 978-1-78412-307-9 (ePub)

Kindle eBook first published by the Scottish Government, April 2014
ISBN: 978-1-78412-308-6 (Mobi)

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St Andrew's House
Edinburgh
EH1 3DG

Produced for the Scottish Government by APS Group Scotland
DPPAS24701 (04/14)

Published by the Scottish Government, April 2014

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MINISTERIAL FOREWORD

MICHAEL MATHESON
Minister for Public Health

Adults and children with a sensory impairment should expect seamless provision of assessment, care and support and the same access to employment, education, leisure, healthcare and social care as everyone else.

With this in mind, the Scottish Government has worked with partners representing local authorities, health boards and the third sector to develop a Scottish Sensory Impairment Strategy: See Hear – A Strategic Framework for Meeting the Needs of People with a Sensory Impairment in Scotland.

For the purposes of this Strategy, sensory impairment includes varying degrees of hearing loss, sight loss and loss of both senses. It also covers people at risk of sensory loss and those who may be living with hidden and untreated loss which may be present in people with learning disabilities or conditions such as dementia or stroke.

See Hear is a Strategy for both children and adults. It recognises the rising incidence of those illnesses and disabilities that increase with age and acknowledges the work for children with sensory loss taking place through policies such as Getting It Right For Every Child (GIRFEC), the Children and Young People (Scotland) Bill which is currently progressing through Parliament and the Scottish Government's response to the Doran Review, all of which will have a positive impact on the lives of children and young people with sensory loss. It is set against a background of increasing demand, the requirement for greater efficiency and effectiveness, and Health and Social Care Integration.

See Hear takes a practical approach and sets out a model care pathway and seven recommendations which should ensure that individuals and service providers have a clear understanding and expectation of what services are available and will be delivered, and a clear understanding of the support that should be available following diagnosis of sensory loss.

The pathway and recommendations provide service deliverers, whether in the statutory or third sector, a framework for structured, co-ordinated, person-centred service delivery and support.

The Strategy will be implemented via local partnerships, including statutory and third sector partners, which will identify local priorities and approaches. To help the establishment of these local partnerships and the subsequent implementation, the Government has committed £1m in 2013/14 and £1m in 2014/15.

I would like to thank all those who contributed to the development of this Strategy and responded to the consultation exercise. See Hear presents an opportunity to make a significant difference for people with vision, hearing and dual sensory loss in Scotland. I know that all parties involved will be keen to engage in the partnership work required to make the opportunity a reality.

COSLA FOREWORD

PETER JOHNSTON
Health & Wellbeing Spokesperson

I am delighted to jointly endorse this Strategy on behalf of COSLA. We are committed to working with the Scottish Government and other partners to ensure that people with a sensory impairment continue to receive high quality and well-coordinated care and support. The development of this new joint Strategy focuses on bringing local authority, health and third sector service partners together to improve outcomes.

Local partnerships will adopt different approaches and the level and pace of progress will accord with local priorities and within available resources. The Strategy does recognise a particularly challenging financial climate and therefore the focus on early intervention and prevention is especially important.

EXECUTIVE SUMMARY

This strategic framework applies to children and adults living with sensory impairment: sensory impairment includes varying degrees of hearing loss, sight loss and loss of both of these senses and can be a recognised sensory impairment; a risk of sensory loss or hidden and untreated sensory loss.

The document offers practical advice and direction plus nine recommendations to help achieve the following aims:

1.1. The seamless provision of assessment, care and support to children and adults with a sensory impairment.

1.2. Children and adults with a sensory impairment should expect the same access to education, employment, healthcare, social care and leisure as everyone else.

1.3. People who have or develop a sensory loss understand what this loss will mean for them.

1.4. People who have or develop a sensory loss are able to access information and be supported to take the maximum possible control over living as independently as possible, while also getting direct assistance when needed: appropriate communication is critical to this.

1.5. Children and young people with a sensory impairment should expect appropriate and timely intervention in the early years and for as long as is required.

Key to the success of the Strategy will be person-centred local partnership working between statutory and third sector agencies.

1. OVERVIEW

1.1. The World Health Organization has recognised that children and adults with disabilities, including those with a sensory impairment, have poorer health outcomes, lower educational achievements, less economic participation and higher rates of poverty than people without a disability. It confirms that the prevalence of disability will rise due to ageing populations and the higher risk of disability in older people and other vulnerable populations. For example, children from poorer households and those in ethnic minority groups are at significantly higher risk of disability than other children. It highlights the different barriers that people with a disability face and acknowledges that they do not have equal access to a range of services, to the extent that disability is now increasingly understood as a human rights issue.[1]

1.2. Children and adults with a disability are entitled to have their human rights respected, but still confront barriers to health care, education, rehabilitation, employment, and support services. This is largely due to difficulties in accessing the services available to them and the obstacles they face in their everyday lives, but it is also in large part due to the level of awareness and understanding that society (including many statutory agencies) has in relation to people with a sensory impairment. These difficulties are compounded by the fact that people with a sensory impairment will frequently have experienced a loss of confidence, and will also require assistance and support in how they experience and communicate with the world around them to make their needs and wishes known to others. Families of children with sensory impairment also experience barriers to securing support and advice in the early years.

1.3. The Scottish Government's National Outcomes outline the top level priorities across all aspects of life in Scotland. These include living longer, healthier lives; having strong and supportive communities; giving children the best start in life; improving life chances for children, young people and families at risk; having young people who are successful learners; and having good employment opportunities. These are all in the context of tackling inequalities within Scottish society.[2]

1.4. For those people who need support, the personal outcomes approach[3] identifies those outcomes that are important to people. In terms of quality of life, people say they want to feel safe; to have things to do; to be able to see people; to stay as well as they can; to live where they would like; and not to have to deal with discrimination. To help them achieve these outcomes, people say that they need to feel listened to and to have a say in the support they receive; to be treated with respect, and to have supports and services that respond to their needs and wishes. When this happens, then people expect to see improvements in their confidence, skills and mobility. This applies equally to disabled children who want the same outcomes as other children but need to have their foundational needs addressed first: being able to communicate; being healthy, emotionally and physically; being safe; enjoying and achieving and having autonomy.

1.5. The Scottish Government's Getting It Right For Every Child approach (GIRFEC) defines wellbeing for children and young people in terms of eight indicators; safe, healthy, active, nurtured, achieving, respected, responsible and included, and each one of these indicators is underpinned by a number of outcomes. All children and young people in Scotland, including those with a sensory impairment, should be supported by society including Government, health, education and social work, to pro-actively address their wellbeing needs throughout their lives.

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[1] World Report on Disability. World Health Organization, 2011. http://www.who.int/disabilities/world_report/2011/report/en/

[2] http://www.scotland.gov.uk/About/Performance/scotPerforms/outcomes

[3] Talking Points, Personal outcomes approach, Joint Improvement Team 2012.

1.6. Implementation of the Getting It Right For Every Child approach throughout Scotland will ensure that all services and agencies working with children, young people and their families take a co-ordinated approach to holistic assessment, planning and service delivery that is appropriate, proportionate and timely, and that children and their families are fully involved in any decisions that affect them. This is irrespective of age, impairment, condition or circumstances and therefore includes all children and young people with a sensory impairment. It is expected that all adult services working with parents and carers will take this approach into account.

1.7. The Scottish Government is committed to ensuring that all children and young people with additional support needs, including those with sensory impairments, are provided with the support they need to reach their full potential. Under the Education (Additional Support for Learning) (Scotland) Act 2004, as amended, education authorities are required to identify, meet and keep under review the additional support needs of all pupils for whose education they are responsible and to tailor provision according to their individual circumstances.

2. WHAT WILL THIS STRATEGY ACHIEVE?

2.1. The seamless provision of assessment, care and support to children and adults with a sensory impairment.

2.2. Children and adults with a sensory impairment should expect the same access to education, employment, healthcare, social care and leisure as everyone else.

2.3. People who have or develop a sensory loss understand what this loss will mean for them.

2.4. People who have or develop a sensory loss are able to access information and be supported to take the maximum possible control over living as independently as possible, while also getting direct assistance when needed: appropriate communication is critical to this.

2.5. Children and young people with a sensory impairment should expect appropriate and timely intervention in the early years and for as long as is required.

3. INCLUDED WITHIN THIS STRATEGY

3.1. For the purposes of this Strategy, Sensory Impairment covers children and adults living with sensory impairment. It includes people with varying degrees of hearing loss, sight loss and also with loss of both senses. Both hearing and sight loss can be present from birth, but for the majority of people a sensory loss will occur later in life, and can range from a relatively low level loss to a much more profound loss.

3.2. There are three main groupings that should be considered:

- people with a recognised sensory impairment;
- people at risk of sensory loss due to a range of factors;
- people who are likely to be living with a 'hidden and untreated' sensory loss, e.g. people who have had a stroke, have a learning disability or dementia.

3.3. Included within the groups above, there will be people who are seeking work or are engaged in work. For these people the impact of a sensory loss can have significant implications for entering work, retraining, and being supported to stay in work.

3.4. It is also important to acknowledge that there are some groups within the world of sensory loss for whom that loss provides additional challenges both to them and to services who are seeking to provide integrated care pathways: examples of these groups are listed below.

Older people

3.5. It is now well understood that people are living longer, and consequently there is an increasing incidence of those illnesses and disabilities that increase with age. This strongly applies to hearing and sight loss (see figures below). The impact on an older person who may already be finding it less easy to continue with previous lifestyles can be very significant. Yet it is still the case that hearing or sight loss is often not recognised or responded to by caring agencies, including home carers, hospital or care home staff.

3.6. Sensory impairment is a major contributory factor in falls and subsequent admission to hospital, which is the major contributory factor to admission to a care home.

People with a learning disability

3.7. People with a learning disability are more likely to have a hearing loss, and are 10 times more likely to have a sight loss than people in the wider community. This can have a profound impact on how they are understood and are able to interact with others, and people with challenging behaviour will be more likely to challenge if there is a limited understanding of any sensory loss that they may have.

Children and young people

3.8. It is estimated that 40% of deaf children have some additional health, social or educational wellbeing need[4] while around 57% of children with visual impairment also have another disability.[5]

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[4] NDCS – Prevalence of additional disabilities with deafness: A review of the literature, 2012.

[5] Visual Impairment Scotland, 2003.

Hidden and untreated sensory loss

3.9. Hidden and/or untreated sensory loss leads to a withdrawal from social interaction. To a person with dementia, for example, failure to recognise and respond to a sensory loss will result in greater isolation, will generate behaviours that can be misinterpreted as symptoms of advancing dementia, and will lead to a consequent failure to respond appropriately to basic physical needs.

3.10. Specifically, neurological sight loss, caused by injury or trauma to the brain, is often undiagnosed and can, therefore, remain untreated. Between 20% and 60% of people who have a brain injury from stroke or traumatic injury have associated neurological visual impairment.[6] This type of sight loss has a significant, detrimental impact on survivors of brain injury and their carers.

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[6] Clarke G. (2005). Incidence of neurological vision impairment in patients who suffer from and acquired brain injury. International Congress Series.
Rowe F. et al. (2009). Visual impairment following stroke: do stroke patients require vision assessment. Age Ageing.
Suchoff I.B. et al. (2008). The frequency of occurrence, types and characteristics of visual field defects in acquired brain injury: a retrospective analysis. Journal of the American Optometric Association.

4. PREVALENCE

Hearing loss

4.1. There are estimated to be around 850,000 people with hearing loss in Scotland, one in six of the population, and of those, 70% are over 70. It is projected that this figure will increase by 50% in the next 20 years. There can be delays of up to 10 years in people addressing their hearing loss, and evidence suggests that GPs do not refer 45% of people reporting hearing problems for any intervention, such as a referral for a hearing test or hearing aids. More than 500,000 people would benefit from hearing aids, or 10% of the population.[7]

4.2. There are around 3,600 young people with a hearing loss in Scotland and the national availability of Universal Newborn Hearing Screening (UNHS) at birth facilitates early intervention and support. It is estimated that 1.1 children per 1000 are born with permanent bilateral deafness and 0.6 children per 1000 are born with unilateral deafness.[8]

Sight loss

4.3. Significant sight loss affects over 180,000 people in Scotland, one in 30 of the population, and it is predicted that this figure will double by 2031. The vast majority are older people, with more than one in two people aged over 90 having a significant sight loss. Evidence suggests that over 50% of sight loss is due to preventable or treatable causes.[9] It has been shown that 78% of people living with sight loss have at least one other condition for which they receive medical care.[10]

Deafblindness/dual sensory loss

4.4. People who are deafblind have a severe degree of visual and hearing loss such that the combination of the two causes extreme difficulty in pursuit of educational, vocational, or social goals; communication; access to information and mobility. Some people are deafblind from birth, others may be born deaf or hard-of-hearing and become blind or visually impaired later in life, or the reverse may be the case.

4.5. Deafblind Scotland estimate that there are some 5,000 people who have significant hearing and sight loss, with most of those people being over 60 and having become dual sensory impaired as part of the ageing process.[11] There is, however, a notable number of people under 60 years of age who live with Usher Syndrome, a genetic or inherited condition that affects hearing, vision and balance.

4.6. People who are deafblind must somehow make sense of the world using the limited information available to them, and experience the most challenging difficulties in engaging with the world around them. Special arrangements must be made if they are to be meaningfully included in society.

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[7] Data taken from - Hearing Matters: Taking action on hearing loss in the 21st century, Action on Hearing Loss, 2011.

[8] Data taken from NDCS How many deaf children are there in Scotland?, 2008.

[9] Data taken from – Success in Sight?, Scottish Vision Strategy Advisory Group, 2012.

[10] Brody et al, 2001.

[11] http://www.deafblindscotland.org.uk/deafblindness/facts/

4.7. A person with dual sensory loss has a degree of both hearing and sight loss but may not identify as being deafblind. They view their condition as age-related and employ a variety of coping strategies to deal with their dual sensory loss and require help with both of their impairments. To meet the needs of someone with a dual sensory loss, care and support needs to be tailored to address both their hearing and sight loss. Large percentages of the over-50s age group have a dual sensory loss. For example, a third of people living with sight loss who are over the age of 65 have a hearing impairment.

4.8. In summary, the above headline trends in relation to prevalence rates for sensory impairment reflect the demographic changes taking place across Scotland, with greater ethnic diversity and significantly more people living to an older age than has ever been the case before. This has a direct impact on prevalence rates given the increased incidence of sensory loss in some ethnic groups and older people.

5. THE STRATEGIC FRAMEWORK

5.1. This strategic framework covers cradle to grave sensory impairment and is set against a background of increasing demand, the requirement for greater efficiency and effectiveness with available resources, and Health and Social Care Integration. It has been developed in the context of a number of wider policy and practice expectations, and has been directly informed by the views of a wide range of stakeholders who have contributed their views on current service provision and made suggestions for future developments.

5.2. It should be a lever for change, promoting the seamless provision of assessment, care and support to people with a sensory impairment. In so doing it:

- recognises that different types of sensory impairment will require different responses;
- recognises that the responsibility for systems of care lies with the statutory agencies, but can be delivered across a wide range of agencies and settings. It therefore requires a partnership approach and the active engagement of a wide range of statutory and third sector agencies in the health, education and social care sectors. It also includes the wider range of public service provision, people with a sensory impairment themselves and parents/carers and young carers where applicable;
- identifies practical steps that can be taken to address the above points across all types of sensory impairment to ensure that needs are recognised and responded to in an outcomes focussed way.

5.3. With regard to children who have a sensory impairment, whilst the intended outcomes for this younger age group are the same as those outlined for sensory impaired adults, the wider context, and the nature of the support requirements, are significantly different. At the time of writing this Strategy, the Doran review has recently been published, and sets out the strategic vision for children and young people with complex additional support needs in Scotland. Additionally, the Children and Young People (Scotland) Bill is currently moving through the Parliamentary process, and the Ministerial Group on Child Protection and Disability is due to report.

5.4. Children who are born with, or who acquire hearing or sight loss in early childhood, have very different developmental and habilitation needs to those of adults who lose their hearing and/or sight later in life, and require very specialist input from a variety of agencies. The Getting It Right For Every Child person-centred care planning approach to addressing holistic wellbeing needs will provide the framework within which the needs of any child or young person will be addressed (see 1.5).

5.5. It is recognised therefore that a Sensory Impairment Strategy cannot, and should not, be the sole driver for developments across the full range of health, education and social care services for children with a visual and/or hearing impairment, nor the local and national policies, and indeed legislation, which direct these. However, it is proposed that the inclusion of children within the scope of this Strategy will serve to:

- bring all relevant agencies together to share information about current and best practice with regard to addressing the wellbeing needs of children and young people with a sensory impairment, reducing duplication of effort and supporting a cohesive approach across Scotland;
- evaluate the impact and/or possibilities of joint sensory service delivery for children with visual and/or hearing impairment and their families;
- support the development of a strategic approach to securing positive outcomes for sensory impaired children which is appropriate and relevant to the wider policy and practice context, and which supports a smooth transition to adult life;
- support timely early intervention to enable children to achieve their potential.

5.6. At the time of writing, the proposed private member's British Sign Language (Scotland) Bill is being drafted for submission to the Scottish Parliament later in 2014. When the detailed proposal has been submitted by Mark Griffin MSP, the Scottish Government will review its position.

6. NATIONAL POLICIES AND PRACTICE EXPECTATIONS

6.1. The Scottish Human Rights Commission has identified Human Dignity and Care, and Human Rights in Healthcare as being amongst its key priorities, and a wide range of Scottish Government policies and guidelines have emerged over the last few years that have addressed a variety of issues across the health and social care agenda in relation to children and adults. These have all sought to focus on changing outcomes for service users.

6.2. It is recognised that increased need in the context of diminishing resources can only be met through the introduction of different ways of responding to need, commissioning and delivering support. While none of these policies and initiatives specifically relates to sensory impairment, they all have relevance to people with a sensory impairment.

6.3. The emerging themes include:

- A strong emphasis on an outcome focused approach that places the person at the centre, believing that the active engagement of the service user and their families and carers is the best means of ensuring effective outcomes in the planning and delivery of care;

- An acceptance of the importance of a redirection of resource towards more targeted preventative strategies that promote healthy lifestyles and the provision of information and advice to assist with this, both in general terms and also in relation to specific conditions;
- Early diagnosis and intervention (assisted by screening programmes) and the provision of information, emotional support and signposting to people and their parents/carers around the time of diagnosis;
- The need to facilitate greater flexibility in the support provided to people. This should be underpinned by greater choice and control for individuals, coupled with an emphasis on facilitating informed choice through good quality information and advice;
- The promotion of greater support to people to assist them to manage their own lives, particularly with regard to long term conditions. This should be done in a way that maximises independence and self-care, with appropriate support and guidance as required, and promotes the development of community capacity to support local responses to identified needs;
- Clear care pathways across a range of conditions that encourage and guide the individual through their engagement with assessment processes and service provision, and support them in managing their own conditions;
- Targeted support to people at time of transitions;
- The need to ensure effective and efficient joined up working across the public, third and independent sectors, with a drive to minimize duplication and encourage the sharing of information across and within agencies;
- Effective partnership approaches with service users and parents/carers;
- A skilled, sustainable and well-trained and supported workforce across all levels and agencies;
- A robust but proportionate means of measuring performance that concentrates on beneficial outcomes for service users and carers.

6.4. **The above points all apply to people with a sensory impairment and represent the essential principles that should guide the development of services.**

6.5. A number of national developments help to support these themes, and have implications for people with a sensory impairment. These include Self Directed Support, Reshaping Care for Older people (with funding from the Change Fund), the Early Years Collaborative, the revision of the National Care Standards, the implementation of the Carers and Young Carers Strategy, the Children and Young People (Scotland) Bill, and the Doran review.

6.6. Linked to these policies and expectations is the recognition that there is a hierarchy of need that requires a different type of response depending on the level of need. This is reflected in relation to sensory impairment in the diagram below.[12]

6.7. An individual may move between these levels over time, and it is the task of services to ensure that an appropriate response is available, in the context that at all times the emphasis should be on supporting the individual to obtain and retain maximum independence consistent with their safety and wellbeing. This can be enhanced by the effective strategic procurement and provision of appropriate community equipment that promotes independence and can link to the developing use of telehealth and telecare.

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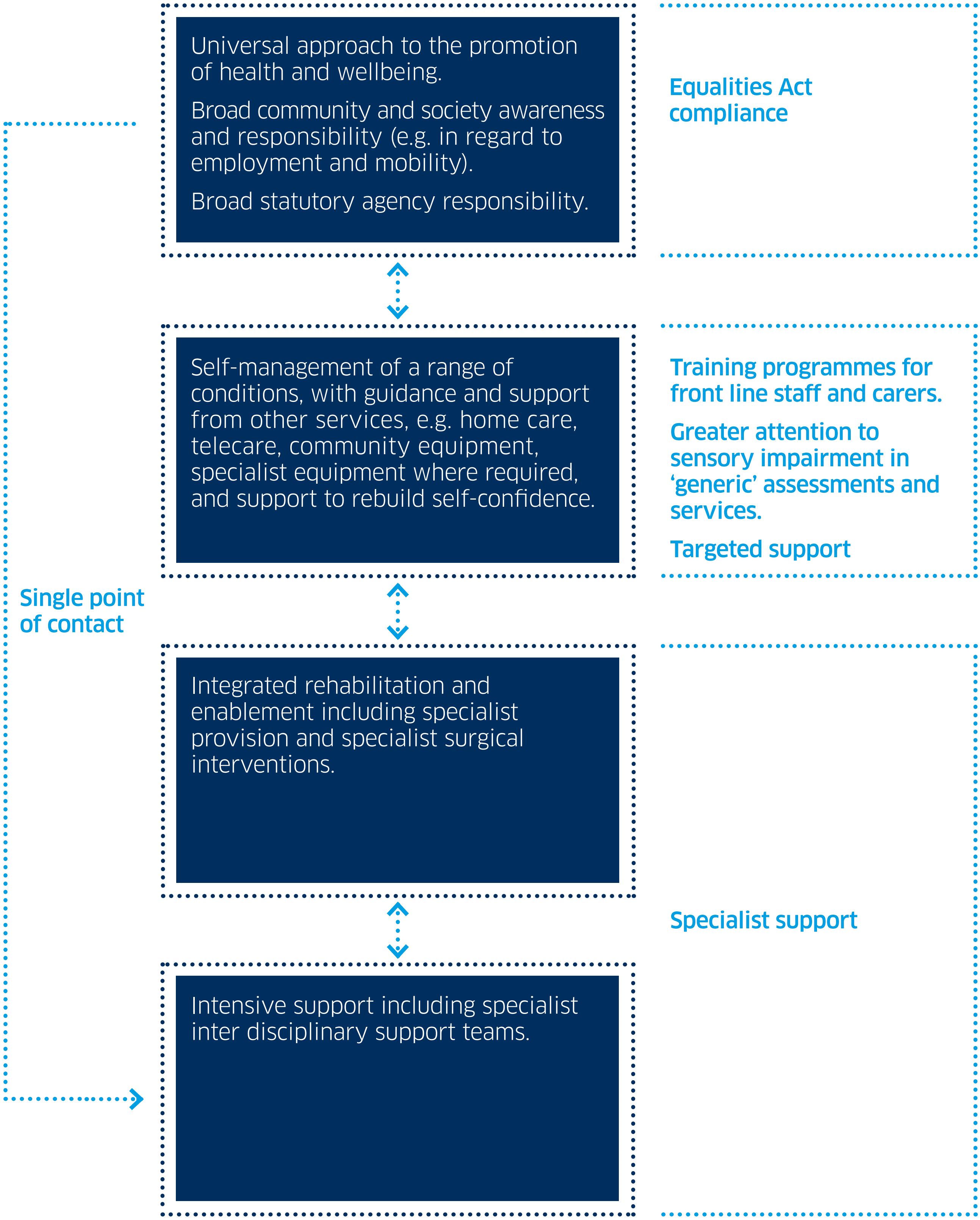
[12] Adapted from Reshaping Care/Change Fund materials.



Universal approach to the promotion of health and wellbeing.

Broad community and society awareness and responsibility (e.g. in regard to employment and mobility).

Broad statutory agency responsibility.

Equalities Act compliance

Self-management of a range of conditions, with guidance and support from other services, e.g. home care, telecare, community equipment, specialist equipment where required, and support to rebuild self-confidence.

Training programmes for front line staff and carers.

Greater attention to sensory impairment in ‘generic’ assessments and services.

Targeted support

Single point of contact

Integrated rehabilitation and enablement including specialist provision and specialist surgical interventions.

Intensive support including specialist inter disciplinary support teams.

Specialist support

7. THE DEVELOPMENT OF CARE PATHWAYS

7.1. Another way of identifying the response that should be made to sensory loss is to consider an individual's journey or pathway through care and their requirement for appropriate and timely interventions from statutory agencies and service providers.

7.2. Care pathways are increasingly seen as a means of ensuring that local partnerships and services have clearly identified and agreed ways of placing the person at the centre, and assisting the individual to move through and across services for particular conditions. Not only does this provide a more integrated and positive experience for the individual, but it is also a way of optimising resources and systems for agencies to provide the most efficient service patterns and respond to changing needs. They provide a structure to guide interventions and to prompt actions and communication between and within agencies and services.

7.3. Every person's needs are different and there can be no typical journey, but the diagram below has been designed to show the main component parts of most people's journey in relation to sensory impairment. Again people may enter at different stages, particularly in relation to the nature/timing of the onset of a sensory impairment.

7.4. Many people can be dealt with through effective mainstream service provision. If these services are accessible and service staff have an awareness of the needs of people with sensory loss and appropriate skills/training to deal with these needs, then a wide range of these staff should be able to not only identify needs relating to sensory impairment, but also assess and provide simple solutions. It also recognises, however, that there will be some people whose sensory loss or complexity of need is such that specialist provision will always be required.

7.5. Parents, carers and other family members can often be the first to recognise a sensory loss in a family member. As such they are a valuable source of knowledge and expertise. Recognising the challenges of sensory loss, parents/carers can also be assisted to support people with a sensory loss if they are aware of the implications of that loss and, where appropriate, are provided with information that can assist them in their role. In many instances the person themselves will be able to relay this information, but in other instances it would be helpful if this could be done either directly with the parent/carer, or with both the person themselves and their parent/carer.

7.6. Meeting the communication needs of people with a sensory impairment is fundamental to ensuring that they can engage with the care pathway, and is an essential element in their everyday lives.

Information and advice in relation to sensory loss prevention and health promotion.

Easily accessible to people, so they know where and how to seek help if sensory loss is suspected.

Effective and accessible assessment and diagnosis.

Clinicians (incuding GPs) undertaking diagnosis should be aware of referral pathways in the local area.

Automatic referral for further infomation/post diagnostic support

Direct referral to other services if required.

Simple referral routes where additional supports are required, including the options of supported self-assessment.

Single point of access for integrated care.

Linking the individual into access to all specialist provision that they may require, and should link to referral pathways.

Support, Service, Treatment

Integrated care across clinical, social and community based support focussing on promoting independence and supported self-management.

Availability of self-help, emotional and peer support. Information on, and access to, communication and support.

Care Planning and Review for people with complex needs.

Information shared across all service providers.

Robust arrangements for helping people through periods of transition and in moving from children's to adult services.

Appropriate forms of communication

Take full account of sensory impairment in all assessments

Screening for sensory impairment at key times

Agreed by all partner agencies

Integrated systems

Measurement of outcomes for the individual

Key factors in care pathways

7.7. To ensure that pathways work as effectively as possible for people with a sensory impairment, they must be confirmed at a local level to take account of local circumstances, demographic and ethnic profiles and a number of key factors must be considered:

- For the majority of people, the point of diagnosis will be undertaken primarily through NHS audiologists, ophthalmologists, optometrists or optometry practitioners. Others will first become engaged through their paediatric services or GP. It is important that referral routes into support services are clear to those undertaking diagnoses, and that information is available in appropriate formats to the individuals themselves and their parents/carers;
- It remains a cause for some concern that there is no standard requirement in relation to maintaining information on people with the various diagnoses of sensory impairment. Such information is basic to understanding the prevalence of impairment and then being able to monitor the reach of services, engage with service users and carers, identify and learn from best practice, and identify gaps and opportunities for service improvement;
- A commitment to the consideration of sensory impairment being included in a range of health and social care assessments;
- The development of integrated service provision that actively promotes opportunities for assessment and service delivery across the different types of sensory loss and also the agencies involved;
- Agencies and disciplines should have robust, coordinated arrangements for information sharing and a commitment to local care pathways to best meet the needs of local service users;
- Agencies and disciplines should be aware of the opportunities offered by their distinct legal and practice frameworks, and to take advantage of any such opportunities to provide person centred solutions for individuals;
- A commitment to maximise basic sensory impairment checks which can readily be undertaken by non specialist staff, with onward referral where there is an indication of sensory loss. This could be done at GP surgeries when the person reaches an agreed age, or at key times of engagement, e.g. assessment for other community care services or admission to a care home;
- A commitment to a single point of access wherever possible, including for ongoing contact. This places a responsibility on services and agencies to work together effectively and reduce duplication and confusion for the individual. For children this will be addressed by the Named Person role, a core component of the Getting It Right For Every Child approach. The Children and Young People (Scotland) Bill proposes to make the availability of a Named Person for every child in Scotland a statutory provision;

- A clearly developed set of local sensory impairment care pathways that are agreed by key stakeholders and understood by all clinicians, assessors, service providers and, most importantly, the person themselves. This should address the needs of people with an identified sensory impairment, people at risk of sensory loss, and people who may be living with a hidden sensory loss, and should reflect the importance of prompting the outcomes based approach outlined earlier;
- A commitment from statutory agencies to seek to agree the maximum possible consistency of approach across Scotland, and ensure similar access to services across Scotland;
- A commitment to awareness raising training for front line staff who may have to deal with people with sensory impairments;
- An awareness of existing mechanisms which may facilitate the achievement of the above, for example, the Managed Clinical Network (MCN), Visual Impairment Network for Children and Young People (VINCYP), which aims to improve services to children and families by providing evidence-based guidance, information and pathways for children identified as having a visual impairment.

8. AREAS FOR ACTION

8.1. As outlined earlier, it is intended that this strategic framework should be a lever for change, and should facilitate that change across agencies and services.

8.2. In the context of the above overview, summary of national policy and practice directions and expectations, and comments on the requirements for an effective care pathway, a number of key issues and areas for action can be identified that lead to a range of broad recommendations.

8.3. These areas for action and recommendations are outlined below:

Sensory loss checks

8.4. Stakeholders repeatedly stressed the centrality of effective assessment and diagnosis. This is the initial point of identification of sensory loss. Timeous diagnosis leads to speedier, and often more helpful, treatment and support, the introduction of Universal Newborn Hearing Screening being a good example of this, whereby screening for hearing loss at birth can lead to earlier intervention.

8.5. Sensory loss, however, can often have a slow onset and individuals may not be aware that their loss is increasing, or may feel reluctant to ask for assistance. As outlined earlier there is also the important group of people who have, or may have, ‘hidden’ sensory loss. In addition to specific assessment for sensory loss, as outlined in the Care Pathway diagram earlier, there is also the need to take full account of potential sensory impairment issues in mainstream assessments, including community care assessments.

8.6. Early identification of sensory loss can have a positive impact in reducing negative outcomes (e.g. it could reduce the risk of falls). To assist this, simple checks can be undertaken by a range of staff that could identify potential sensory loss and lead to appropriate onward referral. Such checks could be undertaken when the person reaches an agreed age, or at key times of engagement, e.g. as a routine part of health or social care assessments.

Recommendation 1:

8.7. Local partnerships should consider options for the introduction of basic sensory checks for example for people of a certain age, and at agreed times in their care pathway.

Awareness of issues relating to sensory loss

8.8. Discussion with stakeholders revealed a clear view that there is a lack of awareness of sensory impairment issues in staff across a range of services that can have a direct impact on the appropriateness of care plans for some people, and the ability of some staff to provide simple solutions. Local initiatives in care settings (such as the provision of sensory impairment awareness training and the introduction of tools to assist in care planning) have provided positive results in staff awareness and the consequent impact this has on the quality of care planning that takes into account the impact of sensory loss for people. The view was strongly expressed that this is particularly important for staff who work with older people, e.g. community nursing staff, home carers, care home staff, occupational therapists and community based health professionals.

Recommendation 2:

At a national level, the Scottish Government should scope out the range of formal and informal training opportunities around sensory impairment awareness, and work with the relevant education, training and qualification bodies to explore opportunities to increase awareness and expertise in the area of sensory impairment awareness, building appropriate content into the core training regimes of different professional groups.

Recommendation 3:

Local partnerships should audit their skills base in relation to awareness of sensory impairment in the workforce and take steps to address any deficits identified, targeted in the first instance at older people's services.

Promoting effective local service provision

8.9. The role of care pathways is now recognised in relation to the provision of a more integrated and positive experience for the individual, but also as a way of optimising resources and systems for agencies that assist in the provision of the most efficient service patterns. They are in place across Scotland for a number of long term conditions, but not so far in relation to sensory loss.

8.10. Local services are organised in different ways to reflect local circumstances, but all local areas should be able to demonstrate that they have planned for services that reflect local need, that promote partnership working, that provide clear integrated care pathways for individuals, and that also promote self-help and self-management of sensory loss wherever possible. Children's service planning, as strengthened through proposals in the Children and Young People (Scotland) Bill, will bring service providers together into a single, integrated planning system. These published plans will provide information on how children's needs will be addressed through an integrated approach; promoting, supporting and safeguarding their wellbeing and making the most efficient use of available resources.

8.11. Current policies across community care reflect the increasing emphasis on providing greater support to people to manage their own conditions, and to have greater choice and control over their support in a way that maximises independence and self-care, with appropriate support and guidance as required. This requires there to be good information available about sensory loss, its impact across a number of areas for individuals, and ways in which people can be assisted to manage their sensory loss.

Recommendation 4:[13]

Local partnerships (in this instance local statutory and third sector agencies) should be able to evidence that their service planning reflects the need in their area, and reflects appropriate responses to the hierarchy of need outlined earlier.

- They should audit current spend and service patterns on sensory impairment, including for carers, in relation to specialist provision and also to those elements of other service provision that impact on people with a sensory impairment. In the light of the findings, consideration should be given to options for service redesign as appropriate;
- They should develop care pathways for people with a sensory impairment, which confirm the component parts of the individual's journey. In so doing they should assess performance against the care pathway and the key factors for effective pathways outlined earlier, and use this as the basis for service improvement, and identify the relevant responsibilities across agencies for the delivery of this;
- Accessible local information strategies should be developed to include preventative measures and good self-care in retaining sensory health, but also providing information on how to access services.

The above matters should be subject to regular reporting and review by local partnerships.

Data collection

8.12. As highlighted in the section on the development of care pathways, reliable information is basic to understanding the prevalence of sensory impairment and then being able to monitor the reach of services, engage with service users and carers, identify and learn from best practice, and identify gaps and opportunities for service improvement. Currently there are no standard expectations in this regard.

Recommendation 5:

There should be robust systems for maintaining information locally, and sharing this between agencies, in relation to people who have received a diagnosis of a sensory impairment at any time from birth onwards.

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[13] The Scottish Government will provide funding to local partnerships for 2013/14 and 2014/15 to assist with the work that will be required to implement this group of recommendations. Partnerships should ensure that attention is given to ensuring maximum sustainability once this funding ceases.

Barriers to everyday life

8.13. As outlined in the overview section of the Strategy, people with a sensory impairment face a number of barriers to participation in everyday life, particularly in relation to how they are able to communicate with the world around them. The Equalities Act 2010 brings together a number of pieces of legislation into one single Act to help tackle discrimination and inequality. The view was expressed from stakeholders that people with sensory loss may not have benefited from the provisions of the Act to the same extent as others.

8.14. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 9 on Accessibility refers to providing accessible information, support and assistance as required to ensure disabled people are treated equally and fairly.

8.15. It would be a helpful exercise to consider the extent to which the provisions of the Act and the Convention have application to people with a sensory loss, and to determine whether there are issues that require to be addressed and that will then require consideration for further action.

Recommendation 6:

Agencies should review their compliance with the Equality Act 2010 and the UNCRPD Article 9 in relation to sensory impairment, particularly in relation to communication, and give consideration to whether any future action may be required.

Children and young people

8.16. This strategic framework is designed to apply to children and adults. It is however recognised that the current work in taking forward the Doran review, and the progress of the Children and Young People (Scotland) Bill through the Parliamentary process, will have a significant impact on how developments will be taken forward for children with a sensory impairment. The detail of this will be influenced by the above work.

Recommendation 7:

The Scottish Government should issue further guidance in relation to children and young people following the conclusion of work on the implications of the Doran review and the eventual enactment of the Children and Young People (Scotland) Bill.

9. SUMMARY OF RECOMMENDATIONS

9.1. Local partnerships should consider options for the introduction of basic sensory checks for example for people of a certain age, and at agreed times in their care pathway.

9.2. At a national level, the Scottish Government should scope out the range of formal and informal training opportunities around sensory impairment awareness, and work with the relevant education, training and qualification bodies to explore opportunities to increase awareness and expertise in the area of sensory impairment awareness, building appropriate content into the core training regimes of different professional groups.

9.3. Local partnerships should audit their skills base in relation to awareness of sensory impairment in the workforce and take steps to address any deficits identified, targeted in the first instance at older people's services.

9.4. Local partnerships (in this instance local statutory and third sector agencies) should be able to evidence that their service planning reflects the need in their area, and reflects appropriate responses to the hierarchy of need outlined earlier.

- They should audit current spend and service patterns on sensory impairment, including for carers, in relation to specialist provision and also to those elements of other service provision that impact on people with a sensory impairment. In the light of the findings, consideration should be given to options for service redesign as appropriate;
- They should develop care pathways for people with a sensory impairment, which confirm the component parts of the individual's journey. In so doing they should assess performance against the care pathway and the key factors for effective pathways outlined earlier, and use this as the basis for service improvement, and identify the relevant responsibilities across agencies for the delivery of this;
- Accessible local information strategies should be developed to include preventative measures and good self-care in retaining sensory health, but also providing information on how to access services.

9.5. There should be robust systems for maintaining information locally, and sharing this between agencies, in relation to people who have received a diagnosis of a sensory impairment at any time from birth onwards.

9.6. Agencies should review their compliance with the Equalities Act 2010 and the UNCRPD Article 9 in relation to sensory impairment, particularly in relation to communication, and give consideration to whether any future action may be required.

9.7. The Scottish Government should issue further guidance in relation to children and young people following the conclusion of work on the implications of the Doran review and the eventual enactment of the Children and Young People (Scotland) Bill.

10. IMPLEMENTATION

10.1. It is intended that the areas for action (above) will be taken forward by the Scottish Government and local partnerships, in this instance mainly local statutory agencies and third sector agencies.

10.2. Scottish Government funding will be made available to local authorities on behalf of these local partnerships. It is intended that the local partnership funding will provide resource to facilitate discussion, planning and action at local level.

10.3. Work will be undertaken, driven by nominated partnership leads (who may work in the local authority, NHS Health Board or third sector agency), to identify local priorities and develop work streams, timescales and implementation plans for the various recommendations and areas for action.

10.4. Outcome measures will be agreed by Scottish Government officials and partnership leads to allow measurement of improvement over years 2014/15 and 2015/16 and identify remaining gaps to be addressed thereafter.

10.5. Annex A lists documents, references and tools which may assist in implementation.

10.6. Annex B lists organisations which may assist in implementation.

ANNEX A

2020 Vision for Health and Social Care
www.scotland.gov.uk/Topics/Health/Policy/2020-Vision

Adult UK Sight Loss Pathway – UK Vision Strategy
http://www.vision2020uk.org.uk/ukvisionstrategy/page.asp?section=299&sectionTitle=Adult+UK+sight+loss+pathway

Advice from the Central Legal Office on Sharing Patient Information
www.clo.scot.nhs.uk

British Sign Language (Scotland) Bill

Carers Strategy for Scotland 2010-2015, Scottish Government
www.scotland.gov.uk/Publications/2010/07/23153304/0

Children and Young People (Scotland) Bill

Community Care Outcomes Framework
http://www.jitscotland.org.uk/about/community-care-outcomes-framework/

Cost of Sight Loss Scotland
http://www.rnib.org.uk/sites/default/files/cost_sight_loss_scotland.pdf

Dementia and Sight Loss
http://www.rnib.org.uk/node/387

Doran Review
www.scotland.gov.uk/Publications/2012/11/7084/0

Early Years Collaborative
www.scotland.gov.uk/Topics/People/Young-People/early-years

Edinburgh and Lothians Joint Sensory Partnership
www.jointsensorypartnership.com

Education (Additional Support for Learning) (Scotland) Act 2004

Education (Additional Support for Learning) (Scotland) Act 2009

Equalities Act 2010

Eyecare Integration Project
www.eyecareintegration.scot.nhs.uk

Getting It Right For Every Child
www.scotland.gov.uk/Topics/People/Young-People/gettingitright

Guidance for meeting Audiological Needs of Adults with Learning Disabilities, NHS Scotland, 2009
www.scotland.gov.uk/Resource/Doc/924/0092407.doc

Guidance on the Procurement of Care and Support Services, Scottish Government and COSLA, 2010
www.jitscotland.org.uk/search/?m=1&start=0&q=guidance+on+the+procurement+of+care+and+support+services

Healthcare Quality Strategy for NHS Scotland, Scottish Government 2010
www.scotland.gov.uk/Publications/2010/05/10102307/0

Human Rights Act 1998

Independent Living in Scotland
www.scotland.gov.uk/Publications/2013/04/8699

Joint Strategic Commissioning Learning and Development Framework, Scottish Government, NHS Scotland, COSLA and the Joint Improvement Team, 2012
http://www.jitscotland.org.uk/action-areas/commissioning/

Keys to Life, Scottish Government, 2013
www.scotland.gov.uk/Resource/0042/00424389.pdf

Local Record of Deaf Children
www.ndcs.org.uk/document.rm?id=6619

Managed Care Networks
www.jitscotland.org.uk

National Care Standards
www.careinfoscotland.co.uk

Older People and Sensory Loss
www.rnib.org.uk
www.actiononhearingloss.org.uk

Opthalmology Short Life Working Group – Diagnostic Report 2013
Please contact jacquie.dougall@scotland.gsi.gov.uk

Principles of Inclusive Communication – an information and self-assessment tool for public authorities
www.scotland.gov.uk/Resource/Doc/357865/0120931.pdf

Public Bodies (Joint Working) (Scotland) Bill

Quality Standards for Adult Hearing Rehabilitation Services
www.scotland.gov.uk/Publications/2009/04/27115807/0

Quality Standards for Paediatric Audiology
www.scotland.gov.uk/Resource/Doc/270506/0080556.pdf

Quality Standards Transition from Paediatric to Adult Audiology Services
www.ndcs.org.uk/document.rm?id=8196

Report on the Future Delivery of Public Services (The Christie Report)
www.scotland.gov.uk/Publications/2011/06/27154527/0

Reshaping Care for Older People: A Programme for Change 2011-2021
www.scotland.gov.uk/Resource/Doc/1095/0097691.pdf

Roles in Audiology
Available via local NHS Audiology Head of Service

Scottish Government Dementia Strategy
www.scotland.gov.uk/Publications/2010/09/10151751/17

Scottish Government's National Outcomes
www.scotland.gov.uk/About/Performance/ScotPerforms/outcomes

Scottish National Action Plan for Human Rights
www.scottishhumanrights.com/actionplan

Scottish Strategy for Autism, Scottish Government, 2011
www.scotland.gov.uk/Publications/2011/11/01120340/0

Scottish Vision Strategy
http://www.rnib.org.uk/sites/default/files/Scot_Vision_Strategy_refresh.pdf

Seeing It My Way
http://www.rnib.org.uk/about-rnib-what-we-do-uk-vision-strategy/seeing-it-my-way

Self Directed Support: A National Strategy for Scotland
www.scotland.gov.uk/Publications/2010/11/05120810/0

Sense Scotland
Undertaking work to mainstream complex communication support needs (CCSN) to ensure that disabled people can exercise more choice and control over their care and access to public service provision.
www.sensescotland.org.uk

Social Care (Self-directed Support) (Scotland) Act 2013

Template for Success
www.skillsdevelopmentscotland.co.uk

UK Vision Strategy
www.vision2020uk.org.uk/ukvisionstrategy

Universal Newborn Hearing Screening
http://hearing.screening.nhs.uk/

Visual Impairment and Learning Disability
http://www.rnib.org.uk/services-we-offer/learning-disability-services

ANNEX B

Action on Hearing Loss Scotland
Represents the 850,000 people in Scotland who are deaf or have a hearing loss.
www.actiononhearingloss.org.uk

Association of Directors of Social Work (ADSW)
The professional association of senior social work managers in Scotland.
www.adsw.org.uk

Convention of Scottish Local Authorities (COSLA)
The representative voice of Scottish local government.
www.cosla.gov.uk

Deafblind Scotland
Aims to help deafblind people in Scotland live as rightful members of their own communities, where they have the permanent support and recognition necessary to be equal citizens.
www.deafblindscotland.org.uk

Children & Young People's Visual Impairment Managed Clinical Network

Joint Improvement Team (JIT)
A strategic improvement partnership between the Scottish Government, NHS Scotland, COSLA, the Third Sector, the Independent Sector and the Housing Sector.
www.jitscotland.org.uk

National Deaf Children's Society
The national charity dedicated to creating a world without barriers for deaf children and young people.
www.ndcs.org.uk

RNIB Scotland
Charity working with blind and partially sighted people in Scotland, supporting children and adults with sight loss to live full and independent lives.
www.rnib.org.uk

Scottish Council on Deafness (SCOD)
National coordinating body for voluntary and statutory organisations which cater for Deaf, deafened, deafblind and hard of hearing people, their families and.....
www.scod.org.uk

Scottish Stroke Vision and Hearing Network
A collaboration between stroke charities, hearing and vision charities, healthcare professionals, researchers and people affected by stroke.
www.knowledge.scot.nhs.uk/sskiacommunity/cop/svsn.aspx

Scottish Human Rights Commission
Promotes and protects the human rights of everyone in Scotland.
www.scottishhumanrights.com

Scottish Sensory Centre
Promotes and supports new developments and effective practices in the education of children and young people with sensory impairments.
www.ssc.education.ed.ac.uk

SCOVI
An umbrella organisation committed to promoting equality and opportunity for people affected by serious sight loss across Scotland.
www.scovi.org.uk

Self-directed Support Scotland
The Scottish Government's self-directed support website.
www.selfdirectedsupportscotland.org.uk

Skills Development Scotland
The organisation charged with the delivery of careers advice in Scotland.
www.skillsdevelopmentscotland.co.uk

Visual Impairment Network for Children and Young People (VINCYP)
The network is due to start on 1st April 2014 and is the first national MCN to fully include health, education, social services and third sector representatives as well as parents. It will promote sharing of good practice and develop service standards which should lead to a reduction in inequity.

Visibility
Supports people with visual impairments to make their own choices and live their lives fully, confidently and independently.
www.visibility.org.uk

NOTES

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The Scottish Government
Riaghaltas na h-Alba

ISBN: 978-1-78412-306-2

ISBN: 978-1-78412-307-9 (ePub)

ISBN: 978-1-78412-308-6 (Mobi)

This document is also available on the Scottish Government website:
www.scotland.gov.uk

APS Group Scotland
DPPAS24701 (04/14)