

Shetland

Disability Strategy

2005-2020

Consultation Responses



Shetland's Disability Strategy

In developing a Disability Strategy for Shetland, the views of a large number of groups and individuals were sought. The Draft Disability Strategy document was produced in October 2004 and circulated for comment. The strategy will be published when it has been agreed by SIC & NHS Shetland in May 2005.

A number of questions were developed for consultation purposes to help people focus their comments.

This document contains all the responses that were received during the consultation period. A number of organisations responded with comments including:

Special Needs Action Group (SNAG) Care Commission
Shetland Enterprise Shetland Welfare Trust
SCSS Voluntary Services Resource Centre

There were also over 90 individual responses.

1. Is there something that we need to do in the 'Recommended Actions for Year One' section that we have missed out?

- There needs to be Joint Agency training including half-day sessions to raise staff awareness about their roles and responsibilities in terms of the Disability Discrimination Act.
- Employing an MS nurse would be valuable as a coordinator of services. People with MS usually require regular, frequent intervention by physiotherapists and occupational therapists, which is not available at present.
- Review the young physically disabled unit in Montfield. Montfield is far from appropriate as it is recognised as an 'older people's' service unit.
- Introduce regular yearly reviews for adults with learning disabilities to check for hidden problems.
- Provide respite and out of school activities for school children and young people.
- Improve wheelchair access to public conveniences.
- Improve Access to Information, especially at the diagnosis stage for diseases.
- Develop a "One Stop Shop" where people can go to get information and advice on

a wide range of disability issues. People should be able to obtain all the information necessary for their individual circumstances.

2. Do you think in the “What Could We Do Better?” section we have listed everything or are there important things that you think we have missed?

- The issue of “access” needs to be highlighted. It not simply about access to buildings, but access to social activities and daily activities.
- There should be more awareness of Supporting People initiative in relation to physical and mental disabilities in the workplace.
- Some service users with special needs are getting older and more frail and can no longer be cared for in their own home. This group does not always sit comfortably in mainstream residential units and therefore, a residential unit needs to be identified that can best meet the diverse needs of this group.
- Look at improving the quantity of affordable wheelchair accessible transport.
- Improve the provision of Dental Services for individuals with Additional Support Needs, particularly for those in transition from children’s to adult services.
- It is important to improve information sharing between service providers and service users.
- There needs to be more emphasis on Direct Payments – how it works, what it can be used for etc. Direct Payments should be discussed at all annual reviews.
- There should be a greater recognition of speech, language and communication disabilities.
- There needs be more focus on elderly services in remote areas of Shetland.

3. In the “Monitoring Actions” section, there are lots of things listed that we hope to do – what are the most important to you?

All Disabilities

- To develop and maintain information systems that allow information to be shared across agencies for the benefit of individual service users and for planning purposes.
- To improve co-ordination of multi-agency assessment and review processes for all people with disabilities.
- To ensure the needs of carers, parents and families are assessed and taken into account in the care planning process.
- To ensure access for disabled people, their carers and families to good quality information on services, benefits and other available support through publicity and raising awareness of sources of information.
- To deliver appropriate home based, respite and day care services that are flexible and responsive to the assessed needs of disabled people and their carers by reviewing and developing existing services.
- To ensure appropriate provision of physiotherapy; occupational therapy and speech and language therapy services for both children and adults with disabilities.
- To ensure people with disabilities living in remote and rural communities in Shetland have access to appropriate services in response to assessed need.
- To ensure coordination of services and efficient communication between agencies in order to guarantee a “uniform approach” and prevent conflicting advice.
- To raise awareness of disability issues amongst the public and service providers through appropriate publicity, education and training

- To ensure the views of people with disabilities, their carers and families form part of the ongoing monitoring of the implementation of this strategy and inform future service development.

Learning Disabilities

- To expand Learning Disability Nursing Service, including developing a specific service for people with autistic spectrum disorders, by recruiting a second learning disabilities nurse.

Physical Disabilities

- To ensure the specific issues affecting younger adults who become physically disabled are addressed; including employment; the needs of their families and age-appropriate services.

Sensory impairment and communication impairment

- To promote lifelong learning; training and employment opportunities for people with sensory impairment
- To ensure staff have appropriate training in sensory impairments and communication

4. What disability services do you think we will need in Shetland in the future that we don't already have?

- A joint education/NHS Shetland communication specialist for children and adults with learning disabilities and adults with neurological conditions.
- There is currently no routine service for children diagnosed with joint problems.
- There is no rehabilitation service aimed at helping people with physical disabilities to return to work.
- A specialist MS unit that could provide day care and residential care.
- There is a need for a mental health / crisis intervention team. This could be housed within a Mental Health Resource Centre, with a view to providing a number of mental health services within a single setting. There is a need for a more flexible service, with extended opening hours which would make it easier for groups to access, and which would also capture the problem areas in under used services such as the young male category.
- There is a lack of support for people with early onset of dementia.
- Counselling services and practical advice for people with relationship / sexual problems.
- There is an ongoing need for a Mobility and Rehabilitation Officer to develop mobility-training and direct teaching of skills to compensate for sensory loss.
- There is no child paediatrician.
- There is a lack of specialism in Shetland in developing and supporting augmentative communication. There is a need for new technology and communication devices to help those with significant communication difficulties.
- There is an essential requirement for a Central Liaison Officer with cross agency authority to ensure that the concerns of patients, carers and service users are addressed.
- There is a need for a centralised sensory and communication unit/service with a resource area, ICT equipment, demonstration area, alternative media centre, information point and a multi-sensory area.
- There is at times poor diagnosis of disabilities putting parents under extreme

pressure to seek diagnosis themselves out with Shetland.

- Services to the elderly who are temporarily disabled or are deteriorating into disability. More focus needed on elderly services in remote areas.
- There is a need for a neurological nurse specialist for coordinating services, advice, information, support and counselling throughout the course of the disease, but especially at diagnosis and severe impairment stages – for patients, partners and families.
- Improved respite that accommodates technological dependant individuals of all ages that can be delivered in one facility that encompasses nursing care and Social Work.
- More adult ‘befrienders’ – to support people without an extended family network. People to help with completing forms/paperwork, ‘chasing up’ services and generally checking people are coping..
- Need for more suitable respite facilities for adults with physical disabilities. There is a need for more purpose built accommodation for people with physical disabilities instead of trying to adapt existing housing that is often unsuitable for adaptation.

5. Any other comments?

- Throughout the document there is an implication that support and services are being designed for those with major disabilities. It is worthwhile recognising that those with minor disabilities can often get considerable benefit from inexpensive adjustments (e.g. handrails on stairs) that are very cost effective.
- There is a long list of targets for year one, but there is no mention of who is responsible for delivering each target.
- Joint training for SIC and NHS Shetland would be very useful to staff in all disciplines.
- It would be advantageous to list the regulatory bodies. This will inform service users that services are not only audited by the SIC, but independently.
- Excellent document however it seems to have concentrated on issues of resources and how needs can be better met by those with a specific and specialist/care worker role in such matters. Whilst this may have been the intention, I would like to see a much broader attempt to move such matters even further into the wider public domain because all of us, whatever type of service we are involved in providing, have an important role to play in how we respond to all members of society to provide equality of provision and reduction of stigma.
- The incidence of MS in Shetland appears to be 1:250 which is four times the world average and twice the Scottish average.
- It is of concern to me that such a glossy document has been produced as a draft.
- More information in relation to resources would have been helpful in the strategy.
- Established and effective monitoring systems need to be put in place to ensure that the delivery of services and outcomes from the strategy can be reviewed to reflect best practice.
- There needs to be clear and defined family support networks developed to assist the families and children who have additional support needs in transition from children’s services to adult services.
- Addressing ‘access to information’ – the need for information, support and counselling for patients and their partners and families. Especially at diagnosis stage.
- Mobility input for the visually impaired is urgently required within the SIC.
- The right of access to Braille/Audio for sensory cover is a legal requirement. To

offer to read the document should not be an option. Availability in this strategy document in suitable format should be made available to all current users.

- As the final meetings relating to the summarised draft took place during school holidays, members of the sensory disability sub group were unavailable for comment. It was, of course necessary to summarise the initial draft to make it a manageable size, however much of the important detail and information in our section (sensory impairment and communication impairment) has been lost. Many people with sensory and communication impairment would most likely be more interested in the detail of that section than other parts of the document. It would therefore be beneficial to make this available as an appendix.
- Paediatric rheumatology – currently no routine service for children diagnosed with joint problems.
- There is no mention that services in Shetland are regulated and registered under the regulation of Care (Scotland) Act and inspected by the Scottish Commission for the Regulation of Care (Care Commission) an independent regulatory body. SCRC ensure minimum standards are applied.
- There is no mention that Scottish Social Services Council will in future regulate the workforce and register those in the field.
- Braille services are available through Sandwick Junior High School.
- Children and young peoples services which are led by the Shetland Childcare Partnership.
- There is an apparent lack of information sharing between service providers and service users, with regard to who is accountable for care services at all stages of life, from cradle to grave. Families need to be empowered by this knowledge to feel in control of their lives.
- There is a lack of specialism locally in developing and supporting augmentative communication, in particular high tech communication devices for those with significant communication difficulties. (With the advances in technology this is as important and emerging field, which requires a dedicated commitment locally to develop expertise).
- Provision of services for teenagers in the transition from the education provision to adult services where there is a current gap.
- There remains an essential requirement for a **central liaison officer** with cross agency authority to ensure that the concerns of the parents/carers and clients are addressed. This is key issue, as it has to be recognised that the parent/carer has enough to do without fighting the system – a service that ultimately affects the health of the parents or carers is an unacceptable service. If this is recognised with the strategy it will be a strategy that will make a real difference in support of those people who are affected by disability.
- Proper transition from Education to Social Care for 19 year olds. There should be a dedicated disability qualified planner/architect for ALL building works.
- Good to see problems are being addressed but services must not be concentrated in Lerwick.
- Good to see problems are being addressed but services must not be concentrated in Lerwick.
- Social Work does not encourage other professionals to perform Single Shared Assessments.
- Throughout the document there is an implication that support and services are being designed for those with major disabilities. Whilst those people have the greatest need, those with minor problems can often get considerable benefit from inexpensive adjustments (e.g. handrails on stairs), which is very cost effective.

Helping such people back to (or into) work also benefits the economy (reduced financial dependence, paying taxes) and should be regarded as self-financing. Needs may be less obvious, and paradoxically, harder to assess, but the rights of those with a minor disability are no less than those with a major disability, and modest input can produce great benefit.

- NHS Shetland has already produced an 'improving mental health and well-being strategy'. How will the goal "to develop a mental health strategy for Shetland" fit in with work already done?
- It would be useful to adopt some universal symbols across NHS, SIC etc. The information symbol would be useful to many for example, symbols for reception and toilets which should be used.
- To the families and carers there is an apparent lack of commitment, response and hence a general apparent lack of concern by professionals to deal with cases.
- There needs to be a genuine commitment to this strategy, not just a 'tick box' exercise. We need to see some genuine progress from this consultation if you are to be taken seriously.
- There is obviously a wealth of information in the document but a feeling that there may be too many 'lists' making it difficult for some people to keep track of the issues at times.
- This is an ambitious project and the working group appear to have pulled together a lot of key issues to produce a good overview.
- Clear lines of consultation and communication need to be developed between service providers and service users, with regards to the strategy and best practice. Families need to feel supported through the changes and informed of planned changes to be implemented

6. Other Recommendations

- There should be a 'fast-track' referral system for people in crisis/rapidly worsening conditions, with a named person to chase up services. (OT, physio, speech and language therapy, orthotics, sensory impairment services, Housing, Social Work etc).
- The overall accountability for the delivery of the recommendations needs to be clear and defined, to ensure that community members are aware of who is responsible for what area of development.
- Would like specific training offered to front line staff who have to manage the demands of new legislation and increased needs of patients/carers.
- Centralise current sensory and communication services (Education). A building should be identified for staff and facilities (office, resource area, ICT equipment, demonstration area, alternative media centre, information point, possible dark room and multi-sensory area). Review roles, responsibilities, terms and conditions and management structure of team.
- Adopt "A Scottish Vision – benchmarking provision for pupils with visual impairment". A publication intended to assist local authorities in planning and development service and to assist young people and parents in evaluating services. The document would be adopted following point 6.6 (perhaps they should therefore be swapped around as point of action).
- Adopt "vision for the future: a framework for minimum standards in Social Work and rehabilitation services for people with a visual impairment". These action points would begin to address most of the current gaps relating to visual impairment as outlined in the strategy and they would provide a starting point for the development and progression of established services encompassing some of the issues outlined

in the Vision for the Future and A Scottish Vision.

- To develop an annually reviewed cross agency information booklet one for children and another for adults informing of all agencies, support services, transport services, opportunities, contacts, telephone numbers, helplines, central liaison officer as mentioned before. The booklet could also include information on all sources/types of grant/financial and allowances that are available, eligibility and how to access.