



Building on the Foundations in Scotland:

Improving Specialist Care, Support and Independence

September 2008

Muscular
Dystrophy
Campaign

Contents

**A report written by the Muscular
Dystrophy Campaign in association
with the Scottish Muscle Network and
families living in Scotland**

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Foreword

In this hard hitting report, the Muscular Dystrophy Campaign and leading clinicians from the Scottish Muscle Network set out a compelling case for an urgent review of health and social care services for families affected by muscular dystrophy and related neuromuscular conditions.

The number of boys with Duchenne muscular dystrophy living into adulthood is increasing each year, largely due to the significant work of the Scottish Muscle Network. The challenge now is to meet their needs effectively as well as the many thousands of other patients living with neuromuscular disorders in Scotland.

We have been dismayed by the number of people who are still forced to go without treatments that prolong and improve their lives. Their plight is made worse by the significant delays and variations in the provision of essential equipment and barriers to living independently.

Leading specialists agree that a care coordinator or key worker has a central role to play in coordinating the multiplicity of health and social care needs while providing valuable support and advice to individuals and families.

However, there are currently only two Regional Care Advisors and both of these posts are vulnerable given their dependence on charitable funding from the Muscular Dystrophy Campaign. With an average case load of 1,000 patients, it is clear that a minimum of 5 key workers are urgently required in Scotland, simply to provide a minimum level of support to each family.

We are calling on the Scottish Government, Health Boards and local authorities to work with us to do three things quickly that will address these issues:

- carry out an urgent review of health and social care services to identify the steps to be taken to establish comprehensive, multi-disciplinary services;
- identify and secure additional posts of key workers so that all patients benefit from their vital support as the lead professional within a specialist multi-disciplinary team;
- conduct a feasibility study to establish the most suitable location and service model for a Scottish Muscle Enterprise Centre that will tackle employment, training and the need for specialist physiotherapy support.

We believe Scotland can lead the way in providing comprehensive specialist services for people with these conditions. Let's build on good practice and make real progress now.

Stephen MacDonald
Chair of the Scottish Council
Muscular Dystrophy Campaign



Dr Doug Wilcox
Scottish Muscle Network



Executive Summary

What are these conditions?

The report reflects evidence obtained from a patient survey, Freedom of Information requests to all Scottish Health Boards and Scottish Councils as well as information from the latest research papers on the impact of specialist services on those affected by muscular dystrophy and related neuromuscular conditions.

There are more than 60 different types of muscular dystrophy and related neuromuscular conditions affecting an estimated 5,000 children and adults in Scotland. These conditions can be genetic or acquired.

A number of these conditions, such as Duchenne muscular dystrophy, are aggressive and cause progressive muscle wasting and weakness, orthopaedic deformity, cardiac and respiratory compromise and result in premature death. Others cause life-long disability. Some conditions present in childhood or young adult life. Others can be late onset conditions in adulthood. There are currently no known cures for these conditions.

Key Findings

- Access to ongoing and timely specialist diagnosis, assessment and interventions, particularly for adults, remains uneven across Scotland leading to a 'postcode' lottery of care;
- Life expectancy for boys with Duchenne muscular dystrophy still falls short of survival rates achieved in other comparable European countries;
- Despite increasing demand and improvements in survival, respiratory services are working beyond capacity and the service is not routinely available to all patients in Scotland;

- A specialist cardiac service for patients with inherited cardiac disorders, which could include NM cardiomyopathies and inherited arrhythmias, is not presently available across all of Scotland;
- Adult rehabilitation services are poorly developed for this patient group and do not provide adequate support to patients; Many patients in Scotland do not receive continuous, specialist physiotherapy or indeed any physiotherapy at all. Services are particularly poor for young adults and adults;
- There is no SIGN guideline for the management of these conditions despite variations in local practice and significant costs involved of some interventions;
- Funding for services are vulnerable given their dependence on charitable subsidy;
- The transition from child to adult services is rarely smooth and seamless with the result that many young people are disengaged and isolated from society and unable to live independently, pursue a career or access further education;
- Families with children who require home adaptations are means tested through the Housing Adaptation Grant which is also capped at £20,000. If the family lived in England or Wales they would apply to a dedicated Disabled Facilities Grant, would not be means tested and the grant is capped at £25,000.
- Patients do not receive regular adjustment of their wheelchair and other adaptations. Specialised equipment is not made available to all patients with these conditions and many families are forced to fundraise for the specialised wheelchairs themselves.

Evidence – the need for action

Action Needed

We are calling on the Scottish Government, Scottish Health Boards and Scottish Councils to:

- Ensure that all patients have access to a key worker at all stages of their life but especially when moving from child to adulthood and making the transition from paediatric to adult services;
- Ensure that all patients have access to timely specialist diagnosis, assessment, treatment and on-going care especially people in rural, urban and island areas across Scotland where services are particularly inaccessible and inadequate;
- Establish a short-life working group in partnership with the Scottish Muscle Network (SMN), to carry out a review of current service provision for patients with muscular dystrophy and related neuromuscular conditions living in Scotland;
- Support a feasibility study for a Scottish Muscle Enterprise. This model could be a variation of the very successful social enterprise centre based in Cheshire, England.
- Carry out an urgent and comprehensive assessment for the development of a home-ventilation service for adults, resourced across Scotland;
- Ensure that specialist cardiac support for patients with inherited cardiac disorders is available to all patients across Scotland;
- Improve current arrangements to ensure that patients with Pompe disease have smooth and speedy access to enzyme replacement therapy when recommended on grounds of clinical need.
- Recommend the production of a set of standards with NHS Quality Improvement Scotland and urge the Scottish Intercollegiate Guidelines Network (SIGN) to work with the SMN to develop guidelines for the management of neuromuscular conditions and tackle current inequities in access to diagnosis, treatments and on-going care;
- Establish a dedicated fund for housing adaptations for disabled people and their families and end means testing for families with disabled children who require aids in their home;
- Introduce scheduled reviews and assessments for all wheelchair users, as recommended by the Review of NHS Wheelchair and Seating Services in Scotland;

1. Access to specialist diagnosis, assessment and interventions, particularly for adults, remains uneven across Scotland

Scottish Health Boards are not ensuring equitable access to specialist care for patients with muscular dystrophy and related neuromuscular conditions living in Scotland. This has led to a 'postcode' lottery of care for these patients.

Sarah from Edinburgh has two sons affected by Duchenne muscular dystrophy. In her own words:

"We had to see 7 doctors before Duchenne muscular dystrophy was even suggested by which time I had given birth to another son who also has Duchenne. There doesn't seem to be enough awareness about these conditions."

Rapid access to accurate and expert diagnosis is essential to ensure a correct assessment of their condition. A number of these conditions are genetic and have implications for the whole family. Thus, an accurate diagnosis is particularly important.

The effective role of multi-disciplinary specialist care has been developed as the best model for delivering effective clinical care for such complex multi-system conditions.

The provision of expert physiotherapy, orthotics, early cardiac monitoring and intervention and corticosteroids has been shown to improve muscle function and maintain independent mobility¹. The judicious use of spinal surgery and expert respiratory services (including non invasive positive pressure ventilation²) helps to improve quality of life, delay the onset of respiratory failure and prolong the life of these patients³.

The National Services Division formally recognised the Scottish Muscle Network (see Appendix 2) as a Managed Clinical Network in April 2007. This recognition is welcomed. However, there remain significant deficiencies in service provision.

Evidence from a Freedom of Information request carried out by the Muscular Dystrophy Campaign in July 2008 to all Scottish Health Boards and Scottish Councils in July 2008 builds a picture of current service arrangements.

Of the 12 Health Boards who responded:

- Over half of Health Boards do not support a muscle clinic.
- Only one in five Health Boards offer a muscle clinic to both children and adults.
- Nearly half of Health Boards refer their patients within Scotland, usually to Glasgow.

Of the 27 Scottish Councils who have responded:

- Only one in five Councils work in partnership with the Scottish Muscle Network. However, little over half of respondents were aware of the Scottish Muscle Network's functions.

Half of the councils don't have information available for people with neuromuscular conditions.

A teenager with limb girdle muscular dystrophy who lives in Fife said:

"I am awaiting a full diagnosis for my condition from the Centre for Life in Newcastle and I have been very impressed with the coordination of my care from the consultants at my local hospital in Fife. I also receive excellent local support from a physiotherapist and my GP. I believe all patients in Scotland should receive a similar standard of care."

Only a handful of clinicians in Scotland have designated funding to provide sessions for muscular dystrophy and related disorders.

Patients in Scotland affected by Pompe disease do not have swift and speedy access to enzyme replacement therapy⁴ despite its use and availability to patients in England.

Commenting on accessing Enzyme Replacement Therapy, a family living outside Edinburgh said:

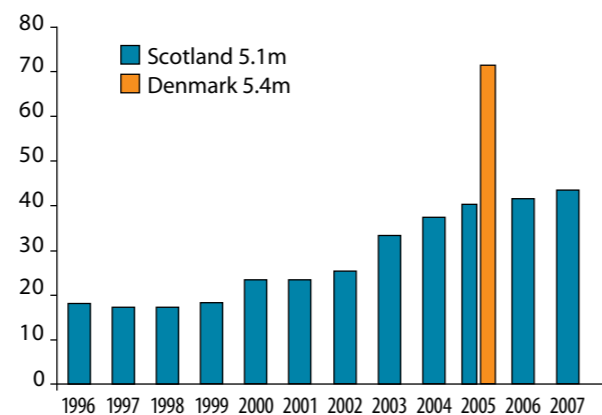
"To receive this treatment, with the potential to be life changing, we had to apply for funding on the grounds of being 'an exceptional case.' If we lived in England we would not have faced such barriers. It is unfair that patients are being disadvantaged because they have a rare condition but it is also unfair that they are further disadvantaged because of living in Scotland."

2. Life expectancy for boys with Duchenne still falls short of survival rates achieved in other comparable European countries

The number of boys with Duchenne muscular dystrophy surviving into adulthood is increasing each year. This is largely a result of the work of the Scottish Muscle Network and the improvements this has brought to the standard of paediatric care (see Appendix 3) for this patient group across Scotland.

However, life expectancy still falls short of standards set by other comparable European countries.

Scottish young men with DMD surviving to age 18



In Denmark, for example, with a population of 5.4 million there were 70 adult survivors in 2005. In the same year in Scotland with a population of 5.1 million there were 39 adult survivors. In 2007 there were 42 adult survivors.

"If we wish to improve the life expectancy and quality of life of these patients we urgently need to review home ventilation services."

Dr Ian Grant, Home Ventilation Service, Western General Hospital, Edinburgh

Dr Douglas Wilcox, Senior Lecturer at the University of Glasgow said:

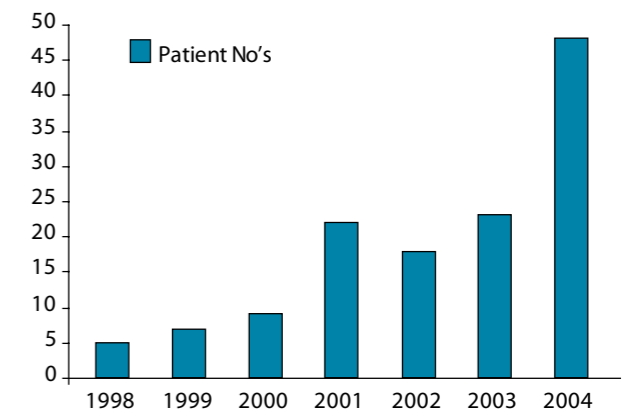
"In Scotland we have shown an increase in survival for a small number of boys with DMD by making sure they had access to existing medical services. However, the challenge will be to meet the needs of the many thousand other patients (mostly adults) who have neuromuscular disorders. This will require additional NHS funding."

3. Respiratory services are working beyond capacity and the service is not available to all patients in Scotland

An increasing number of young people with muscular dystrophy and related neuromuscular conditions are surviving into adulthood. Respiratory care is becoming critical to the enhanced life expectancy and quality of life for these young people.

The benefits, both in life expectancy and quality of life, of non-invasive ventilation and other technological treatments to support respiratory care have been shown⁵ resulting in an incremental growth in demand.

New referrals to Glasgow home ventilation service 1998-2004



Despite this, respiratory services (see Appendix 4) in Scotland have not, until recently, received any additional resources. Adult Home ventilation services in Scotland are currently beyond capacity with the number of referrals for assessment increasing consistently year on year.

The Freedom of Information request in July 2008 to all Scottish Health Boards revealed that:

- One in three Health Boards that responded do not offer home ventilation as a service to adults and children

In the East of Scotland there has been a recent move to fund additional nurses to support the Home Ventilation team, as well as Consultant sessions. Negotiations are also underway with the Respiratory Planning Group and Greater Glasgow Health Board to develop business case for the West of Scotland service.

**Dr Ian Grant, Home Ventilation Service,
Western General Hospital, Edinburgh**

“Home ventilation services have been developed on a sporadic basis rather than in a systematic manner. Hence in some areas of the country accessing home ventilation services is virtually impossible.

“If we wish to improve the life expectancy and quality of life of these patients we urgently need a review of home ventilation services.”

4. Cardiac services

At present a specialist cardiac service for adults with inherited cardiac disorders, which could include a number of neuromuscular conditions, for example, cardiomyopathies and inherited arrhythmias is **not available** throughout Scotland.

Cardiac involvement is an invariable feature of a number of neuromuscular conditions, including Duchenne and Becker muscular dystrophy and myotonic dystrophy Type 1. Expert treatment guidelines have been developed and published to the management of cardiac involvement.⁶

The West of Scotland has recently secured funding for a cardiac service (one day per week) for adults with inherited cardiac disorders. However, it is not yet clear whether this will meet clinical demands of the service, particularly as asymptomatic mutation carriers are diagnosed/contacted and offered screening. Furthermore, this service is not available to all patients across Scotland.

“I am very concerned that my son’s chest physio is being overlooked as we do not have regular access to a qualified physiotherapist who understands the complexity of his condition.”

Parent living in Glasgow whose son has DMD

5. Adult rehabilitation services are poorly developed in Scotland

There are few adult physicians in Scotland with a specialist interest in neuromuscular disorders.

The provision of adult rehabilitation services remains an area of significant concern and requires the co-ordinated and integrated framework advocated in the current delivery framework.

The relatively poor provision of adult rehabilitation services is one of the major concerns of the Scottish Muscle Network. Developments in adult rehabilitation over more recent years in Scotland have prioritised periods of intensive therapy to maximise recovery in areas such as adult brain injury, stroke and myocardial infarction. Thus there are only a few areas in Scotland where a specialist or rehabilitation service is available to adults with muscular dystrophy and related neuromuscular conditions.

It is essential that current work, *Shifting the Balance of Care* in Scotland recognises the specialist nature of care for these patients and improves outcomes through the use of anticipatory care activity, the use of SPARRA data (Scottish patients at risk of readmission and admission) to ensure appropriate and timely follow up, enabling care at home support, and multi-disciplinary approaches involving family carers and service users as partners.

6. Many patients do not receive continuous, specialist physiotherapy or indeed any physiotherapy at all. Services are particularly poor for young adults and adults

Current provision

- There is currently **only one** Clinical Specialist Physiotherapist (CSPT) involved in the care of neuromuscular disorders in Scotland;
- This service is provided to the West of Scotland and is limited to children and young adults;
- Very few patients, particularly adults, have access to a local physiotherapist, let alone a local physiotherapist who understands the complex and progressive nature of their condition;
- There is no CSPT dedicated to the adult population and referrals have to be returned to the Lead consultant creating an inequitable service;
- Two out of three Scottish Health Boards that responded do not offer ongoing physiotherapy for patients with muscular dystrophy and related conditions (FOI July 2008);
- Patients who live on the 95 inhabited islands off Scotland are often unable to access the local ferry or small aeroplanes to take them to the specialist muscle centre in Glasgow. Travelling can take in excess of 13 hours.

It has been agreed that there is the need for a full time clinical specialist physiotherapist in the East of Scotland. We are pleased that funding for this post has come from the Genetics Review and Scottish Government.

“If we had more specialist physiotherapy posts throughout Scotland we could deliver a more local and personalised service to families and provide much needed training and support to community physiotherapists.”

Clinical Specialist Physiotherapist, Scotland

However, this will leave patients in the North of Scotland and outer islands unaccounted for. Furthermore, this will not be sufficient unless the post holder is encouraged to advise and support community physiotherapists.

The CPST commented on the current state of physiotherapy provision in Scotland. In her own words:

“I often travel over 100 miles to see patients in my care and a number of families travel these same distances to receive specialist care in Glasgow. If we had more specialist physiotherapy posts throughout Scotland we could deliver a more localised and ongoing service to families and provide much more support and training to local community physiotherapist.”

Adults – There are no specialist physiotherapists dedicated to adults with muscular dystrophy and related neuromuscular conditions living in Scotland. Adult referrals to physiotherapy appear to be especially limited as they are only seen on request for an initial assessment and referral to a local physiotherapist. Furthermore, many adult patients only receive short bursts of therapy with no ongoing input. Those adults living in isolated areas have no access to physiotherapy at all.

Children and young adults – The CSPT is provided for the West of Scotland. She aims to undertake annual assessments of all patients with Duchenne but realistically these sessions are around every 14-24 months due to the increasing caseload which currently is in excess of 200 patients.

The CSPT undertakes specialist assessments both at the clinic and in the community setting and enters patient details into the North Star database as well as undertaking teaching sessions to students, voluntary agencies and other professionals involved in the care of muscular dystrophy and related neuromuscular disorders.

The need for Continuing Professional Development

Local community physiotherapists who treat patients with muscular dystrophy and related neuromuscular conditions do not always have expertise and knowledge about the complex and progressive nature of these conditions.

Additional specialist physiotherapy posts are needed if we are to ensure that ongoing care can be provided in the community. Specialist physiotherapists can provide much needed training and support to local physiotherapy teams which would be beneficial to families.

In addition, a Physiotherapy Network has been set up by the Muscular Dystrophy Campaign to improve the shortage of professional training and knowledge of physiotherapists

This Network runs conferences each year to provide support and learning for physiotherapists across the UK. The conferences are funded by the Muscular Dystrophy Campaign with a small fee to be paid by each attendee. This report calls on all Scottish Health Boards to ensure that community physiotherapists have access to this Network and are provided with the support they need to develop their skills.

James, an adult patient in Ayrshire with Becker muscular dystrophy, was developing contractures at the ankles which made him liable to fall. It was not possible to get adult physiotherapy for this. He fell and broke his ankle. He was able to get physiotherapy while the ankle was healing but even though the physiotherapist recognised the need for continuing physiotherapy he was discharged. As a result his contractures have continued to worsen and he is now virtually unable to walk.

Douglas, who lives in the Scottish Borders, has limb girdle muscular dystrophy. In his own words:

“I find hydrotherapy excellent both physically and mentally. It really makes me feel more positive as well as helping to keep my contractures under control, my balance and posture.”

“Unfortunately, I only receive two lots of six week sessions each year. People just don't seem to understand the progressive nature of my condition which requires ongoing therapy and support.”

7. Lack of nationally recognised standards of care and guidelines for the management of these conditions

The Scottish Muscle Network (SMN) successfully provides a forum for the development of standards of care across Scotland. However, wide variations exist at a local level in both provision and practice and there is currently no SIGN guideline for the management of patients with these conditions.

The following work by the SMN is currently underway:

- Physiotherapists in Scotland with an interest in neuromuscular conditions have created a comprehensive Duchenne muscular dystrophy Scottish Management Profile.
- The paediatric subgroup of the SMN has established referral care pathways with clinical genetics, Scottish spinal surgical services and paediatric cardiologists.
- The Scottish Paediatric Respiratory Interest Group (SPRIG) is working to develop guidelines for respiratory monitoring and assessments, referral pathways and respiratory interventions.
- A subgroup of the SMN will develop care standards in the management of myotonic dystrophy in Scotland. Draft guidelines are being developed, including cardiac management.

Progress is also being made internationally in developing standards of care for neuromuscular conditions through the TREAT-NMD initiative.

- Consensus has been agreed for a standard of care for spinal muscular atrophy.⁷
- The Centre for Disease Control in the US is currently coordinating a project – Care considerations for Duchenne muscular dystrophy. The project will draw up a comprehensive set of recommendations for standards of care in Duchenne muscular dystrophy. These are likely to be completed in the Autumn of 2008.⁸

International consensus for standard of care for all other neuromuscular conditions has not yet been realised.

8. Lack of care coordinators to provide information and support to families

There are currently only two care coordinators (key workers) in Scotland who provide direct support to families with muscular dystrophy and related conditions. These are only part-time posts and they are dependent on funding from the Muscular Dystrophy Campaign. One is based in Glasgow and one in Edinburgh.

The care coordinator (key-worker) plays an essential role in providing a holistic package of care to individuals with muscular dystrophy and related conditions. They successfully coordinate their health and social care needs, provide support and information to families and other local professionals and ensure a seamless transition from child to adult services.

The Big Lottery Fund non-cancer palliative care programme employed an 'outreach' worker who worked with adolescents and young adults (and their families) with muscular dystrophies and congenital ataxias. Despite the evidence showing the success of this model, NHS funding has not been provided to ensure the continuity of this support.

With an average case load of 1,000 patients, it is clear that a minimum of 5 key workers are urgently required in Scotland, simply to provide a minimum level of support to each family.

“The successful and seamless transfer of adolescents is one of the greatest challenges facing both paediatric and adult services.”

Royal College of Nursing, 2004.

9. Transition and challenges on reaching adulthood

The transition from child to adult services and child to adulthood for young people affected by a neuromuscular condition is rarely smooth and seamless. The result is that many young people are disengaged and isolated from society and they are often not able to live independently, pursue a career or access further education.

The Freedom of Information request in July 2008 to all Scottish Health Boards and Scottish Councils revealed that:

- One in three Health Boards that responded do not have dedicated links with both Education and Social Services in relation to transitions.

For the 27 Scottish Councils who responded, the following picture emerged:

- Four out of five of the Councils that responded offer services in line with the Education (Additional Support for Learning) (Scotland) Act 2004 with a transition starting at 14, but one Council extends beyond this to offer help with transition from the age of 12.
- One in three Councils who responded do not offer Key Workers who coordinate health, education and social services, but of these two Councils stated they were looking to implement this type of service in the near future.

Moving to adult-oriented healthcare services can be a very stressful time for patients, families and carers, particularly as the complexity of their care increases.

Young people will also be making the same transition to adulthood as their able bodied peers. For example, they will be moving from school to training/employment, financial dependence, leaving the family home, beginning sexual relationships, coupledness, marriage and parenthood.

Transition planning is still poorly carried out, capacity planning for future demand patchy, decisions are made at the last minute, and the lack of continuous support from health and social care agencies is characterised as a 'struggle'.

Furthermore, despite the significance of this period for people with these progressive neuromuscular conditions, there is no dedicated key worker to support their transition to adulthood and there is a lack of facilities for adolescents to support any preparation for transition to adult services.

● In Scotland, disabled people are twice as likely to have no recognised qualification as their non-disabled counterparts. (Labour Force Survey 2003)

● There is a dramatic reduction in employment aspirations as disabled children grow up. At age 12 the aspirations of disabled children are on a par with those of non-disabled children, but by the age of 17 their career expectations are much narrower than their non-disabled peers. (Disability Agenda Scotland)

“The key worker post transformed the lives of many people from being virtually housebound or even bed-bound to being able to live a reasonably active and rewarding life both in and outside the home.”

Dr John Womersley, Manager of Big Lottery-funded non-cancer palliative care programme 2003-2007

Key transition worker

There are considerable published data which recognise the importance and benefits of a dedicated key worker or co-ordinator for young people with long-term conditions.⁹

The NHS Quality Improvement Scotland (2003) report on physical disability services in Glasgow identified:

- The lack of independent advocacy and difficulties in getting information.
- The difficulties experienced during transition from child to adult services; the need for robust protocols to support transitions.
- Little attention given to the diverse needs of people with disabilities.
- Relatively common conditions such as acquired brain injury and neuromuscular disorders not being included in chronic disease management programmes or in managed clinical networks.
- The need to improve co-ordination and information transfer between hospital, voluntary sector, social work, education and housing providers.
- The need to promote health and wellbeing, and health promotion initiatives for people with physical disabilities.

Between 2003-2007, the Big Lottery-funded non-cancer palliative care programme employed ‘outreach’ workers to identify, and help meet the needs of, people with long-term disabling conditions that are not included in ‘chronic disease management’ programmes or part of a managed clinical network.

One of the ‘outreach’ workers worked specifically with adolescents and young adults (and their families) with muscular dystrophies and congenital ataxias.

The posts were very successful in securing services and ‘benefits’, in providing information and advocacy, and in directing clients to other sources of help. This was particularly important for the many individuals who had ‘fallen through the net’ during the transition from child to adult services. In collaboration with a diverse range of other professionals, all these issues were addressed by the ‘outreach’ worker for neuromuscular conditions.

Despite conclusive evidence supporting the benefits of this model, this post is no longer in place as local health boards were not forthcoming in providing much needed long-term funding and support.

In Scotland, disabled people are twice as likely to have no recognised qualification as their non-disabled counterparts.

Labour Survey Force 2003

In Dundee, a pilot project is currently engaged in providing a care coordination process for young people reaching transition. The organisation advice:

A lead person will be chosen by the young person & parent/carer to be their link between all actively involved services/agencies. The lead person will ensure relevant information is shared between involved professionals and the young person is central to all planning.

At present, funding for this pilot is only assured to March 2009. However, it is anticipated that the care co-ordination process will be adopted if the pilot illustrates the advantages of this system.

Young people with Duchenne muscular dystrophy will be amongst the client groups to be considered for inclusion. As we have not yet received all nominations for inclusion in the pilot, we cannot confirm (at this time) whether any young people from this category will be part of the pilot study.

10. Access to training and employment remains an obstacle which prevents people from leading independent and fulfilling lives

There is currently no dedicated service in Scotland for this patient group which provides support for accessing work, further education, support for independent living, self directed care and support, and ongoing physiotherapy and occupational therapy in order to maintain mobility and live independently.

An increasing number of young people are reaching transition and living into adulthood and this patient group should expect to seek further education, employment, develop relationships and live an adult life independently of their families, if they choose to do so.

However, current arrangements do not ensure that adults with these conditions can play an active role in society.

The Freedom of Information request in July 2008 to all Scottish Councils revealed that:

- Only two Councils out of the 27 who responded collected information on educational qualifications and employment of disabled people.

A recent study examining access to employment and training found that:

- Glasgow has the highest incidence of disability but the lowest numbers of disabled people in employment
- Those with disabilities are much less likely to have qualifications than those without disabilities clearly affecting their chances of gaining employment.
- Of those taking part in employment schemes four in five were still unable to gain jobs.
- When those with disabilities do find themselves in work they are far more likely to be in low paid jobs compared to those without disabilities.¹⁰

A further study also found that:

- Edinburgh has an employment rate of 77.1% (higher than the Scottish average).
- However, only 39.4% of those that fall within the Disability Discrimination Act or possess a work limiting disability were in employment.
- Mid and East Lothian have merely 28% and 30% respectively.

This research uncovered that many of the problems arose from:

- no standardised performance data collected by disability and employment intermediaries;
- a 'revolving door' or 'training cycle syndrome' with those with disabilities taking the same courses again and again;
- employment and disability intermediaries being limited to short term goals due to short funding time-frames;

- a lack of support for those with disabilities after gaining jobs, limiting retention rates.¹¹

It is crucial that health and social care services, private companies, the public sector and higher education facilities work in partnership with people with neuromuscular conditions, specialist disability organisations such as the Muscular Dystrophy Campaign and the Scottish Muscle Network to meet this challenge.

This report calls for a feasibility study for a Scottish Muscle Enterprise. The model could be a variation of the very successful social enterprise centre based in Cheshire, England.

The Neuromuscular Centre (NMC) in Cheshire is the only centre in the UK which provides the unique combination of on-going physiotherapy, employment and training support for young people affected by muscular dystrophy and related conditions. The NMC also offers distance learning and remote support for a growing number of clients.

Heather has been receiving physiotherapy at the NMC for eight years. She attends one or two sessions a week. In her own words:

"If I hadn't started attending the NMC I don't think I would ever have accepted my condition. I used to feel inadequate and downtrodden, embarrassed about having to use a manual chair. But meeting people who were in the same boat as me was a revelation – I could see how they were getting on with their lives. I've made lots of friends and I'm close to the physios too – I confide in them in a way I wouldn't with other people. They don't just provide physiotherapy; they also provide me with emotional support. The NMC has given me my confidence back. It's given me everything really."

"It is grossly unfair that because we live in Scotland our son with a severe disability is means tested for home adaptations. If we lived in England we would be entitled to a grant of up to £25,000."

Parent with son affected by DMD living in Glasgow

11. Wheelchair provision and home adaptations

Home Adaptations, Community Equipment, and Assistive Technology

Many people with muscular dystrophy and related neuromuscular conditions will have to make changes to their home at some stage, in order to remain independent and to allow them to live safely.

In Scotland, they have to apply for a Housing Adaptation Grant from their local authority – a fund that is capped at £20,000 and is also used by people seeking non-disability related adaptations.

If they lived in England or Wales, they would apply to a dedicated fund, the Disabled Facilities Grant, capped at £25,000, which is not means tested for families with disabled children.

A parent living in Glasgow whose son has Duchenne muscular dystrophy talked about their experience of home adaptations. In her own words:

"The local authority will only contribute £10,000 towards the cost of my son's adaptations forcing us into debt. This is a really stressful situation at a time when our family needs more and not less support."

The Freedom of Information request in July 2008 to all Scottish Councils revealed that:

- Waiting times seem to vary widely between those that answered, for instance, stair-lifts could take between five weeks in one council and 10 months in another. The average for minor adaptations is anywhere between two and six weeks depending on where you live in Scotland. Averages for major adaptations were between one year and two years again depending on your location in Scotland.

This continues to reflect the findings of Audit Scotland 'Adapting to the Future' in their study several years ago where recommendations for improvement were made and subsequently added to through 'Equipped for Inclusion'. We would urge the Government to bring forward proposals to improve this position, and to increase the use of telehealth and telecare provision.

Wheelchair provision

"Significant investment was needed to improve 'what must be one of the oldest fleets of wheelchairs in Western Europe'"

Roseanne Urquhart, Chair of ReTSAG (Rehabilitation Technology Services Group), BBC – 19 March 2007

The FOI request to all Scottish Health Boards revealed:

- Health Boards do not have a dedicated budget for the provision of wheelchairs for people with muscular dystrophy and related neuromuscular conditions;
- Only two Health Board's have introduced a system for wheelchair reassessment but this is only for children;
- Health Boards do not provide a systematic reassessment or scheduled review for adult wheelchair users;
- Waiting times for wheelchair assessments vary across Scotland from just 2 weeks in one health board to over 20 weeks in another. Completion of wheelchair from receipt of referral to delivery can take over 30 weeks in some areas.

“There is simply not enough provision to ensure that my children and other families receive timely support and adequate funding for their wheelchairs.”

Julie has two children affected by congenital muscular dystrophy.

Unpublished data suggests that Internet access, computer games, environmental control systems, electrically operated beds and indoor–outdoor electric wheelchairs are important factors that contribute to quality of life and independence.¹²

It is recognised that in Scotland there is an urgent need to improve and provide additional funding for the wheelchair services.

Julie from Edinburgh has two children affected by congenital muscular dystrophy. Commenting on wheelchair services, she said:

“An electric wheelchair contributes to the quality of life and independence of my children. Despite this we had to find the money to buy our daughter’s first electric wheelchair and both of our children had to wait for two years to receive wheelchairs previously.”

“My son has now been waiting over a year for the correct head rest. There is simply not enough provision to support my children and others in this situation.”

An independent report **“Moving Forward: Review of NHS Wheelchair and Seating Services in Scotland”** was published in March 2006 with little action taken so far.

The recommendations from this review can be summarised in five key points:

1. The remit of the NHS Wheelchair and Seating Service should address the lifestyle requirements of users and carers ensuring maximum possible social inclusion;
2. Service delivery should be based on holistic requirements and not coloured by available funding for equipment;
3. The service should measure performance and demonstrate accountability;
4. The service should be adequately funded to meet its core values – additional resources should be provided to fill large gaps that exist in current service provision;
5. A multi-agency approach to deliver a seamless service, from the user and carer perspective, should be established at national level delivered locally;

The Scottish Government is investing £16 million over 3 years to modernise and redesign the wheelchair and seating service. Despite the announcement of extra resources, people in Scotland are still making out-of-pocket payments for wheelchairs and face lengthy waiting times for assessment and repairs.

Dr Geoff Bardsley, the head of Tayside’s Seating & Wheelchair Service, had an average budget of £166 per person.

He said the basic wheelchair costs £120 but some of the more complicated powered chairs could cost more than £5,000

BBC 19 March 2007

Patients with neuromuscular conditions also have specific concerns which need to be addressed:

- Their needs are changing, sometimes with a rapid progression, or following spinal surgery. This necessitates more regular adjustment and review than for those with non-progressive disability.
- Specialised equipment, for example a height adjustable chair, should be available to all patients who have a complex physical disability as a result of their neuromuscular condition.
- In the past families have had to purchase their own specialised wheelchairs themselves.

Stella Morris, from Perth, who uses a powered wheelchair and has limb girdle muscle dystrophy said:

“I’ve found Wheelchair Services in Dundee to be understaffed and under funded. I’ve been assessed by healthcare professionals to need a ‘rising seat’ facility on my wheelchair – which would assist me in standing and getting out of the wheelchair – but I’ve been advised that I can’t have this on cost grounds.”

“In my current chair, I have difficulties with traction on uneven pavements, and yet wheelchair services are unable to fix this. This makes getting out and about a lot more unsafe for me as the wheelchair can tip onto the road.”

Conclusion

We have illustrated those gaps in service provision and the actions necessary to improve outcomes in care and support for adults and children with muscular dystrophy and related neuromuscular conditions living in Scotland.

We are calling on National Services Division, as well as Health Boards and Scottish Councils, to work with the Scottish Muscle Network and the Muscular Dystrophy Campaign to undertake an urgent review of current service provision for patients with muscular dystrophy and related neuromuscular conditions living in Scotland.

It is also essential that *Shifting the Balance of Care* and the *Disability Equality Scheme* result in improvements both in outcomes and services for people with muscular dystrophy and related neuromuscular conditions.

The Muscular Dystrophy Campaign urges all readers to support our *Building on the Foundations* Campaign. If you would like to join us in seeking improved access to specialist care please email your details to campaigns@muscular-dystrophy.org

Appendices

Appendix 1 – What disciplines should a specialised network include?

The medical specialists that can deliver different facets of diagnosis and care vary from neurologists (paediatric and adult) to *inter alia* clinical geneticists, paediatricians, rehabilitation physicians, cardiologists, orthopaedic surgeons, pathologists and palliative care specialists.

In addition, specialist physiotherapists, occupational therapists, speech and language therapists and various specialist nurses relating to the above groups have important roles in supporting and monitoring the care needs of the patient and their family.

As these are complex multi-system conditions, a network requires a managed multi-disciplinary team approach to care. Patients, families as well as local health and social care professionals should have access to specialists who would include:

- clinical or non-clinical manager to take a lead role to ensuring clear structures and lines of responsibility;
- adult clinician with specific training in muscle diseases including myasthenia;
- adult clinician with specialist training in neuropathies;
- adult and paediatric clinicians with specialist interest in congenital myasthenia
- paediatric consultant specialising in neuromuscular disease;
- adult and paediatric respiratory physicians who run non-invasive ventilation services;
- adult and paediatric cardiologists with specialist interest in neuromuscular disorders;
- neurophysiologists with special interest in neuromuscular disorders including single fibre EMG;
- clinical geneticist or genetic counsellor;
- specialist paediatric and adult neuromuscular physiotherapist;

- neuromuscular care advisor/key worker;
- neuromuscular nurse specialists for children and adults;
- clinical psychologist with a special interest in neuromuscular disorders;
- muscle and nerve pathologist with a special interest in neuromuscular disorders;
- orthopaedic and spinal surgeons with a special interest in neuromuscular disorders;
- orthotist;
- adult and paediatric dieticians with a special interest in neuromuscular disorders;
- adult and paediatric neuromuscular speech and language therapists;
- occupational therapist.

The specialist network would involve combined activity with:

- combined respiratory clinic;
- neurogenetic clinic;
- orthopaedic shoulder clinic;
- orthopaedic spine clinic;
- Orthopaedic soft tissue clinic;
- Peripheral neuropathy clinic;
- Hyper-mobility clinic;
- Meetings with the anaesthetists and the spinal surgery nurse;
- Sitting clinic OT.

Appendix 2 – The Scottish Muscle Network: a model for the delivery of specialist care

The Network was initially set up with a grant from the Muscular Dystrophy Campaign in July 1999 and is now funded by Yorkhill Division, Greater Glasgow and Clyde Health Board and the University of Glasgow. The Network is highly reputable and is being used as an example of good practice in other parts of the UK.

The Scottish Executive's commitment to the concept of a managed clinical network (MCN) was made clear in *Our National Health: A plan for action, a plan for change* (December 2002), which highlighted the potential of MCNs to improve services for patients with chronic conditions.

The Scottish Muscle Network (SMN) became formally recognised as a Managed Clinical Network¹³ in April 2007 when funding was agreed through NHS National Services Division (NSD) and the network became hosted by Greater Glasgow and Clyde Health Board through the Managed Clinical Network Department.

The NSD currently funds a part-time (2 sessions, 1 day) clinical lead for the Scottish Muscle Network, a part-time network manager and a part-time administrative assistant.

Activities of the Scottish Muscle Network

The SMN aims to improve patient care in terms of quality, access and appropriateness. The approach is particularly suitable for Scotland as it addresses the problems arising from the mix of rural, urban and island areas that exist across Scotland. The network also incorporates social with clinical aspects of care.

The SMN promotes access to local health, social care, and educational professionals who are aware of their condition and its complications and who are provided with training and support offered by appropriate tertiary referral specialists.

The Scottish Muscle Network's main activities include

- Increasing communication between health, social and educational professionals and voluntary organisations across Scotland;
- Providing educational opportunities for professionals;
- Creating a consensus for standards of care;
- Providing patients with information about how the Health Service can help them;
- Setting up a variety of ways in which patients and their representatives can communicate their needs to the service deliverers.

The Network is directly influenced by the patients it serves, for example, in the West of Scotland, there are regular meetings for patients and families where half of each meeting is dedicated to open discussion. Patients also have a vast input at the annual meeting with equal representation of elected members and patients.

Following the formalisation of links with NSD the SMN group reviewed its structure and representation. As a result the steering group has become a larger more geographically diverse steering group to move the Network forward. The first multi-agency steering group was held on 18 April 2008.

A clear work plan for 2008-9 has been agreed with NSD, with targeted on-going work through various specialist subgroups focussing on the agreed priority areas. NSD also supports audit and review of clinical practice. An annual review report will continue to be published. The SMN has established five working subgroups to reflect key needs of children and adults with specific neuromuscular disorders. They are:

1. paediatric subgroup
2. adult myotonic dystrophy subgroup
3. transitional care group
4. adult respiratory care subgroup
5. cardiology (DM1)

Despite the improvements made by the SMN, there remain significant gaps within the service for patients with muscular dystrophy and related neuromuscular conditions as this report highlights.

Appendix 3 – Paediatric model of care

In Scotland the paediatric model of care is more advanced than the adult model at present.

The role of the paediatrician within the neuromuscular multi-disciplinary team includes medical interventions, as well as co-ordinating other specialist medical aspects of care.

The Scottish Muscle Network has identified a local Paediatrician in each Health Board area with an interest in paediatric neuromuscular disorders and the paediatric group are currently gathering a database of children affected by neuromuscular disorders across the country.

A Consultant Paediatrician (Neurologist/Neurodisability) runs a specialist neuromuscular clinic in each of the four Teaching Hospitals regions. In the West of Scotland a model of shared care is implemented with the neuromuscular clinic at Yorkhill and locality based paediatricians.

The Paediatric subgroup of the SMN is established with a core group of clinicians and NM AHP. Current work includes developing care standards and pathways for the management of Duchenne muscular dystrophy, and implementation of SMA management guidelines, establishing a Scottish database of paediatric onset neuromuscular disorders.

Appendix 4 – Respiratory services in Scotland

Respiratory Management involves a holistic respiratory care plan including:

- preventative measures including immunisation
- optimising nutrition
- management of secretions
- assisted coughing and chest physiotherapy techniques
- regular monitoring of respiratory function for timely intervention
- non-invasive ventilation
- invasive ventilation

Scottish Adult Home ventilation services are traditionally provided from three main centres in Scotland.

- At present in the West of Scotland there are 250 patients receiving NIV, 59 of these patients have a neuromuscular disorder.
- A further 204 are on regular monitoring for anticipated support, to commence treatment before the insidious onset of symptoms of respiratory failure, and crisis intensive care admission.
- In the East of Scotland there are 65 patients with a neuromuscular disorder receiving ventilation, having risen steadily from only 11 such patients 10 years ago and a further 30 on regular monitoring with future ventilation anticipated.

The Scottish Muscle Network adult respiratory care subgroup, chaired by Dr Steve Banham, has been developing a model of care for respiratory support.

- This would involve a multi-disciplinary team of medical, nursing, therapy and technology staff, and social work and care staff providing specialist in-patient assessment and interventions, with outreach support to the local respiratory teams and a community specialist nursing service to patients at home.
- This model would allow patients to be managed closer to home and supports and empowers local teams to monitor, review and consult as appropriate.
- A recent review shows most clinicians have favoured a shared care model.

Appendix 5 – The importance of physiotherapy for all patients with muscular dystrophy or a related neuromuscular condition

For all neuromuscular conditions, the physiotherapist will help to:

- minimise the development of contractures and deformities through a programme of stretches and, where appropriate, exercises
- anticipate and minimise any secondary physical complications
- identify and prescribe aids and equipment (orthoses, callipers, wheelchairs and standing frames, for example)
- advise on moving and handling issues
- monitor respiratory function and advise on techniques to assist with breathing exercises and methods of clearing secretions
- optimise function and positively manage deterioration.

Patients, carers and families require access to a physiotherapist with specialist knowledge of neuromuscular conditions so that they can be given training on exercises recommended to be done regularly at home. A home physiotherapy regime would be based on:

- the needs of the patient
- the advice of a specialist physiotherapist
- the needs of the family (a practical routine to suit the family's lifestyle).¹⁴

Appendix 6 – Survey of Scottish Councils and Scottish Local Health Boards on Muscular Dystrophy Services

Introduction

The purpose of the survey was to identify the existence and standard of muscular dystrophy services offered in Scotland.

Method

In June 2008, the Muscular Dystrophy Campaign contacted 32 Councils in Scotland by email under the Freedom of Information (Scotland) Act 2002 asked the following questions:

- Do you work in partnership with the Scottish Muscle Network and are you aware of its functions?
- What information do you provide about services available for people with neuromuscular conditions?
- What arrangements are in place to ensure the smooth and seamless transition for young people with muscular dystrophy and related neuromuscular conditions into employment and further education?
- Do you have Key Workers or Care Co-ordinators who coordinate involve health, education and social services for a) children b) young people with muscular dystrophy?
- How many disabled people within your area have a recognised educational qualification?
- How many disabled people within your area are in some form of employment?
- What is the average waiting time for the provision of home adaptations?

Councils who responded

Out of the 27 Scottish Councils that have responded thus far, the following picture has emerged:

- Only one in five Councils work in partnership with the Scottish Muscle Network. However, little over half of respondents were aware of the Scottish Muscle Networks functions,
- Half of the councils don't have information available for people with neuromuscular conditions,
- Four of the five Council's that responded offer services in line with the Education (Additional Support for Learning) (Scotland) Act 2004 with a transition starting at 14, but one Council extends beyond this to offer help with transition from the age of 12,
- One in three Councils who responded do not offer Key Workers who coordinate health, education and social services, but of these two Councils were looking to implement this type of service in the near future,
- Only two Councils out of the 27 who responded collected information on educational qualifications and employment of disabled people,
- Waiting times seem to vary widely between those that answered, for instance, stair-lifts could take between five weeks in one council and 10 months in another. The average for minor adaptations is anywhere between two and six weeks depending on where you live in Scotland. Averages for major adaptations were between one year and two years again depending on your location in Scotland.

Method

In July 2008, the Muscular Dystrophy Campaign contacted 14 Scottish Health Boards by email under the Freedom of Information (Scotland) Act 2002 asked the following questions:

- Does your Local Health Board have a system in place to ensure ongoing physiotherapy for patients with muscular dystrophy and related conditions where required?
- Does your Local Health Board currently support a muscle clinic that offers a comprehensive service to (a) children and (b) adults with neuromuscular condition?
- If you do support a muscle clinic for children and/or adults, where is the clinic located and who is the lead clinician/head of service?
- If patients are referred out of the local area, please could you indicate numbers and provide details.
- Do you have a system in place to ensure that adults and children with muscular dystrophy receive home ventilation?
- Do you have dedicated links and policies /protocols with Education and Social Work Services in relation to transitions?
- Do you have a carer support policy?
- Do you have protocols and arrangements for assessment and provision of community equipment?
- Does your Local Health Board have a dedicated budget for the provision of wheelchairs for people with muscular dystrophy and related neuromuscular conditions?

- Does your Local Health Board recognise the progressive nature of muscular dystrophy and related conditions and provide regular assessments for wheelchair users with these conditions?
- What is the average waiting time for a) manual and b) powered wheelchairs?
- What is the average waiting time for wheelchair assessment?

Scottish Health Boards who responded

Out of the 12 Scottish Health Boards that have responded thus far, the following picture has emerged

- Two out of three Scottish Health Boards that responded do not offer ongoing physiotherapy for patients with muscular dystrophy and related conditions
- Half of Health Boards that responded do not support a muscle clinic. Only one in five of Health Boards offer a muscle clinic to both children and adults.
- Half of Health Boards that responded refer their patients within Scotland, usually to Glasgow. However, one in four refer patients as far a field as Newcastle in England.
- One in three Health Boards that responded do not offer home ventilation as a service to adults and children
- One in three Health boards that responded do not have dedicated links with both Education and Social Services in relation to transitions.
- Just over half of Health Boards that responded do not have a carer support policy.

- One in five Health Boards that responded do not have protocols and arrangements for assessment and provision of community equipment.
- Health Boards do not have a dedicated budget for the provision of wheelchairs for people with muscular dystrophy and related neuromuscular conditions;
- Only two Health Board's have introduced a system for wheelchair reassessment but this is only for children;
- Health Boards do not provide a systematic reassessment or scheduled review for adult wheelchair users;
- Waiting times for wheelchair assessments vary across Scotland from just 2 weeks in one health board to over 20 weeks in another. Completion of wheelchair from receipt of referral to delivery can take over 30 weeks in some areas.

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