



Multiple Sclerosis Society
Cymru

Wheelchair waiting times in Wales

Briefing for the Health, Wellbeing and Local Government Committee

About Multiple Sclerosis and MS Society Cymru

Multiple Sclerosis is the most common disabling neurological disorder affecting young people in the UK with more than 100,000 affected by the condition. We estimate that over 4,000 people are affected in Wales. It is a disease of the central nervous system. MS is unpredictable and can cause a wide variety of symptoms such as loss of mobility, pain, fatigue, vision problems, and numbness, loss of balance, depression and cognitive problems. The disease may progress steadily or involve periods of active disease followed by periods of remission.

The MS Society is the UK-wide charity dedicated to supporting people who have MS, as well as providing help to those people's families, friends, carers and colleagues. A significant number of our trustees, staff and volunteers either have MS or a personal connection with MS.

The Society provides care and support through services which include our information and helpline service, publications, a website that receives more than 40,000 visitors each month, welfare grants, funding research, funding MS specialist nurses and delivering respite care.

We are a democratic organisation with over 44,000 members. Our network of 340 branches delivers local services to people with MS across the UK.

Multiple Sclerosis and wheelchair use

Approximately a third of the 100,000 people who are affected by Multiple Sclerosis will need a wheelchair. Many more will rely on crutches, frames or other pieces of equipment to assist their mobility.

Approximately 10-15% of people affected by Multiple Sclerosis are diagnosed with 'Primary Progressive MS.' This type of MS leads to a steady worsening of symptoms and increase in disability. People affected by this type are far more likely to need a wheelchair and are most likely to suffer if waiting lists are lengthy.

The majority of people with Multiple Sclerosis will live with the condition for decades, before developing 'Secondary Progressive MS' later in life. This type of MS will lead to an increase in disability, most likely requiring use of a wheelchair.

Background

In Autumn 2008, MS Society Cymru was approached by a number of individuals who had been waiting for a specialist electric wheelchair for over 18 months. The Society contacted the Multiple Sclerosis Team in Morriston Hospital and the MS Team in North Wales, and they confirmed that there were a large number of patients, who had been waiting for a specialist

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wheelchair for 18 months to 2 years. It appeared that the problems were centred around the Artificial Limb and Appliance Centre (ALAC) in Wrexham, rather than the Cardiff ALAC, and that the waiting lists were typically longer the further someone lived from Wrexham.

Research

Members Research Service

In November 2009 Jonathan Morgan AM submitted a Members Research Service Question on wheelchair waiting times. The key findings are below, but the complete documents are attached separately.

Key findings:

- MRS revealed that the Artificial Limb and Appliance Service (ALAS) had missed all of its Quality Indicators.
 - Quality Indicator 6: Standard wheelchairs delivered within 21 days of referral. Target 95% - Actual – 80.6%
 - Quality Indicator 7: Wheelchairs delivered on time. Target 95% - Actual – 91.3%
 - Quality Indicator 8: Wheelchairs repaired on time. Target 95% - Actual – 87.3%
 - Quality Indicator 9: Wheelchairs collected on time. Target 95% - Actual – 89%
- Wrexham ALAC only managed to achieve 55.1% of Quality Indicator 6 in 2005 (as opposed to Cardiff ALAC on 95.1%). Although this is old data, the pattern continues that people served by the Wrexham ALAC have longer waiting lists.

MS Society Cymru research

MS Cymru wrote to all of our members in January 2009 to ask them whether they were currently waiting for a wheelchair. The worst examples of delays are listed:

- Example 1 – man in Rhyl has been waiting 2 years for an indoor/outdoor electric wheelchair. He was contacted by ALAS before Christmas 2008 but has not had the chair yet.
- Example 2 – man from Bettws-y-Coed has been waiting since October 2008 for an electric wheelchair. He has been told that it will take at least 18 months.
- Example 3 – female from Berthengan in North Wales. She has been waiting for a wheelchair for 9 months already and has been told it will take another 9-12 months. May 2008 – her MS OT measured her. July 2008 – she filled the paperwork in. February 2009 – she was measured a second time by separate members of staff from ALAS. She was told at this point that it would take another 9-12 months.

Reforming the Artificial Limb and Appliance Service (ALAS)

In May 2008 Edwina Hart, Minister for Health and Social Services announced that she had commissioned a review of all wheelchair provision in Wales, encompassing long term and short term loans and paediatric wheelchair services. The Review was to recommend Service Standards and Specifications for the delivery of wheelchair services and identify resource requirements to deliver the service for future years. This work was to be in the wider context of a strategy for independent living.

<http://new.wales.gov.uk/about/cabinet/cabinetstatements/2008/disabledchildmatter/?lang=en>

On Thursday 15th January a Steering Group and an Expert Advisory Group were established and met for the first time. Both Groups agreed:

1. The first stages of the assessment process
2. To accept that the outcome of the 2003/4 review undertaken by SHSCW / HCW in partnership with the NHS and user groups is still valid and will inform this current review process
3. To seek an update from Health Commission Wales on progress against the plan resulting from the 2003/4 review

The Expert Advisory Group had representatives from at least one children's charity (Whizz-Kidz), but MS Society Cymru was not aware of any adult disabled charities who were invited to attend. In early 2009, the Wales Neurological Alliance, an umbrella organisation that MS Society Cymru sits in, asked whether its chair, Judi Rhys could join the Expert Advisory Group. A Civil Servant informed her that she would be involved in the second stage of the review and didn't specify a time frame.

On 26th August 2009, Andrew RT Davies AM asked the following written question:

Andrew R.T. Davies (South Wales Central): When does the Minister expect to bring forward the results of the Welsh Assembly Government's review into wheelchair services? (WAQ54705)

The Minister for Health and Social Services: I have received the first report of the steering group which I am currently considering.

Almost three months has passed since this written question and the report of the steering group has not been published.

Concerns about the current services

MS Society Cymru has the following key concerns about the provision of specialist wheelchairs in Wales.

Lack of targets

There appears to be a lack of firm Welsh Assembly Government targets on wheelchair waiting lists and those that do exist do not appear to be met. The research undertaken by the Members Research Service presented a list of internal performance indicators that were recorded but not met by the organisation, particular the Wrexham ALAC.

There are specific targets for children and the '***National Service Framework for Children, Young People and Maternity Services in Wales***' sets a target of assessing a child for a wheelchair within 6 weeks, whilst a wheelchair would be provided by a maximum of 8 weeks later. However in March 2009, Dragons Eye revealed that a large number of children were waiting over 12 months for a wheelchair in North Wales, whilst one child had been waiting over 20 months (more information on this particular case can be read here:

http://news.bbc.co.uk/1/hi/wales/north_west/7927215.stm)

There are no targets for adult wheelchair waiting times and in the recent Adult Neurosciences Reviews in North Wales, and in Mid and South Wales; there was no reference to targets in this area, despite the fact that people with rapidly evolving neurological conditions often need specialist wheelchairs.

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In contrast in Scotland the Government has published the **'Wheelchair and Seating Services Modernisation Action Plan'** that sets a target of 18 weeks from referral to treatment by 31 December 2011.

Structure of ALAS

MS Society Cymru is concerned that the current structure of the Artificial Limb and Appliance Service (ALAS), based on two centres is too centralised and that responsibility should be devolved to the Local Health Boards.

At present the Wrexham ALAC serves half of Wales and covers an area as far south as Ceredigion. This is huge geographic area, and staff and equipment have to be transported great distances, whilst patients waiting for an assessment might have to travel over 100 miles to the centre.

In England, the responsibility for assessing and providing a wheelchair rests with the Primary Care Trust, the local health organisation. English PCTs have been encouraged to reduce wheelchair waiting lists to 18 weeks. Many have succeeded including Sefton PCT in Merseyside, meaning that depending on whether someone lives in Wrexham or across the border into Merseyside, the difference in wait for a wheelchair could be 18 weeks or 18 months.

The other factor to consider at this stage is the wider review of the NHS in Wales. Under the old system of 22 LHBs, 7 Trusts and Health Commission Wales (HCW) commissioning specialised services, there was a strong rationale for centralising specialist services, such as wheelchair provision, on one or two sites. However HCW is currently being reformed and by April 2010 many of the specialised services will be devolved to the 7 Local Health Boards, which are being tasked with greater responsibilities.

MS Society Cymru believes the time is right to make every Local Health Board responsible for assessing and supplying wheelchairs in their local area. LHBs would then be able to tailor services to fit their local needs and failure to deliver improvements could be scrutinised by the Board of Directors.

Assessment

MS Society Cymru is concerned about a possible shortage of Occupational Therapists in the Wrexham ALAC that might be contributing to the delay in assessment for a specialist wheelchair. In the examples given to MS Society Cymru most of the delays appeared at the start of the process, when the individual was waiting to be measured, weighed and have their home assessed for how compatible it was with a wheelchair.

MS Society Cymru would suggest this is an area that should be explored with the Artificial Limb and Appliance Service (ALAS) and with the College of Occupational Therapists.

MS Society Cymru welcomes the opportunity to give evidence to the Health, Local Government and Wellbeing Committee on 18 November, whilst Judi Rhys and Joseph Carter would be happy to take questions on any of the points raised in this document.