

Health and Social Care Committee

One-day inquiry on wheelchair services in Wales

Shine Cymru – WC 1



Wheelchair Services in Wales Inquiry 2012

A response from Shine Cymru

(Spina Bifida. Hydrocephalus. Information. Networking. Equality)

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This paper provides examples of the issues faced by individuals living with spina bifida across Wales. It is submitted in response to the call for written evidence to support the one-day inquiry into wheelchair services on 8 March 2012.

Shine Cymru

Shine Cymru (formerly ASBAH Cymru) is the only national organisation in Wales focusing on spina bifida and hydrocephalus. Its unique work supports and empowers people to overcome the disadvantages, which result from these two profound, complex disabilities.

We are leaders in our field, an advocate for all those who are disadvantaged by these conditions. We share our experience wherever possible, creating opportunities for people with spina bifida and/or hydrocephalus to play their part in mainstream life.

Shine Cymru supports over 750 children and adults affected by spina bifida and hydrocephalus, many of whom are wheelchair users.

Evidence

This evidence is based on the experiences of the individuals we support and those of the area adviser team.

The issues raised by our members are experienced in North and South Wales, and are representative of both adult and children's services.

The following case studies provide examples of where Shine Cymru members are still experiencing a host of issues in wheelchair service provision, thus impacting greatly on the independence and day-to-day lives of our members throughout Wales.

The key issues are:

- Waiting times for assessment and wheelchair provision

- Process and delivery of services for maintenance of wheelchairs
- Communication and clarity of message – from one service member of staff to another, and with service users.

Waiting times for assessments and wheelchair provision

Response times from referral to receipt of service vary across Wales, but in some cases the delays in both the referral and assessment processes are very long. There are also long delays between an assessment being undertaken and the receipt of a wheelchair.

Member: 11-year-old young person

Location: Pembrokeshire, West Wales

Issues: Assessment for new wheelchair.

Waiting time

Wheelchair not delivered to agreed spec.

Communication

Cost to family and NHS

A physiotherapist saw the young person in December 2010, when discussions started in preparation for him to attend comprehensive school in September 2011. It had been some years since he had had a wheelchair assessment and it was agreed that a new chair, to encourage and promote independence, would be required.

Mum had heard nothing at the end of January 2011, so contacted ALAC in Cardiff. She was told that the referral had been received and the earliest appointment for assessment would be June 2011, as there would be no assessment clinic planned for Pembrokeshire before then. She was also informed that it would be unlikely that the chair would be ready for return to school in September 2011.

Mum offered to attend an assessment in Cardiff so as to speed up the process, and she was offered an appointment for 26 April 2011.

A full assessment of need took place, including discussions about encouraging independence but recognising that the young person was still fairly young to be expected to self-propel all the time. It was agreed that the chair be fitted with handles that could be used if necessary but could also be folded away when not required.

The wheelchair was ready in mid-August. Mum attended clinic in Cardiff to collect the chair, as there would have been further delays if the wheelchair were to be delivered to Pembrokeshire.

On receipt of the wheelchair, there were no handles fitted, with the occupational therapist explaining that Mum had not requested them. This was despite a 20-minute discussion and reference to the accessories catalogue at the initial assessment. Mum reluctantly accepted the chair, on the agreement that someone would visit the house to fit the handles.

This visit to fit the handles took place in early September, at the member's home in Pembrokeshire. However, the handles were incorrectly fitted and a second person had to make a second visit to the home to rectify the issue. This no doubt added considerable cost to the provision of the service.

Member: Adult member

Location: North West Wales

Issues: Waiting time for assessment

This member has been waiting for an assessment for a new wheelchair since last year, as her current wheelchair is no longer fit for purpose and has pieces falling off it.

The North Wales wheelchair service has not provided her with an appointment or a timescale for assessment, stating that they are unable to do so, and she will have to wait.

Reviewing individual need and the updating, maintenance and repair of wheelchairs.

Wheelchairs need to be designed to suit individual need. One 'size' does not fit all. However, service users have reported that sometimes wheelchairs have not been adapted properly and need further adjustment following the supply of the wheelchair.

Member: Adult member

Location: North Wales

Issues: Wheelchair not delivered to agreed spec.

Wheelchair repair.

Waiting time

Communication

Impact on member's health

Mrs X was provided with a new wheelchair approximately 15 months ago. Since being issued with the wheelchair, she has experienced a number of different problems making it difficult for her to use the chair effectively.

The major issue relates to a footplate that does not support her legs adequately, given the fact that one leg is significantly shorter than the other. Attempts have been made to compensate for this difference by the provision of a built up, stepped "cushion" insert into the footplate. However, Mrs X had to request a number of revisions of the insert due to both ALAC and Serco getting the measurements wrong.

Mrs X has spent the last 15 months 'making do'. However as a result of a lack of a stable support for her feet, she has fallen out of her chair regularly and repeatedly and can no longer tolerate the physical pain and indignity this causes.

Furthermore, since coming into possession of the chair, Mrs X has begun to suffer severe, chronic pain in her knees. In her view, the pain is caused, primarily, by the rotation of the knee resulting from a lack support afforded by an inadequate footplate and, also, the number of falls she has had where her knee came into direct impact with the floor/pavement. In order to determine the exact nature of the injury to her knee she has sought an orthopaedic assessment and is currently awaiting an MRI scan.

An additional factor affecting her ability to use the chair properly relates to the

considerable amount of weight loss, approximately four stones, that Mrs X experienced between the date of her original assessment, the eventual receipt of the chair and subsequent to it's receipt. As a result of the weight loss her body shape and sitting position have changed significantly, making the chair's existing prescription inappropriate for her needs.

Mrs X attempted to address the issue of a reassessment on a number of occasions, specifically through her dealings with the technician and with the occupational therapist (OT) who carried out the initial assessment of her needs. However she had no success, possibly due to a lack of communication between the individuals concerned who appeared to just refer Mrs X to each other.

Shine Cymru wrote to the Head of ALAC North Wales in September 2011, requesting a reassessment of needs as a matter of some urgency. Our member was not requesting a new chair, but the appropriate adaptations to her existing one.

The re-assessment took place in early December, to address the issues outlined above, with the promise of a new footplate and canvas for the existing wheelchair.

Mrs X contacted ALAC on 13 January 2012, as there had been no follow up, and discovered that nothing had been done since the re-assessment in December.

The OT seemed very unclear about what had happened and eventually informed Mrs X that the measurements taken at the assessment were incorrect. Ross Care (the replacement for SERCO) attempted to deliver a new seat canvas recently but it was, again, incorrectly sized.

Two weeks ago, Mrs X received a call from the technician, who wanted to deliver the new footplate as well as try to fit the same canvas. This appointment took place on Tuesday 21 February. As expected the canvas was the wrong size and so now has to be re-ordered.

As far as the footplate is concerned, once again ALAC have supplied a level one rather than a "stepped" one to allow for one leg being shorter than the other.

We question why ALAC do not seem to check that the parts delivered to them from the manufacturer are the ones that were ordered – i.e. that the parts actually match the specifications ordered at the assessment?

The issue is no further resolved than 15 months ago, when it was initially raised.

Member: Adult member
Location: Newport, Gwent
Issues: Repair of wheelchair
Waiting time for repair
Missed appointments
Poor communication

An adult member recently requested Shine Cymru support in dealing with wheelchair services in South Wales as she had been waiting for a repair to her chair and it simply hadn't happened.

She had arranged a date and time for the technician to call. As this member works, she had to take a half-day annual leave for the appointment, which is perfectly acceptable, except that the technician didn't arrive for the appointment. This happened on two occasions.

Our member felt that there appeared to be little communication between those booking the appointments and the technical side of the service.

Shine Cymru's local Support and Development Worker also rang the complaints Manager at Rookwood and left a message. However, the call has not been returned to date.

Summary

These delays and the lack of delivery of services compromise the progress towards independence. They inhibit mobility and an individual's access to equality of opportunity, prohibiting them from making the most of general opportunities for day-to-day living.

Delays also create a specific issue for children as they grow and their needs change. Late delivery of a wheelchair impacts on both the physical and emotional needs and well being of the individual. This delay can also mean that a new assessment is required almost immediately after the delivery of the first wheelchair. The whole process, which is time-consuming and stressful, has to start again.

It is recognised that, in certain circumstances, delays are inevitable. However, there appears to be a lack of focus on communicating these delays to the individual services users and their families/carers.