Children in Wales
Plant yng Nghymru

Health, Wellbeing & Local Government Committee

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Health, Wellbeing and Local Government Committee

Inquiry into wheelchair services

Children in Wales is the national umbrella organisation in Wales, bringing organisations and individuals from all disciplines and sectors together. Its aim is to make the United Nations Convention on the Rights of the Child a reality in Wales. Children in Wales also fights for sustainable quality services for all children and young people, special attention for children in need, and ensuring children and young people have a voice in issues that affect them.

Children in Wales has over 200 organisations in membership, including the major voluntary children's agencies, professional associations, local authorities and health bodies, as well as many smaller community groups. Children in Wales facilitates as variety of forums including a disability forum for professionals and a network for young disabled people, a parenting forum, a poverty network and practice exchange groups in North and South Wales. Children in Wales works in partnership with the National Children's Bureau in England, Children in Scotland, and internationally with Eurochild and the International Forum for Child welfare.

Introduction

Children in Wales welcomes this opportunity to feed into the Health, Wellbeing and Local Government Committee Inquiry into wheelchair provision in Wales. As one of the founder members of Disabled Children Matter Wales (DCMW) we have been at the forefront of campaigning for better wheelchair services for children and young people.

We welcome the Minister's statement of 8th December 2009 outlining some key recommendations for wheelchair services in Wales and are very keen to see a timetable for implementation. Children in Wales also welcomes the Ministers commitment to finding additional funding for both adult and paediatric wheelchair services and await an announcement giving details on this issue.

However, a recent survey carried out by Children in Wales has shown that children and young people are having to wait considerably longer for their chairs than the three weeks noted in the Minister's statement.

Context for the delivery of services.

United Nations Convention on the Rights of the Child (UNCRC)

The UNCRC was formally adopted by the Welsh Assembly Government in 2004 as the basis for all policy making. Article 23 of the UNCRC states that children who have any kind of disability should have special care and support so that they can lead full and independent lives. As such, children and young people who need wheelchairs should have access to the chair that best suits their needs as quickly as possible.

In the document 'Getting It Right 2009' launched by the Welsh Assembly Government in response to the Concluding Observations of the UN Committee on the Rights of the Child 2008, priority 9 states that WAG will work to eliminate discrimination against children and young people with disabilities, improving their access to services and support..

United Nations Convention on the Rights of People with Disabilites

The United Kingdom signed the Convention on the Rights of Persons with Disabilities in March 2007 and it was ratified in June 2009. It contains 50 articles and one article of relevence to this Paper is Personal mobility (Article 20). The Article states that State Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities.

Report evidence

Two reports published in 2006 highlighted the major problems and long delays disabled children and their families were experiencing with assessment, supply and maintenance of wheelchairs in Wales. Barnardo's & Whizz-Kids: Don't push me around! Disabled children's experiences of wheelchair services in the UK (2006) and Contact a Family: Wheelchair Services for Children and Young People in Wales (2006)

The work undertaken by Contact a Family Wales, included a survey, that asked families about their experiences of wheelchair services.

The survey highlighted a number of specific concerns for families

Over 80% of families waited longer than the NSF target of 6 weeks for an assessment.

Over 60% of families waited longer than the NSF target of 8 weeks for delivery.

Review, repair and maintenance of wheelchairs vary from family to family and area to area.

Parents highlighted the need for training in the use of wheelchairs for themselves and their children.

There are often difficulties in obtaining the appropriate accessories for wheelchairs.

A lack of choice and control

National Service Framework (NSF)

Chapter 5 of the NSF refers to the needs for Disabled Children and Young People. In key action 5.17 there are agreed protocols and standards for wheelchair / specialist seating services. The eight recommendations contained in this key action are:

Providing a comprehensive service which meets particular needs of disabled children

Provision of clear information for professionals, parents, carers, children and young people regarding access to seating and wheelchair services;

A single referral process which encompasses services provided through the Artificial Limb and Appliance Services and those provided by rehabilitation engineering;

Assessment within 6 weeks of the referral being received;

Provision of a wheelchair or equipment within 8 weeks of assessment;

Quality assurance systems;

Repair and maintenance procedures;

Review of the child’s needs as a minimum on an annual basis in accordance with individual assessed needs.

While there is evidence in the reporting mechanism, the Self Assessment Audit Tool, that progress is being made, there are still significant challenges to be faced. Written evidence given to support the key action highlights that:

There is confusion over who leads on this key action. HCW report that they are not responsible whilst local organisations state that they are not either as they regard it as an all Wales service issue.

The Manufacturers of wheelchairs do not make a wide choice of chairs available to users.

The timescales for the assessment and delivery of the wheelchairs are unachievable because of the large number of service user requiring a service and current resources available.

The Wales Specialist Seating Service is unable to meet the 8 weeks target set as it can take up to 14 weeks to receive the original wheelchair. The 8-week target could be met if the service was allowed to count the weeks from when they receive the original wheelchair.

Evidence from the Children in Wales questionnaire

In response to the call to give evidence to the Health Wellbeing and Local Government Committee Inquiry into Wheelchair Services, Children in Wales distributed a questionnaire to gain an up to date snapshot of paediatric wheelchair services in Wales. It was distributed via members of the Children in Wales Disabled Children Policy Group, All Wales Forum on Issues for Disabled Children and Young People and the Young Disabled Person’s Network. A full copy of the questionnaire is attached in Annex A.

Respondents were asked if they could return the completed questionnaire within one week. 19 responses were received from the following local authority areas.

Area	Number
Pembrokeshire	5
Cardiff	2

Vale of Glamorgan	1
Swansea	1
Neath	1
Ceredigion	3
Powys	3
Denbighshire	1
Wrexham	1
Ynys Mon	1

Of the above responses, 13 were from parents/carers of children and young people; five were from young people themselves, and one response came from a professional.

From all the respondents, the individual from the Wrexham area had the most positive experience of accessing wheelchair services, however, even in this area the individual believed the wait from assessment to delivery of chair was too long.

Summary of responses

Where do you get your chair?

18 out of 19 respondents received their wheelchairs from ALAC. However, two respondents had also bought wheelchairs privately. One respondent had obtained a wheelchair from Whizzkids.

Can you describe your experiences in accessing wheelchair services?

The majority of respondents had a negative experience of dealing with wheelchair services although two respondents stated that the service was good. All respondents stated that they had no say in choosing their chair.

Comments from respondents included: -

"The physiotherapist referred us to ALAC but we had to wait at least six months to be assessed”.

‘’I have had difficulties with the service. I have been given no say in choosing my chair and have had no access to ALAC.”

"We asked if we were able to have a buggy instead of wheelchair but were told no.”

‘’We had no say in choosing the wheelchair. It was just supplied on OT's measurements. My daughter is very narrow but the wheelchair is wide and heavy to push.’'

"Actually seeing the man from ALAC is quite easy and he is very good. However, the wait once your chair is picked is considerable and children grow fast."

"We did not have a say on which chair we could have but the service is good.”

‘’We were given no choice, just told what we are to have and to be grateful for it…they then altered it at school without consulting us. The chair is 5 years old and my child has cried in it from the start.”

"We have specific requirements which are not taken into consideration and the resulting manual chair is potentially unsafe to use…if we want to sort out any safety issues we’ll probably end up doing some DIY repair.”

How long did you have to wait from the time you were assessed to the delivery of the chair?

One respondent said that they did not wait long for a chair and one could not remember. However, most had to wait a long time after the assessment had taken place. Comments include: -

"We have already waited 5½ months for the chair and are still waiting."

"My child only needed a new cushion and parts for her existing wheelchair. This took six months and during that time my child was uncomfortable."

"They don't communicate with you after the assessment has taken place and just turn up a couple of months later with the chair."

"Children grow fast and the service therefore needs to be very responsive."

"Still awaiting assessment for my daughter for a new chair, been told at the earliest April, been waiting months, second urgent request 16/7/09"

"We waited about nine months from assessment to delivery. We also purchased another chair, which was not available from ALAC. Our child loves this chair and is comfortable in it. However ALAC are not happy with us using it."

When you received your new Chair did it need adjusting? If yes, how long did you have to wait for this to happen? Could you still use the Chair whilst you were waiting for it to be adjusted? How did this affect you?

There was a mixed response in terms of servicing. Most were happy with the service regarding adjustments as they were made on the spot / on delivery of chair. However some respondents had negative experiences: -

"'One part needs adjusting, a referral has been made by the physiotherapist but a month later were are still waiting."

"The chair didn't need adjusting but key things were missing from it. These included a pommel that we are still waiting for."

'The chair needed adjusting completely. This had to be done on site, and we had to drive to Swansea (from Ceredigion). This process took all day. We can't use the chair for everyday use as it is too big and bulky, we have a child who is only 30kg in weight and the chair weighs 18 stone."

What happens if your chair needs repairing? Please describe your experiences, for example: do you know who to contact, where to go, how long does it take? Do you have to pay anything yourself towards the costs?

Respondents who commented on cost acknowledged that they did not have to pay anything for repairs through ALAC. However, one respondent who had to buy an electric chair from a different source has significant costs to bare, for example, £300 for to service the chair and replace two wheels.

Other comments on this issue included: -

"I had a repair needed on my manual chair recently. I had to stay in bed as power chair is not suitable for all day use."

"Nightmare, we live in the centre of Wales, South Wales say we are under North and North say we are under South Wales repair service, we get passed from one to the other."

"Serco come to service the chair. If it needs taking away they will leave any chair as replacement - last time, the chair that was left was totally inadequate, as it had had no side support."

How often are you asked about your wheelchair to find out if your needs have changed or if your chair needs updating? Can you tell us how this process works?

11 respondents stated they had never been contacted for a review of their chair. Two respondents stated that they rely on their child's physiotherapist and one parent / carer stated that the chair is reviewed regularly at clinic. With regards updating the chair one parent commented: "it is like mean they just add and take bits off the seat all the time."

The professional who completed a questionnaire stated that in her experience there was no formal review or follow up system to review seating needs.

How easy is it to access information about wheelchair services? Do you know where to get information? Is the information easy to read and understand?

65% of respondents stated they did not know where to get information. Comments include:

"Not easy. No. What info?"

"It is easy to contact ALAC. Getting information is not so easy."

"Although I live in a wheelchair I don't know where to get information and I have never read information about wheelchairs myself."

"Unless you are in contact with the hospital contact on a regular basis you do not find anything out."

"I assume you could find it on the Internet but really have no idea."

"No. Info used to be from paediatric physiotherapist but now my child is 19 I don't know where to go."

"It isn't there. There is no information."

Positive comments include: -

"It's quite easy to access information."

"In our area it is quite easy but I know people who struggle. There seems to be a big difference between north and south Powys."

"Information is accessed via ALAC directly. The literature I have viewed is easy to read, follow and interpret"(comment from professional).

Is there anything else you would like to tell us about your experiences?

One respondent stated they were quite happy with the service at present. Several respondents were unhappy with the state of their chairs, over the years they have become worn and look tatty however, they cannot be issued with new chairs for these reasons. Individuals can only get a new chair if they have grown. A young person who has stopped growing asked 'when will I ever get a new chair?!'

Other comments from respondents included: -

'It shouldn't take so long to get an appointment or to receive your chair.'

'We would like a lighter chair which fits my child, and is easy for me to push. Originally she had one with self-assist wheels but we had to take what they sent us last time. It was changed because she had grown taller. She is no wider but had to use an adult size chair.'

"We purchased a wheelchair for our child 6 years ago because he was so unhappy in the chair ALAC gave him, but that chair is not on the list that can be used in Wales by ALAC, they can in England. We have now purchased a second chair costing £5,000 so our child can be comfortable and included in family activities..."

"Why don't they look at individual needs and what the person needs the chair for rather than just funding?"

'Only that I feel it needs to be an easy, understandable one-stop service instead of lots of different companies doing different jobs to do with the same chair.'

In conclusion, the picture that has emerged from this snapshot survey carried out from 10th - 17th December 2009 and from previous work carried out by Children in Wales is a rather bleak one.

The evidence gathered through the above-mentioned survey and from discussions with other wheelchair users and professionals highlights that children and young people are having to wait considerably longer than the standards laid out in the Children's National Service Framework ie: assessment within six weeks of referral and provision of wheelchair within eight weeks of assessment. It is unacceptable that in 2009 children and young people in Wales have to wait, in some cases, more 12 months for a wheelchair.

Finally, the Ministers announcement of 8th December is welcome however, Children in Wales would like clarification on the following key issues:

What is the timescale for Phase Two of the wheelchair review and how will the views of young people be included in the review?

What is the timetable for the implementation of the recommendations in the Minister's statement?

How much additional funding is to be invested in paediatric wheelchair services and when will this be made available?

Recommendations:

As an active member of the Disabled Children Matter Wales (DCMW) campaign, Children in Wales endorses all the recommendations made by DCMW on this issue. These are:

1. An integrated service

Implementation of a single referral process so that families have easier and more co-ordinated access to wheelchair service (ALAC) and the specialist seating service (Rehabilitation Engineers) i.e. working within the existing structures.

An integrated system for providing wheelchairs and seating would enable a more user-focused, seamless service. It should look to incorporate a single point of contact or a designated key worker who can support families to access the right support from mobility services over time - incorporating repair, maintenance and review.

2. Delivering holistic assessments

A genuinely holistic assessment of a wheelchair users need

Should take place early in life as soon as mobility needs are identified; be a collaborative process, based on joint decision making with respect to the user’s social, developmental and educational needs as well as their lifestyle preferences and provide clear information and guidance to families.

Health professionals should take a 'social model’ approach to disability (focusing on independence, empowerment and participation) and be able to make recommendations on a range of equipment based on paediatric expertise;

Remove eligibility criteria which is primarily 'clinical’, can limit the choices of families, and has historically discriminated against children and young people in terms of the type of equipment they can access;

Be independent and not guided by budgetary constraints or be based on historic or routine purchasing patterns

3. Investigating systems and structures

Appointment of a dedicated team tasked to investigate wheelchair service provision in Wales and develop the new model of service required to deliver the agreed vision.

Identifying current overhead, and equipment costs;

Developing a wheelchair product commodity strategy to improve the range and quality of equipment available and delivering better value for money;

Workforce planning and training (to build paediatric expertise, encourage a 'social model’ approach and support provision new technology);

Establishing a user-pathway which delivers a seamless and responsive service, (the right mobility equipment in a timely way, with ongoing support);

Identifying the right systems and structures that are needed to deliver the new vision of service for both complex and non-complex users;

Consideration of key learning and best practice for children’s services through the pilot working;

Devising data collection and forecasting methods to understand the needs of users and support service planning

Children In Wales
January 2010.

Annex 1

Wheelchair services inquiry

The Health, Wellbeing & Local Government Committee of the National Assembly for Wales has launched an inquiry into wheelchair services. Children in Wales has been asked to give written evidence in the form of a position paper and has been invited to give oral evidence to the Committee at the Senedd on Thursday 14 January.

In order to include the views of as many wheelchair users as possible we would like to ask for your input into the Children in Wales position paper. We will not use your name in the position paper but would like to quote the county that you live in. If you would prefer us not to include the county you are from then that is fine, just let us know when you return this form.

Name:..County................................

Q1	**Where do you get your chair from? Eg: Artificial Limb and Appliance Centre (ALAC)?, Whizzkids? Other?**
-	-
Q2	**Can you describe your experiences in accessing wheelchair services? Are they generally good or have you had any difficulties? Do you have a say in choosing your chair?**
-	-
Q3	**How long did you have to wait from the time you were assessed to the delivery of the chair? Were you happy with this wait? How did this affect you and your ability to get out and about?**
-	-

Q4	**When you received your new Chair did it need adjusting? If yes, how long did you have to wait for this to happen? Could you still use the Chair whilst you were waiting for it to be adjusted? How did this affect you?**
-	**-**
Q5	**What happens if your chair needs repairing? Please describe your experiences, for example: do you know who to contact, where to go, how long does it take? Do you have to pay anything yourself towards the costs?**
-	**-**
Q6	**How often are you asked about your wheelchair to find out if your needs have changed or if your chair needs updating? Can you tell us how this process works?**
-	**-**
Q7	**How easy is it to access information about wheelchair services? Do you know where to get information from? Is the information easy to read and understand?**
-	**-**
Q8	**Is there anything else you would like to tell us about your experiences?**
-	-

Thank-you for your time and your support. We will let you have a copy of the Position Paper and will be in touch after the Committee meeting to let you know how we got on.

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Children in Wales is a joint sponsor in the Reach the Heights project

Mae Plant yng Nghymru yn gyd-noddwr yn y prosiect Cyrraedd y Nod