

Wheelchair Services for Children and Young People in Wales Interim Report

During the spring of 2006, Contact a Family Wales conducted a survey of families asking about their experiences of wheelchair services. This is a short interim report, based on the results of the survey. The final report will be published during the summer of 2006.

For the families of many disabled children, wheelchair services are a major concern. Having the appropriate wheelchair is the only way many children and young people can attain any degree of mobility and independence. The National Service Framework for Children, Young People and Maternity Services in Wales ("The Children's NSF") contains specific key actions relating to assessment for, supply of and maintenance of wheelchairs:-

"There are agreed protocols and standards for wheelchair/specialist seating services that include;

- *Providing a comprehensive service that meets the 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 system 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."*

National Service Framework for Children, Young People and Maternity Services in Wales. Key action 5.17.

The survey aimed to:-

- Find out the major areas of concern for families with children who use wheelchairs
- Look at how the Children's NSF has so far impacted on wheelchair services for children and young people in Wales

Methodology:-

A questionnaire was issued with the Contact a Family Wales Newsletter (spring 2006 edition). The questionnaire asked for parents and carers of children and young people who use wheelchairs to tell us about their experiences of wheelchair services for children and young people in Wales. Responses were analysed and collated to form the basis of this interim report.

Results:-

At time of writing (May 2006), 43 responses had been received. Completed questionnaires were received from 13 counties across Wales and the ages of the wheelchair using child or young person ranged from 20 months to 18 years. Respondents used a variety of different types of chair including buggies, manual chairs (both pushed and self propelled) and motorised chairs. A number used a combination of manual and motorised chairs. Two parents had not yet received wheelchairs for their children.

Waiting Times

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

Waiting Times for Assessment					
Total Number of Respondents who Specified	0- 6 weeks	6 weeks – 3 months	3- 6 months	6 months- 1 year	Over 1 year
32	6 (18.75%)	6 (18.75%)	12 (37.5%)	4 (12.5%)	4 (12.5%)

Over 55% of families waited longer than the NSF target of 8 weeks for delivery.

Waiting Times for Delivery					
Total Number of Respondents who Specified	0- 8 weeks	8 weeks – 3 months	3 – 6 months	6 months - 1 year	Over 1 year
38	13 (34.21%)	6 (15.79%)	11 (28.95%)	6 (15.79%)	2 (5.26%)

Monitoring and Review

The NSF sets a target for annual review. 21 parents told us that their children had been reassessed in one year or under of being supplied with a wheelchair: 8 told us that they had waited for more than 12 months.

The survey highlighted the importance of regular monitoring and review of wheelchairs:-

- Children and young people grow and their needs change. It is vital that they are regularly reassessed and their wheelchair requirements reviewed. Because of delays in supplying wheelchairs in the first instance, many children need to be reassessed immediately.

“By the time the wheelchairs have been delivered (anything from 4 months – 1 year), he has grown and they are far too small”

Parent

- Fifteen parents told us that their children’s wheelchairs were regularly reviewed and maintained as opposed to twenty four parents who told us that their children’s wheelchairs were not regularly reviewed and maintained. There were parents from both groups who told us that the chairs were repaired on request.

Training

Twenty three parents (53.49%) told us that neither they nor their children had been provided with any training. A number of parents felt that their training needs and those of their children had been met by the wheelchair services and the efforts of one occupational therapist at the Artificial Limb and Appliance Centre in North Wales and another hospital occupational therapist in South Wales were noted.

Several parents told us that they would like training for themselves or for their children on using wheelchairs. Subjects for parents included negotiating curbs, correct posture whilst pushing the chair, how to lift chairs safely (especially into and out of cars) and general safety checks. One parent highlighted the need for training for children and young people themselves:-

“I think it is very important that the child has guidance on moving the chair, guidance how to get in and out of the chair – all aspects very important for independence but are neglected by this service”

Parent

Choice and Flexibility

We asked if parents and young people were given a choice of wheelchair and accessories. 23 parents (53.49%) told us that they had not been offered a choice.

There were parents who were happy with what they had been offered.

“Wrexham wheelchair services over the past year have done everything they can to select the correct powered wheelchair for my daughter’s needs.....I only have praise for the OT’s help and assistance.”

Parent

However, there is evidence from parents’ comments that even when there is a choice, it is limited:-

“...there was only one model available, we chose the colour and accessories”

Parent

Some parents told us that they thought that it was often a case that the child should fit the system, rather than the other way round.

“We would like them to get chairs that fit the children. Not make the children fit the chairs”

Parent

There was also the issue of the system not being flexible enough to cater for the needs of all children:-

“Just because he needs a power chair most of the time does not mean he could not self propel some of the time”

Parent

Another major issue for parents was the fact that they felt that the designs of wheelchairs were more suitable for older adults than children.

“I would like my son to have a more modern chair. He and my neighbour who is 78 yrs have exactly the same chair”

Parent

Accessories

A number of parents told us that they had encountered difficulty obtaining accessories, once they had received the wheelchairs. Some parents told us that they needed to purchase accessories like rain covers, padded covers or cushions. Others told us of long waits for foot rests, trays and cushions to be supplied:-

“We are still waiting for the cushion. This was ordered 18 months ago and still waiting for the table that goes on the chair”

Parent

Funding

For parents in Wales, funding is an issue where local wheelchair services are not able to supply the chair or piece of equipment their child needs or when parents felt that their child’s particular needs demanded greater flexibility than wheelchair services could allow for.

A number of parents told us that they had paid for their children’s wheelchairs themselves because the system could not provide them with the particular model of chair they felt their child needed.

Only one parent mentioned that they would like to have received a voucher or direct payment so that they could have sourced a wheelchair for their son.

Satisfaction

Given the long delays for assessment and delivery, we were keen to know if parents and young people were happy with the end product. Of 41 parents who answered this question, 12 parents (29.27%) expressed high levels of dissatisfaction.

Three parents told us that the chairs were too small for their children. Six told us that the chairs are unsuitable because they do not have the features they need:-

“It is, at best, a compromise because we had to become extremely awkward and argumentative with wheelchair services because they weren’t listening to us at all”
Parent

Other reasons included problems with obtaining suitable accessories and the chairs breaking:-

“.....we need a recliner and a tray. Plus, parts tend to fall off very easily.”
Parent

And problems with the appearance of the chair:-

“As he spends all his time in his chair, it could look better and be more comfortable”
Parent

Conclusion:-

There were parents who had very positive comments and cited examples of good practice:-

“The engineer at Rookwood is a star. He gets to know the child and parents so can judge what wheelchair is needed”
Parent

However the majority of parents told us of their frustrations with the current system and our survey highlighted a number of specific issues including real concerns around:-

- ☐ **Waiting times for both assessment and delivery of wheelchairs and there is much to do before the target waiting times set out in the Children’s NSF Wales are achieved.**
- ☐ **Review, repair and maintenance of wheelchairs vary from family to family and area to area. There are those who are happy with the service they receive, but these experiences are not universal.**
- ☐ **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 number of parents felt that the current system is not flexible enough to meet their child’s needs and called for a service that is centred on the child or young person. This would include:-**
 - **A wider choice of chairs designed specifically for young people**
 - **A service which recognises and is able to respond to the needs of the individual child/young person.**

Martin Davies (Paediatric Project Officer)
Contact a Family Wales The Exchange Building Mount Stuart Square Cardiff CF10 5EB
Tel 029 2049 8001
E-mail:- wales@cafamily.org.uk