

contact a family

for families with disabled children

incorporating

The Lady Hoare Trust

Wheelchair Services for Children and Young People in Wales

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Executive Summary

During the spring of 2006, Contact a Family Wales conducted a survey of families asking about their experiences of wheelchair services.

Our aim was to:-

- Find out the major areas of concern for families with children who use wheelchairs
- Look at how the National Service Framework for Children, Young People and Maternity Services (The Children's NSF) has so far impacted on wheelchair services for children and young people in Wales

A total of 52 responses were received from parents whose children used both electric and manual chairs.

Whilst there were some very positive comments, the majority of parents were able to tell us of frustrations with the current system. Our survey highlighted a number of specific concerns for families.

- There is much to do before the target waiting times for both assessment and delivery of wheelchairs set out in the Children's NSF Wales are achieved.
 - 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. 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.

Introduction

Why have we compiled this report?

Quite simply, we know that wheelchairs play a huge part in the lives of disabled children, young people and their families. Having the appropriate wheelchair is the only way many children and young people can attain any degree of mobility and independence. Whenever we meet with families, wheelchair services always crop up in conversation, without fail, and we are aware that there are major concerns.

Contact a Family Wales has joined with Barbardo's Cymru and Whizzkidz to campaign on wheelchair issues. On 13th June 2006, the Barnardo's/Whizzkidz report on wheelchair services for children and young people "Don't Push Me Around!" was launched at the Welsh Assembly in Cardiff. "Don't Push Me Around!" looks at the situation across the UK. Our aim in this report is to highlight the key issues raised by families in Wales.

In October 2005, the Welsh Assembly Government launched the National Service Framework for Children, Young People and Maternity Services (The Children's NSF). This sets standards for health and social care for children and young people and contains a number of specific key actions relating to assessment for, supply of and maintenance of wheelchairs:-

"Disabled Children are able to use the equipment they need in all the places where they spend time e.g. school, home, leisure settings and during short break care."

National Service Framework for Children, Young People and Maternity Services in Wales.
Key action 5.15.

"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.

Parents/carers and other non professionals are offered appropriate and on-going training to assist them in meeting the needs of their disabled child. As a minimum this includes:

- *Appropriate training in the use of equipment. The arrangement of this training and support is co-ordinated by the person ordering the equipment in collaboration with the supplier;*
- *Manual handling training;*

An extract from Key action 5.31 of the National Service Framework for Children, Young People and Maternity Services in Wales.

The Children’s NSF is a ten year strategy to improve services for children and young people. We wanted to find out whether it has started to make a difference to families’ experiences of wheelchair services.

Methodology:-

A questionnaire was issued with the Contact a Family Wales Newsletter (spring 2006 edition). The parents and carers of children and young people who use wheelchairs were asked 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 report. Parent’s views and comments are printed in italics within quotation marks.

The questionnaire also asked families if we could use their stories as case studies. We collected these stories by means of telephone interviews and e-mail exchange. A number have been included within the report.

Contact a Family Wales would like to thank all the parents who took part in the survey, with particular thanks to those who allowed us to use their experiences as case studies.

This report has been compiled by Martin Davies, Paediatric Project Officer, Contact a Family Wales.

Results:-

- ☞ **A total of 52 responses were received from 18 counties across Wales.**
- ☞ **The ages of the wheelchair using child or young person ranged from 20 months to 19 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.**

Our Findings:-

Waiting Times for Assessment and Delivery

The Children’s NSF set’s specific targets for waiting times for assessment for wheelchairs and their subsequent delivery.

- **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
37	6 (16.22%)	8 (21.62%)	15(40.54%)	4 (10.81%)	4 (10.81%)

- Over 60% 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
46	17(36.96%)	7 (15.22%)	14(30.43%)	6 (13.04%)	2(4.35%)

Re-assessment

The Children’s NSF sets a target for annual review of the child’s needs.

- A third of children are still not being reviewed annually.

Waiting Times for Re-assessment		
Total Number of Respondents who Specified	Review in one year or less	Review in more than one year
33	22 (66.67%)	11 (33.33%)

Case Study – the frustration of waiting.....

*(My son) was seen by his physio and she advised that a lighter weight chair would be more suitable. He was referred in March 2005 and we were told that an appointment would not be available for five months. His existing chair was then already too small. I complained and a bigger version of his existing chair was sent out. We received no appointment. When I rang I advised that we were unavailable during certain times due to holidays and hospital appointments. An appointment came on one of these dates! I complained again and was told a new appointment would come. After a further four months I was told we did not attend an appointment. I explained that we had cancelled and informed them straight away as my son was in Bristol Children’s Hospital on this day. We are still waiting.....
Parent (writing in April 2006)*

The survey highlighted a number of problems around regular monitoring and review of wheelchairs:-

In addition to the 33 parents above, there were a number of parents (4) who told us that their child’s needs were only reviewed on request. The parent’s comments suggest that this happens only when the child’s chair is no longer suitable or there was a problem.

“I requested a re-assessment because she had outgrown the previous chair”

Parent

“We always have to request a re-assessment”

Parent

- Delays in supplying wheelchairs in the first instance can mean that 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

Re-assessment frequently means that the child/young person needs a new wheelchair. We asked parents how long they waited to take delivery of a new wheelchair following re-assessment.

- Of the 26 parents who specified, over 70% waited more than 8 weeks for the delivery of their child’s new wheelchair following re-assessment.

Waiting Times for Delivery after Re-assessment					
Total Number of Respondents who Specified	0- 8 weeks	8 weeks – 3 months	4 – 6 months	7 months - 1 year	Over 1 year
26	7(26.92%)	7(26.92%)	5(19.23%)	5(19.23%)	2 (7.69%)

Does your child’s wheelchair meet their needs?

We asked this question to find out if, after waiting for assessment and delivery, children and young people were at least provided with wheelchairs that meet their needs.

- ☞ A total of 28 parents (53.85% of respondents) did feel that their child’s wheelchair met their needs and who were happy with the positive effect having the right chair has made to their lives and those of their child.

“We can go for walks together. If we need to go shopping, we can go as a family without (my daughter) getting too tired and someone having to sit in the car with her. She feels she can go places knowing she will keep up with everyone else”
Parent

There are examples of good practice. We did hear from parents who were happy with the service they had received and the wheelchair provided for their child, but these experiences were far from universal

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

Several parents pointed out to us how having the appropriate wheelchair/buggy can make a real difference.

“The specialist buggy has been measured to meet (my son’s) needs. He has requirements added to meet his needs. (He) is now able to be comfortable and sits upright. He is a much happier little boy in his buggy now that “the right bits” are supported correctly”.

Parent

□ Another four parents (7.69% of respondents) answered both yes and no to this question (their child has two chairs and only one meets their needs, they feel that the chair meets only some of the child’s needs or, in one case because although they felt that the chair meets the child’s needs, it does not meet their own)

□ Taking into account the two parents who told us that they were still waiting for wheelchairs and could therefore not comment and also the fact that one parent did not answer the question, this does mean that 17 parents (32.69% of respondents) felt that the chair they had been provided with did not meet their child’s needs.

The reasons were varied:-

- Wheelchairs which are too small

As has already been pointed out, lengthy waits for the delivery of a chair can mean that by the time it has arrived, the child/young person may well have grown out of it.

- Wheelchairs which have not been adapted properly and need further adjustment or which need frequent repair

Parents told us about footrests that did not adjust, seats which were the wrong height and cushions which did not fit.

“Foot plates don’t support feet effectively, small parts have come off easily, my daughter has put screws from the chair in her mouth, no trunk support, no spoke guards, small holes for small fingers to get stuck in, wheels jam up....”

Parent

- Wheelchairs which are not suitable for use in all settings

A number of parents told us of wheelchairs which are not suitable for use outside on anything other than a smooth surface. Parents pointed out that children need to be able to use their wheelchairs in a wide variety of locations.

“...we cannot use the wheelchair for going for family walks etc – because of the terrain we live in, the wheelchair will not go over unsurfaced roads and fields and we find this a real problem living in a rural area.”

Parent

“Powered chair that is attendant controlled. Very heavy, can’t access shops, friends’ homes and some public buildings or any emergency transport”

Parent

- Wheelchairs which are too heavy or bulky for the child to manoeuvre

“Chair is difficult for (my son) to push himself. We asked for a lighter chair and we were advised he would need to be assessed. 18 months later, we are still waiting.”

Parent

- Wheelchairs which are too heavy or bulky for the parents to manoeuvre

“When I’m on my own, to get it out of the car is a nightmare”

Parent

“It’s heavy and bulky and you catch your feet on the bottom”

Parent

Repair, Review and Maintenance of Wheelchairs

Thirty one parents (59.62% of respondents) 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 (although some comments reveal a sense of frustration!).

“...only if I scream my head off and threaten to report them to the papers”

Parent

In other cases, comments indicate that parents feel that they can call upon engineers whenever they need.

“...if we encounter a problem with the chair, we have had some fairly prompt attention”

Parent

Interestingly, one parent told us that it was they who maintained their child’s wheelchair and, when we later asked about training another parent mentioned that they would like to know how to perform safety checks whilst another stated that they would like to have literature on the care and maintenance of the wheelchair (see below).

Training

Thirty one parents (59.62% of respondents) told us that neither they nor their children had been provided with any training.

However, the comments of some of the parents who said that they had received training illustrate just how limited this training often is.

“It was the person who delivered it showed us how it was set up”

Parent

“Two minutes on the controls”

Parent

“We were shown how to fold the wheelchair and where the brakes were”
Parent

There were those who felt that they had been given sufficient training and the efforts of one occupational therapist at the Artificial Limb and Appliance Centre in North Wales and two hospital occupational therapists in South Wales were noted. Other families noted the training provided by the Wheelchair Association and Contact a Family Wales.

What sort of training would parents like for themselves and their children?

- Training for the child/young person to foster independence and improve mobility.

“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

- Subjects for parents included correct posture whilst pushing the chair and how to lift chairs safely (especially into and out of cars).

“I find pushing puts a strain on my back because I have to stoop”
Parent

“Getting it in/out of the car”
Parent

- Some parents also felt that they would like information on care and maintenance of wheelchairs and how to perform safety checks.

“How to safely lift the chair and general safety checks”
Parent

“Some literature on care and maintenance of the chair would have been useful. Chair delivered with no paperwork at all.”
Parent

- One parent stated that she would like information on the choices available to her and her child, the equipment available and how it can be of benefit.

“I would like to have information on what is available, ideas about mobility, ramps, devices, wheelchair bags, covers, how and why powered devices help”.
Parent

Are you and your child happy with the wheelchair they have?

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 50 parents who answered this question, 19 parents (38%) told us that they and their children were not happy with the wheelchair that they currently have.

- Four parents told us that the chairs were too small for their children.

“Far too small, only had recently, but too small by the time it arrived”

Parent

- Then there were those who 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

Choice and Flexibility

Thirty one parents (59.62% of respondents) told us that they had not been offered a choice of wheelchair.

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

Some parents felt that they have had to battle to get the appropriate chair.

“I had to fight to get (my son) the correct wheelchair for his condition.”

Parent

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

Others were resigned to the fact that choice will be limited because of financial constraints imposed upon the wheelchair service:-

“I think I was given adequate choice of a wheelchair for my child and for his disability also, I also understand the funding for wheelchairs and other equipment, so no good making a fuss about it.”

Parent

There was also the issue of the system not being flexible enough to cater for the needs of all children. Parents pointed out that children and young people do not all fit into the categories set by the current wheelchair service and that their needs change and develop.

Case Study – the system is not flexible enough....

The service does not take the child’s development into account. Our son has a powered chair, but, with practice, encouragement and the opportunity, he could perhaps manage to self propel using a suitable lightweight chair which would give him more freedom and independence. However, because of the supply rules, he cannot have both a powered chair and a suitable lightweight chair. The manual chair he has is classed as a “spare” and so we cannot be given a lightweight, self propelling chair which denies our son the opportunity to learn to do this.

Children’s development and their conditions change constantly. For example, during the summer months, our son would like to be able to self propel, but cannot, because of the supply rules. Just because he needs a powered chair most of the time does not mean that he could not self propel some of the time. His medical condition is still changing and unfortunately, his current needs are not met appropriately

Parents

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

One of the concerns was that the current system does not consider the child or young person as a whole.

Case Study – the system does not consider the child’s emotional and intellectual well-being.....

I was told that the “Blade Plus” was the only chair available to children under the age of 13. Children were not expected to self propel until that age. The fact that (my son) had been attempting to do so since the age of 3 seemed irrelevant to them. It was during this period that (my son) attended his first manual wheelchair course organised by our paediatric occupational therapist and run by the Wheelchair Association. I am not aware of and have never been informed of any similar training being carried out by Welsh wheelchair services. (My son) was placed in a relatively inexpensive Remploy Roller and we suddenly were able to see what this child could achieve. He really could be self reliant in terms of his mobility and we determined to do something about it.

I was once again told that the Blade was the only chair that they issued to children of this age who desired a manual wheelchair and that there was no need for (my son) to see one of the wheelchair service’s assessors. I was determined to fight our corner and said that to (my son), the wheelchair was the equivalent of another child’s legs and shoes and that I was sure that she would not send her own children to school with ill-fitting shoes. I explained that the ill-fitting wheelchair was detrimental to my son’s emotional and intellectual well-being. He had become increasingly frustrated having seen what he could do in a suitable chair. I was told that as a service they were not concerned with a child’s emotional and intellectual needs. Their only concern was a physical one. The Blade allowed (my son) to get from A to B and as far as they were concerned, this meant their role was fulfilled.

I was told that if I insisted, I could ask our occupational therapist to request another assessment but that it would take a minimum of 18 months. We were not prepared to let (our son) languish in a totally unsuitable chair and therefore with the help of our family we purchased a Remploy Roller and the Blade was assigned to our garage. The result? (My son) has not looked back.

Parent

The NSF states that disabled children should be able to use equipment in all locations, but, we have already heard how one mother in a rural area had difficulty taking her child out for walks. She was not alone with this problem.

“(My son) needs a chair for outside, if I try to take him on a walk – along a rough path, the little wheels get stuck straight away and I cannot push him. There is no suspension so I cannot take him off paved areas. There is no cushion, so, for journeys in the bus his seat is very hard.”

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

“Wheelchair designers should consider that a lot of disabled children are fully aware of their surroundings and would like more modern, jazzy chairs. My 12 year old refused to go in one wheelchair because he thought it more suitable for an “old granny”

Parent

Key to finding wheelchairs that meet the needs of children and young people is the ability to source and obtain accessories. A number of parents told us that they had encountered difficulty obtaining accessories, once they had received the wheelchairs. Some parents 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

Others told us that they needed to purchase accessories like rain covers, padded covers or cushions and a problem is the cost associated with these items.

“I have requested a shopping basket and cosy toes (pram/wheelchair). I can have these but will cost over £200.00”

Parent

Funding

The issue of funding cropped up where wheelchair services are unable to provide the particular chair or piece of equipment that a child or young person needs or when parents felt that their child’s particular needs demanded greater flexibility than wheelchair services could allow for.

“We have even gone so far as to offer to pay towards the correct wheelchair being provided, he needs an RGK wheelchair, (but) services wouldn’t even discuss the option with us. They don’t have a contract with RGK and therefore they won’t look into the possibility at all. I said I would gladly remove the responsibility from them if this was the problem. They said that if I went outside the service, they could not help with the costs at all. I asked them why they could not put what it would cost for a chair towards the cost of an RGK and we would raise the money to meet the difference Services weren’t interested in even discussing it with us.”

Parent

There were numerous incidences of families purchasing their own chair (see also the case study above “...the system does not consider the child’s emotional and intellectual well-being...”).

“We needed a wheelchair with a (removable) motor to aid us to push (my daughter). She is a big, 12 stone girl. The wheelchair provider could only provide a motorised chair. The car would have to be adapted. We are a family of five and could not afford to lose the luggage space of our car. We eventually had a grant from Red Dragon Radio to purchase a lightweight chair and removable motor”

Parent

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.

Conclusion:-

What do parents want from the Wheelchair Service?

Although there are those who are pleased with the service they receive when their child is assessed and supplied with a wheelchair, for many parents, the whole process is one of delays and frustration.

Above all, parents need to know how long they will have to wait for their child to be assessed and how long it will take for the wheelchair to arrive. The Children’s NSF sets targets for assessment for and delivery of wheelchairs, but our findings show that these are not being met.

“Timescales are appalling – when these children rely on their chairs for basic every day life.”

Parent

The Children’s NSF also sets a target for annual review of wheelchairs. This is not happening in one third of cases and parents would like to see a system that ensures that their child’s chair is automatically reviewed

“Would like to see reviews of needs on at least an organised annual basis from either O/T or physio.”

Parent

More than half of parents told us that neither they nor their children had been provided with any training and many would like training both for themselves and for their children.

“Think there should be basic training to every user and carer”

Parent

For many families, one of the major criticisms of the current service is that, for one reason or another it is not flexible enough to meet the needs of their child and, having obtained a wheelchair, nearly a third of the parents we spoke to said that the chair supplied did not meet their child’s needs. 40% of parents stated that they had not been offered a choice of wheelchair. There are major issues around choice and flexibility:-

- In particular, parents would like wheelchairs which look like they were designed for children and young people.
- There is also the issue of wheelchairs which function in all settings which the child/young person needs to access (outdoors as well as indoors for example)
- Parents would also like to be able to obtain accessories such as trays and rain-covers easily and at a reasonable cost

Finally, on the parental wish list is a system that takes into account the holistic needs of the child and takes into account the fact that parents’ lives, as well as those of the children are affected when the child is a wheelchair user.

“The chair is part of our freedom. A means to get it in/out of the car would be the icing on the cake!”

Parent