SCHOOL WHEN YOU ARE ON WHEELS

Young Wheelchair Users in Wales: A Snapshot of Challenges and Experiences in Education
Introduction

Following a joint campaign on wheelchair services for children and young people during 2006, Barnardo’s Cymru, Contact a Family Wales and Whizz-Kidz were asked by Jane Davidson, former Welsh Assembly Government Minister for Education and Lifelong Learning, to look at how using a wheelchair can affect a child or young person’s education. We asked some of the parents and young people we work with to tell us of their experiences of using wheelchairs in the school setting and this short report is the result.

Key Themes

The themes which have emerged point to the fact that some young wheelchair users are missing out on opportunities that most children take for granted.

• Many children and young people encounter difficulties and delays in accessing the appropriate wheelchair. When you do not have the appropriate wheelchair, school life is much harder.

• When a child is assessed for a wheelchair, school activities are often not taken into account. In this case, although the wheelchair may meet the clinical need, it will fail to support the social and educational needs of a growing child. Adapted mobility equipment would enable them to use existing school facilities.

• There is evidence that some pupils encounter difficulties because they do not have use of the appropriate equipment such as desks of the proper height.

• Even when a child is normally able to access all parts of the school building, there are often lifts which break down or are vandalised, chair lifts which did not work and pupils having to take alternative routes which involve going outside in all weathers or using a different door to enter the school.

• Children and young people who use wheelchairs can encounter difficulties with school activities such as trips and excursions, playtimes, school meals and swimming.

• Transition from primary to secondary school can be problematic due to delays in adapting the school and installing special equipment cited as common causes for concern. Fundamentally, the fact that a child or young person needs to use a wheelchair is often the over-riding consideration when it comes to choosing which school they will attend.

• If we accept that school is not only about gaining academic qualifications but also about friendships and social experiences; for many children and young people, one of the most concerning effects of using a wheelchair in school is that all of the key themes listed can result in their segregation, albeit inadvertently, from their friends and classmates. This in turn can have a negative impact on a child’s confidence and self esteem. It can also make it harder for them to integrate fully with society in the longer term.
The title of this report was suggested by Sasha, a young wheelchair user who left school in 2006. In her very thorough recollection she touches on almost every other issue raised by the parents and young people we have spoken to and so her story has been used to begin the report.

I am 18 years old and have cerebral palsy that affects my legs and right arm which renders me completely reliant upon a motorised wheelchair for mobility. I use an indoor-outdoor wheelchair that I use both at home and at work though it was incredibly difficult to acquire this chair. My hip collapsed during my second year of comprehensive school and meant an electric wheelchair was my only option. Prior to this I had more mobility and used a combination of a walking frame and a manual wheelchair which my friends pushed me around in but when the time came for me to have an electric chair none were available and my family had to independently raise the funds for an electric chair as I was in desperate need of one. A little while later I was given one by the government which is what I use now but we still had to fund my original chair ourselves and the waiting lists for bigger sizes, upgrades etc on the government provided (chair) are absurd.

I left school after passing all my A levels last summer and would like to share my personal experiences with you about my time there.

Being in a wheelchair, you realise things that you’ve never ever thought about before. This whole other world full of doubts, precautions and barriers opens up to you and results in you having to plan virtually everything you do, often faced by endless restrictions and education was no exception to this rule. However I assure you that though my experiences through education could be seen as ‘challenging’ that does not mean that it was completely saturated with misery. In fact, if it wasn’t for the help of the Learning Support Assistants (LSAs) at my school I can honestly say that I would have given in to defeat a long time ago. My school was integrated with a combination of mainstream classes and a specialist support centre that catered for a wide range of impairments and disabilities whilst still incorporating the freedom of equal opportunity for intellectual stimulation to all who chose it. This seems idyllic but with all good ideas come faults and the system was far from perfect.

To get to classes involving ICT, Mathematics and Humanities, you were forced to use a lift as the school was split into ‘sections’ that spread across two floors. Different classes required travel to different buildings and the use of different lifts. The lifts were very old and highly susceptible to vandalism, often breaking down as a result and prevented the user from a true education in the sense that whenever the lifts broke down, you would go to the support centre and complete your studies there. Meaning you were often subjected to a considerable misfortune of becoming segregated from your fellow pupils and not benefiting from being immersed in the proper learning environment and sometimes resulting in increased work loads and pressure because you may have missed an important explanation on an exam technique etc. Also the 6th form common room and majority of registration classes were also held upstairs which proved to be a MAJOR problem.

For me I did feel a great deal of social rejection, I’m a confident young person who thrives on social interaction but if the lift was broken I’d often be forgotten by my friends it would seem and spent most break and lunchtimes down the Support Centre as luck would have it the majority of my friends were afraid of lifts,
meaning I’d have to go in there alone. Although I was extremely close to all the LSAs and still remain even to this day and they would gladly accompany me, the point I’m making is of that of independence and the confidence in doing so. Access was also a highly prominent example of restriction to me. We have NO automatic doors other than to the entrance of the Support Centre, there was often 3 sets 2 sometimes even 3 sets of heavy doors to go through before you were fully inside a building and this still proves to be a terrible struggle for anyone with reduced mobility and strength. Toilet facilities were limited too. We only have 3 disabled toilets, 2 of which were in the Support Centre and one in the 1st floor of the humanities area. You’d therefore have to leave your friends to go to the Support Centre or risk the unreliability of the lifts, which was NEVER practical.

The classroom set up needs to be greatly evaluated. Some classrooms especially in the technology areas are often grossly unacceptable for satisfactory working conditions for wheelchair users and disabled people in general. Often being too high for the pupil to work comfortably or even get close enough to the desk to work on with their chair. This once again reduces the self-esteem and independence of the individual and possibly posing a health hazard. A recent visit to my school reiterated this when I visited the new ICT suite full of sparkling new computers and I couldn’t have used a single one of them on account of the height of the desks. This suggests that funding should be looked at-instead of new computers that only able-bodied people can use they should be thinking about improving the overall access to the school!

School excursions were also troublesome. Each excursion would have to be carefully thought out often resulting in me having to go a different route to my other classmates and although I appreciate that sometimes this is unavoidable, you couldn’t help but feel slightly excluded from everyone else and what they experienced.

Theme One: Delays and difficulties to accessing the right wheelchair can impact on school life.

Our reports “Don’t Push Me Around” (Barnardo’s and Whizzkidz, 2006) and “Wheelchair Services for Children and Young People” (Contact a Family Wales, 2006), highlighted the importance of independent mobility to a child’s overall development and the significant challenges faced by families in accessing appropriate mobility equipment. Many children and young people face difficulties and delays when waiting for assessment and delivery of wheelchairs. The provision of an appropriate wheelchair supports participation and inclusion in mainstream educational and recreational activities, broadens horizons and affords opportunities in line with established principles such as the UN Convention on the Rights of the Child.

A recurring theme in our conversations with parents is that their children encounter difficulties at school because of delays or difficulties in securing the appropriate wheelchair.

“My daughter was measured for a new wheelchair in November 2005, it finally arrived in September 2006. Her old chair became too small and unsafe and so affected all areas of school life. The school became very concerned and found it difficult”.

Parent
Theme Two: In many cases, assessment for a wheelchair does not take school activities into account.

Given the importance of school in the life of a child or young person, we were interested in finding out whether school activities were taken into account when they were assessed for their wheelchairs. Paediatric mobility equipment has an important role to play, not only in addressing clinical need, but also the social and educational needs of the child. We wanted to see whether children and young people are provided with equipment which meets their needs in all settings in which they spend time (with reference to the National Service Framework for Children, Young People and Maternity Services Wales, Key Action 5.15). A significant number of parents tell us that school activities were not taken into account.

“No questions were asked about school”
Parent

“School activities not discussed, only his weight and sitting position”
Parent

Even when parents have been able to find out which type of wheelchair their child would need in order to participate in school activities, there remains the hurdle of whether or not they are able to acquire it. One parent told us that she sought alternative advice as to which chair she should request in order for her daughter needed to take part in PE lessons but was still unable to acquire it:

“(My) child needs an active user chair. So much trouble getting chair she needed – we settled for less and accepted a different chair as so much trouble getting one which Association of Wheelchair Children recommended”
Parent

Theme Three: Getting Around in School. Can children who use wheelchairs participate in all classes and activities relevant to the school curriculum?

We have received no reports that the use of a wheelchair had physically prevented children from undertaking a particular piece of schoolwork. Indeed, there have been some very positive comments:

“I don’t think there is anything impossible to do from the wheelchair”
Parent

“Has been able to be involved in all class activities. All classrooms ramped to enable this”
Parent

However, although using a wheelchair might not actually prevent a child or young person from completing their schoolwork: that is not to say that they did not encounter difficulties.
There are often problems with equipment.

“My daughter has to go to school in her really old wheelchair, cause the tables are too small for her legs to go under...........When she goes in her new chair, she has to lift up the table and then put the table on her legs, so she is very stressed out about this.”
Parent

“Whilst (my son) was in school, it was difficult to access work desks and no appropriate desk was provided.”
Parent

As Sasha pointed out, there are also difficulties with getting from one part of the school to another and having to leave lessons early in order to get to her next class on time which meant that she missed out on crucial parts of lessons.

Theme Four: Getting About in School. Can children and young people who use wheelchairs access all parts of the school?

Relatively few parents have reported that their child was unable to access all parts of the school (buildings, play grounds etc). However, this does not mean that there were no problems.

• Access to different parts of the school is often by means of lifts which are subject to malfunction or vandalism.
• Access to different parts of the school and classrooms for children and young people who use wheelchairs can be via a different route to that used by others.

One parent, when asked if her child could access all parts of the school told us:

“Yes, all school buildings, but cannot access the main entrance. (She) has to enter by the kitchen door – often blocked with kitchen produce”
Parent

Special schools which are usually purpose built to accommodate wheelchairs generally have good access:

“Access to the school is no problem as the school is a special school for children in wheelchairs”
Parent

Theme Five: Getting About in School. What about other school activities?

We were keen to find out whether a child or young person’s wheelchair had affected their opportunities to take part in all school activities including play times, after school clubs, school trips and school meals. Some parents made very positive comments:

The school buses are equipped for wheelchair users, so that they can take the children places. I’ve not heard that there is a problem with any activities.
Parent
However, a large number of parents tell us that their child has experienced some degree of difficulty.

- Several mentioned that their child had not been able to take part in school trips. Some parents understand the practicalities involved here and take a pragmatic view:

  “The only time he has not participated has been certain school trips e.g. quarry/castle that obviously have no ramp access”
  Parent

Other parents told us that their children had not been able to go on any school trips:

  “In school (my son) was unable to access any school trips at all”
  Parent

- Access to playgrounds was also a problem for some children:
- There are sometimes problems accessing school lunch:
- There is also the case of another child who could not go swimming with her school:

  “Swimming – local pool is not accessible. School transport - bus to pool not accessible to wheelchair”
  Parent

**Theme Six: Transition from One School to Another**

A major theme to emerge has been transition from one school to another and our second case study illustrates some of these concerns perfectly.

>I am writing concerning my son’s transition to High School.

*Our son is in year 6 in school, he currently attends our local primary school. My son has CP, he walks very short distances and will be using a powered wheelchair to get around in high school, this is the dilemma of deciding which secondary school our son should attend:*

*We live in a small town, the local high school was attended by both my husband and myself, and is currently attended by my elder son. There are 60 children in my son’s year at primary school and approximately 43 of them will be going to this local high school. Our local high school currently has approximately 1200 pupils, it is currently not fully accessible for my son. It has a variety of buildings, one has two stories and one three, there is no lift access. Ground floor access is level and generally good, most technology classes are on this floor. Currently no wheelchair users attend the school. The school does have children with other special needs and caters well for these children. However, one major concern is the lack of experience and insight into providing care and accessibility to a wheelchair user, systems are not in place for PE, lunchtimes, school trips etc. His lessons will be timetabled on the ground floor for the first year, definitely.*

*The nearest accessible school is approximately 25 minutes drive away. No other children from our son’s primary school would be attending it. However, they already have a number of wheelchair users and other children with various medical, physical and learning disabilities. The staff have a high level of*
experience with children who are wheelchairs users with lots of systems in place for PE, lunchtimes, medical needs and general needs around everyday life at school.

At our son’s annual review last year we were encouraged to choose our local high school by the LEA. However, the staff who attended the meeting from the local high school were obviously very concerned about him going there. They were originally not very positive and certainly were keen to point out all the difficulties they would face, they did not point out all the difficulties he would face, but I did!!!

My son has been very upset by having to make such a major decision about his schooling, especially as it is not really about his schooling but the access to it. After much thinking and discussing my son decided to go for the accessible school, he just couldn’t face being the pioneer yet again in the local school. We left it for a few weeks for us to really think about it, and did not give our decision to the LEA, then as we discussed matters further a few things came clearer, that there is no easy answer and we can only support our son with his decision. He is the one who has to attend school and deal with things everyday. My son therefore changed his mind and decided that he would attend our local high school.

My son wants to go to school with his good friends from primary school, he has a good support network and they very much see him as a person first and very rarely refer to his disability. He has been very brave, and we have supported him in this. We have informed the LEA that he does want to attend our local high school. However, since we informed the LEA and school of our decision we are happy to say their attitudes have changed for the better. They are now pushing much harder for the lifts to be installed, there are some minor adaptations taking place (hopefully) during the summer holidays to doorways and ramps for better ground floor accessibility. We are also hoping that as it is the teachers that will have to move from the upper floors to the ground floors to give their lessons, that maybe they will also use any influence they can to get the lifts put in as soon as possible.

We sincerely hope that other children in the future won’t have to make these kind of choices when choosing high schools. It is not fair to put 11 year olds through the emotional stress of realising that because of their disability they need to make choices for different reasons to other children. Accessibility should not be an issue. My son still gets a little upset if we dwell on the negative aspects of high school. He knows that when he starts in September he will have to be very mature and level headed but mainly very patient with the school. We still have the accessible school as plan B if necessary, we hope we won’t have to use it and that the LEA will realise their duty to children with disabilities and make all schools accessible very soon.

Parent
Several parents told us of problems which occurred with transition from primary to secondary school.

- Fundamentally, the fact that a child or young person uses a wheelchair will often dictate which school they attend.
- The parents in the case study above were told by one secondary school that they did not need to know that their son was going to attend until year six (i.e. the year before he was due to go there). However, other parents tell us that adaptations can take up to two years.

> “There were 3 stair/chair lifts which were not working even though they knew she was going to the school 18 mths before”
> Parent

> “It took two years to alter the primary school for wheelchairs after my child started school – the next 11 months will probably be a nightmare to ensure his choice of local secondary school will be accessible – I very much doubt that this will be addressed in time, although LEA were aware of which was his nearest secondary school.
> Parent

**Theme Seven: Fitting in with Other Children and Young People**

“Why is it that disabled young people are always left until last” is a recent report by the Assembly’s Equality of Opportunity Committee (Welsh Assembly Government 2007). It acknowledges that “Education for disabled young people is not just about gaining qualifications but about meeting new people and establishing friendships”

Sasha tells us how she frequently found herself unable to enjoy the company of her friends because of her inability to access various parts of the school premises and, in our second case study, the writer points out that her son does not want to be the “pioneer”.

Essentially, children and young people who use wheelchairs, like most other children and young people, want to fit in, make friends and be part of the class. They do not want to be different, yet, the issues we have highlighted make them feel different and serve to separate them from their peers:

- They may be unable to access all parts of the school.
- They may only be able to access parts of the school via different routes.
- They may be unable to join in with activities such as school trips and excursions.
- Transition from primary to secondary school may result in them attending a different school to the friends they have already made.

In spite of the efforts of all concerned, the child or young person in the wheelchair may still be separated from their friends.
Conclusion

This is a small snapshot of experiences of parents from within a previous survey, yet, the picture which emerges does ring true with anecdotal evidence from across Wales.

- Problems with adapting the built school environment are still leading to discriminatory practices such as when children have to use the kitchen entrance to get into the school.
  
  “(She) has to go outside the school building to get to some lessons even in the pouring rain. She has to leave lessons 10 mins early to get to the next”
  Parent

- Disabled children and their families have limited choices when it comes to choosing schools.

  “(My daughter) attends her local comp which was also the best option we could find for her. However, we have found that inclusion in its true form doesn’t actually exist. This is not due to lack of trying on our part, the school staff’s part (in the main) but due to the lack of accessible areas/rooms in/around the school”
  Parent

- The issue of wider social inclusion in schools has yet to be fully addressed with many disabled children and young people unable to eat lunch and join in at break times with their classmates.

  “For me I did feel a great deal of social rejection, I’m a confident young person who thrives on social interaction but if the lift was broken I’d often be forgotten by my friends it would seem and spent most break and lunchtimes down the Support Centre”
  Sasha, wheelchair user

Opportunities to take part in many of the social activities which take place in schools such as trips and after school clubs are also limited.

  “Doesn’t go out to play. Doesn’t attend after school clubs – never invited”
  Parent

- Attitudes to inclusion vary from school to school. Some schools are better than others.

  “The nearest accessible school is approximately 25 minutes drive away.........The staff have a high level of experience with children who are wheelchairs users with lots of systems in place for PE, lunchtimes, medical needs and general needs around everyday life at school.

  At our son’s annual review last year we were encouraged to choose our local high school by the LEA. However, the staff who attended the meeting from the local high school were obviously very concerned about him going there. They were originally not very positive and certainly were keen to point out all the difficulties they would face, they did not point out all the difficulties he would face, but I did!!!”
  Parent
Early provision of an appropriate wheelchair would help support a child’s educational experience, but families face unacceptable challenges in accessing the right mobility equipment and wheelchair assessment does not take into account the varied activities which are part of life in a mainstream school.

“School use was not discussed”
Parent

“School When You Are on Wheels” and other organisations

We approached a number of other organisations which work with children and young people who use wheelchairs and their families and asked them to comment on our report “School when you are on wheels”. What follows are the responses we received.......
Children in Wales welcomes the report developed by Contact a Family and fully endorses the issues and concerns raised. It is a major concern to us that these issues remain unchanged despite many discussions and many reports over many years. Children in Wales have held two sessions focusing on wheelchair provision, one in preparation for the International congress in 2002, and another as part of the young disabled persons’ network meeting in 2005. The feedback from both events lists the same catalogue of delays, missed opportunities and exclusions for young people.

I really am concerned that children and young people are being denied their rights, to participate, to fully access education and to socialise with others.

The following is an extract from a piece of work undertaken in 2002, looking at barriers to Education, I have selected out the issues that directly relate to comments on wheelchair provision.

**Barriers:**
- Lack of accessible transport to get to school
- Attitudes of teachers
- Lack of self-confidence in disabled young people
- Poverty
- People do not listen to the educational issues brought forward by disabled people and call us stupid.
- Ineffective statements
- Bullying/attitudes of classmates (especially in inclusive education)
- Lack of opportunities
- Teachers and parents trying to tell you what subjects to do
- Schools not offering special sports facilities
- Young disabled people being categorised as ‘special needs’
- Access to buildings
- Difficult and heavy books

**Solutions**
- All teachers should have appropriate training run by disabled people
- Human rights organisations should pay more attention to young disabled people
- Pass on positive experiences to others
- Make sure young people are aware of their rights
- Increase funding for disabled young people in schools
- Encourage inclusion of disabled people in schools to prevent negative attitudes of future generation

Lynne Hill  
Policy Director  
Children in Wales
The Family Fund is a registered charity helping families with severely disabled or seriously ill children to have choices and the opportunity to enjoy ordinary life. Covering the whole of the UK, it is funded by the national governments of England, Northern Ireland, Scotland, and Wales.

As the largest independent grant giving organisation helping such families in the UK, it distributes around £27m a year on behalf of more than 40,000 children and young people living at home.

The Family Fund also carries out research and manages a vast database - a powerful tool for influencing policy makers and campaigning for change.

Family Fund in Wales and in the rest of the UK frequently works alongside Contact a Family on campaigns to improve services for families with severely disabled or seriously ill children.

Family Fund fully endorses and supports the excellent Contact a Family report “School When You Are on Wheels”. It provides a very real portrayal of the situation for so many families in Wales and shows how independence and integration can be limited or enhanced by the correct and timely wheelchair provision.

Family Fund gets many requests for financial assistance with wheelchairs and specialist buggies. Historically, due to funding from the governments of the UK, we cannot normally help with items such as wheelchairs that are the responsibility of a statutory agency. Governments feel they have provided for this through other channels.

The Family Fund can help with a contribution towards the cost of a wheelchair where:

- The child has been assessed by their local Health Authority or NHS Wheelchair Centre and the family need additional help over and above statutory provision
- Or
- The need for the wheelchair or buggy is outside the local Health Authority or NHS Wheelchair Centre criteria and the family are therefore unable to access help through statutory provision

A recent example in Wales was a request for a powered wheelchair for a child of 4 with spinal muscular atrophy as the wheelchair they have is for indoor use only. The new chair is to replace this one. There is no wheelchair voucher scheme in Wales. The family applied to several organisations who were either unable to help or had a waiting list of 18/20mths. The Fund was able to provide a contribution of £3800...50% of the full cost of the item and a further £2850 was paid from out of our voluntary fund plus The Jennifer Trust assisted with a
further £1000. This was an exceptional award based on available funding at the time and there are many, many more requests that we are unable to meet.

We have Family Fund Advisers who visit families in their own homes to assess their needs and they could give 100s of examples of experiences from families as described in this CAF Report.

School When You Are on Wheels raises many important and very real everyday issues for young wheelchair users .....the strongest, all too real, and most powerful, are, as so often, those described by young people themselves....frequently now given the opportunity to experience mainstream education, but that experience is often limited by the lack of moving wheels.

Wheels can make or break their quality of experience and opportunity within education.

Ann Shercliffe  
Country Co-ordinator  
Wales  
The Family Fund

**Whizz-Kidz** is the national charity and leading provider of paediatric wheelchairs and customised mobility equipment, wheelchair skills training and advice outside the NHS. We transform the life chances of a disabled child by supporting their capacity to move around independently, and giving them the confidence and freedom to be themselves.

**Whizz-Kidz** is focused on addressing the unmet need among disabled children and young people for vital mobility equipment which they are not always able to access through the statutory services.

**Whizz-Kidz** provides services throughout England and Wales through a network of paediatric therapists. The charity runs two mobility centres in Birmingham and Newcastle, and works to identify opportunities to work in partnership with local health and education authorities wherever possible.

**Education and the Provision of Mobility Equipment**

The shortfall in provision of effective wheelchair services for disabled children and young people across the UK has been widely documented, over many years (McColl 1986; Audit Commission, 2000, 2002, Prime Minister’s Strategy Unit, 2005, HMT and DfES 2007).

The NSF for Children in Wales outlines ambitious targets for improving access to the quality mobility services and support that parents, children and young people need (5.17) yet many families still face undue delays for wheelchairs, vital adaptations and upgrades to mobility equipment as their child grows - or are simply unable to access the wheelchair they need in order to support their child’s participation in educational and social life.
• Mobility equipment which meets a child’s individual needs can transform their ability to participate in mainstream educational and recreational settings. The right wheelchair supports integration of disabled children with their peers, and the achievement of the Seven Core Aims for Children and Young People. Children are empowered to develop their skills and confidence to participate socially and economically in adulthood.
• Without the means to move around with independence children are more prone to rely on others, and may develop a pattern of behaviour known as ‘learned helplessness’, in which they become withdrawn and may fail to develop the critical faculties and confidence to achieve their potential in life.¹

Recommendations
All disabled young people deserve the right start in life through the early provision of appropriate mobility equipment without undue delay. Mobility equipment must be provided on the basis of a complete assessment of a child’s needs in all places they spend time (including recreational and educational settings) using a responsive, multi-agency approach to fulfil the individual and changing needs of a growing child.

Progress must be made against key minimum standards contained in the NSF in Wales by providing:
• a genuinely holistic assessment of need (2.8);
• joint working between health, social and education services to support participation in education (5.28);
• a school health plan to ‘identify the child’s needs and how they will be met in the school setting’ (5.29).

Whizz-Kidz would additionally endorse:
1. Increased collaboration across the wheelchair and education services and voluntary sector, building on examples of effective partnership working. Regular satellite clinics in schools would offer wheelchair skills training for staff, and provide an opportunity to conduct a review of a child’s mobility needs and the suitability of the school premises.

2. Increased involvement of young people in the design of services – for example through the establishment of a young persons user group to ensure that services are responsive to the needs of young wheelchair users in all aspects of their lives.

Stephanie Bell
Parliamentary Officer
Whizz-Kidz

¹ Professor David Hall (President, Royal College Paediatrics 2000-2003)