

February 2007

Contact a Family

## Consultation with parents of disabled children undertaken on behalf of the National Patient Safety Agency

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## The consultation

The consultation with parents of disabled children was aimed at gathering their experiences and views of safety issues for their children and young people receiving NHS care.

### Method

3 focus groups were arranged with parents:

- 1 was based at a tertiary care setting
- 1 was based in London
- 1 was based in Wales

Short articles in electronic news bulletins asked for any parents who would like to contribute to get in touch to give their views. 3 parents responded and were interviewed on the phone.

Two of the focus groups encountered practical problems which meant they were quite small.

In Wales a good number of parents were interested in taking part but were unable to travel to the focus group. Instead they were sent a questionnaire for completion.

In Wandsworth the focus group was scheduled for a day when heavy snow fell. Follow up telephone interviews were held to gather views from those who had been unable to attend.

This work was carried out by several members of Contact a Family staff and compiled by Liz Ranger, Parent Participation Manager.

Thank you to all those parents who took part.

### The parents who contributed

The following is a summary of the ages and disabilities of the children of the parents who contributed to the consultation.

Number of parents/carers taking part in focus groups: 20

Number of parents/carers interviewed by phone: 6

Number of parents/carers completing questionnaire: 19

### Ages of children

Age	<1	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18+
No.	1	3		1		2	1	3	2	3	1		6	5	1		2		8

Plus 4 children under 10 years

3 unknown

1 child died aged 11 years

2 parents had more than one disabled child

## **Disabilities of the children**

Parents gave varying amounts of detail regarding the nature of their child's condition. Many of the children had combinations of diagnoses.

- ADHD
- Autistic Spectrum Disorders / Asperger syndrome
- Bladder Exstrophy and Epispadias
- Brittle Bones disease, Epidermal Naevus syndrome, profound learning disabilities
- Cerebral Palsy, epilepsy, motor, hearing and vision impairment
- Cerebrocostomandibular syndrome
- Cleft lip and palate with cardiac and feeding problems
- Cleft palate with hearing/speech difficulties
- Celiac disease
- Complex health problems caused by chemotherapy
- Costello syndrome
- Dandy Walker syndrome with cardiac problems
- Down syndrome
- Down syndrome, deafblind, asthma
- Down syndrome, Hirschsprung disease, aortic aneurism
- Dyspraxia and ASD
- Epilepsy
- Gastrostomy
- Heart defect
- Learning difficulties and complex health needs
- Learning disabilities, epilepsy and challenging behaviour
- Lung and bowel problems caused by prematurity
- Meningitis
- Oxygen dependent with gastrostomy
- Perisylvian syndrome
- Profound disability (blind, tube fed, wheelchair user)
- Progressive neurological condition
- Psoriasis
- Spina Bifida and Hydrocephalus
- Sturge-Weber syndrome with complex health needs
- Tourette syndrome, ADHD, Asperger syndrome and challenging behaviour

## 1. Listening to parents

For a large number of the parents who responded to this consultation, being listened to by health professionals was an important issue. They referred to a range of health professionals who, on occasion, failed to listen: GP's, hospital doctors of all levels and nurses. Parents of disabled children have usually been living with the condition for close to the life of their child and are often expert in how their child is affected and what their child needs. Several of the parents who took part have children with rare disorders, or undiagnosed syndromes. These children have particular needs which many doctors will be unaware of. The needs of these children are different from a non-disabled child.

The specific dangers their children faced as a result of not being listened to varied, but all resulted from health professionals failing to recognise that the parent knows more about the health of their child because they live with it all the time. Examples include:

A doctor not listening to a parent's concerns when their son had Bacterial Infective Endocarditis. It was not diagnosed for over a week and was then much more established.

A parent still has to lift her son from bed to chair to shower/bath even though they have a specially built accessible extension. The extension was built too small despite the parents outlining the potential problems before it was built. This means lifting equipment will not fit in. There are resulting health problems and dangers for parent and disabled young person.

A child who has had repeated surgery. His parents know that on coming round from the anaesthetic he will try and rip the needle out of his arm. They have asked staff to make sure it is well covered so he can't hurt himself but the staff do not listen.

A parent whose daughter had breathing problems for the first two years of her life. The mother told various doctors but none listened to her. When they did diagnose her daughter's condition the child had already sustained brain damage.

Parents who know that their daughter must receive medication for epilepsy within 30 minutes of the time it becomes due. Staff do not understand this, do not want to listen and do not respond when the parents tell them. This leads to increased convulsions, adversely affecting the daughter's health and in response the parents say they must stay with her 24/7.

There were numerous responses from parents on this subject and many were very strongly worded. The following is just a sample.

*'There is a high percentage of doctors who don't listen and we are the experts about our child. She doesn't follow the book. I never leave her. Perhaps I should have more trust but I don't feel I can because of the past.'*

*'Doctors etc must respect the parents/carers as experts in their child and to be more supportive of them.'*

*'LISTEN TO MUM – she knows her child best.'*

*'Consultants (some) should climb down off their high horses, act like a human being and not God, respect parents and listen to them.'*

*'Nobody listens to me until I start becoming more aggressive. This is not part of my culture: I was brought up to respect people.'*

*'Parents/carers know their children best. Please listen to us. Don't assume we are all paranoid parents. These children fall into the most vulnerable group. They cannot speak for themselves. Please listen to us!'*

## **2. Understanding of children with challenging behaviour / behavioural phenotypes**

Parents of children with Autistic Spectrum Disorders (ASD) and other conditions which affect a child's behaviour (e.g. Down syndrome and other learning disabilities) raised particular issues which put their children in danger. They felt that generally there was a low level of awareness amongst staff of the difficulties children with behavioural conditions might have. A lot of children find waiting to be seen by a health professional very difficult. There are also a number of other behavioural triggers which their children might react to and this could easily put them in danger:

- Children unable to wait
- Children who do not like physical contact
- Fear of strangers and unfamiliar situations
- Children who feel uncomfortable with eye contact

By not making allowances for children with ASD/behavioural conditions they are far more likely to become so anxious they run off, thereby putting themselves at risk, particularly if they also have a low understanding of danger. For one parent, inflexible care for her daughter with ASD increases her daughter's anxiety to such an extent that she is also likely to self harm.

*'It's a problem if she starts running – I can't keep up with her.'*

*'We phoned to make an appointment and explain that autism meant our child would be stressed by waiting. We arrived at the appointed time to then be kept waiting for 30 minutes by which time the child was so stressed the GP could not examine him. He has never seen a GP since.'*

*'I absolutely dread the thought of my son ever needing in-patient care, as he requires 24/7 supervision, mostly due to his risk taking behaviour.'*

Parents made suggestions for limiting this risk to the child:

- Flexibility of appointments and the routines for appointments: a fast track or other ways to reduce waiting times
- Listening to the parents and children about what would make them most comfortable
- Use appropriate language when talking to the child – clear and direct
- Not forcing eye contact with the child

- Explain to the child if you need to touch them. Tell them what you need to do
- Assess the state of the child before asking whether medical students can come in to an appointment
- Provide pictures of the rooms where the appointments will happen and pictures of the staff who the child will meet. These need to be available before the appointment so parents have a chance to talk about what will happen with the child and prepare them. A level of familiarity will help to reduce the child's anxiety, reduce the chance that they will run off and also reduce the chances of them disrupting the clinic/service or requiring a repeat appointment at a later time

*'I think that children with ASD should be seen on time. I think that it is imperative that people understand their inability to sit still in one place safely.'*

*'It always comes down to seeing the world in a different way. For some people with autism the hospital may be too bright, too loud, things go too fast, restraint too tight. Understand these difficulties and you can start to understand the apparently meaningless behaviour and ballistic tantrums that often result from sensory overload.'*

*'From front line to specialist staff I would like to see the child's 'special' needs being recognised and acted on professionally and sensitively. If a child cannot 'wait' then ensure s/he is seen at the appointed time. If a child has sensory issues and struggles to move from one room/environment to another, then see the child in one place only. Tell exactly what the procedure entails so that the parent can make an informed decision as to whether to inflict it on their child.'*

*'Over the last eight years we have had a few awful episodes with the 'caring' professions. However we have also had some 'quality' service by those professionals who have understood, appreciated and altered their way of working to do the best for our child...It is when we meet these professionals that we realise that our child can get a quality service.'*

### **3. Training for staff**

A significant number of parents reported occasions when staff member's lack of awareness about disability had put their child at risk. This included children being on wards where no-one had the necessary communication skills to speak to a child with a disability. Parents cannot always be there: they may have to go and care for their other children, and staff members need to be able to communicate with disabled children directly.

*'They would not have been able to look after him unless I was there to explain everything.'*

*'I couldn't even leave him [in hospital] to get a cup of tea.'*

A child being assessed for a wheelchair without the parent there. The staff did not recognise that an electric wheelchair would be inappropriate for a child with learning disabilities.

A child with learning disabilities who looks different and consequently the nursing staff did not listen when the parent told them she was drowsy and unresponsive. This lasted for over five hours until the new nursing shift started. The new nurses listened and the child was on HDU within half an hour and medical treatment sought.

*'My child was using a central line at home. No community paediatric nurses were available. The adult nurses were frightened of his disability and not experienced at using the central line.'*

*'The nurses were scared of us.'*

*'When he had breathing difficulties I took him to A&E. The staff didn't know what to do with a young child with a learning disability who was terrified of the oxygen mask. The best they could do was to wave a tube around near his face.'*

The parent of a child with profound disabilities talked about the frustration of the rotation of ward staff. On occasions when the nurses assigned to her son were really responsive, had become familiar with the care he needs and she felt confident enough to leave him and go home for a time, the nurses would then be reallocated to another patient and she would have to start again with new nurses who knew nothing about her son.

*'I can understand that they don't want favouritism on the wards, but surely when a patient is without speech and with profound needs, it makes sense for the same nurses to care for them each time wherever possible? With special needs children, so much of looking after them is knowing what is normal for them and it puts a lot of pressure on the parents to be there to interpret for them the whole time.'*

Parents, of disabled children, and particularly those with children with rare disorders, found that some doctors saw the condition first and foremost and sometimes this meant they failed to see the child at all. One parent explained how a new GP had told her *'I know as much about jet engines as I do about your child's condition.'* The parent felt that he was failing to see her child who was ill and needed care. Generally parents felt that the existing medical condition can overshadow everything else, parents concerns can be ignored and sometimes a crisis has to develop before a doctor takes notice.

There were also examples given which did not put the child in danger but where professionals having a greater awareness about disability would improve the care that the child received e.g. children who can't read needing eye tests, children who need their parents to be with them to reassure them during examinations, treatments. Disabled children may need their parents to be with them when a non-disabled child of that age may be happy on their own.

#### 4. Medication mistakes / not reading notes

Some parents talked about incidents caused by professionals not reading the information about the child available to them in the child's notes. Examples of problems that this had caused include the following:

By not listening to a parent and not following the information in a child's notes doctors had caused broken bones to a child with Brittle Bone disease. This could have been avoided if they had read her notes because they would have known how to move her.

A family arrived at hospital for an operation and were told their daughter had been put to the back of the list because she had MRSA. The parents knew this was not so because they had only just arrived. When they questioned them they found the notes they were reading had been transferred from another patient.

A few parents talked about the difficulties of changes in branding of drugs, particularly important in anticonvulsant medication. They reported that it was very difficult to get their child's needs for a particular brand recognised in both hospital and community settings. One parent talked about PCT Directives which meant pharmacists were unable to dispense the correct type, and a repeat prescription with a variety of makes within it which had caused particular problems for her daughter. This problem was a specific danger for a number of the children.

Parents mentioned situations where medication amounts had been altered but major mistakes had been made and it was only the parent checking which prevented the child being given the wrong amount. In one case this was double the amount it should have been and this was not the first time this had happened. One parent thought that mistakes were much more likely to happen when the night staff, which tends to be from agencies, came on shift.

One parent gave an example of a child having seizures on holiday. Following an EEG medication was increased. The family were told to see the specialist nurse before resuming their holiday, but could not get a response. They got in touch with the paediatrician who authorised the dosage be increased further. The child became very ill again and a family friend who was a doctor arranged hospital admission. Tests revealed the child was overdosed on Epilim

A parent had sought the advice of a pharmacist as to whether she could give an over the counter cough medicine to her daughter who has epilepsy. She was told she could, but on double checking later found that it would be unsafe for her daughter to take it.

*'As it was my first child I believed everything that the health professionals told me, when things started to go wrong I learnt that I had to question everything and insist that information was checked.'*

*'Bristol Children's Hospital was excellent. One of the main things was that they never administered medication until it had been checked by two nurses.'*

Another example of good practice was also from Bristol Children's Hospital. The mother of a child with a tracheostomy reported how a simple step by step guide to looking after a child with a tracheostomy was hung next to her child's bed so all staff could use it.



## **5. Discrimination due to disability**

There were examples of children not receiving care and the parents feeling that this was because of their disability. This put the child at risk and required a great deal of perseverance on the part of the parent to secure treatment for their child.

A child needed urgent hospital treatment for a detached retina. Despite the parents phoning every day and obtaining an emergency appointment, nothing was done. The parent had to threaten the consultant before something was done but it was too late and the child is now blind.

A child with learning disabilities and who can be hyperactive fell and hurt his arm. His parent knew he had hurt it because he was not moving it. When they went to casualty the triage nurse said he was just doing it to get attention. The parent had to explain that he had abnormal responses to pain. The family had to wait a long time, causing chaos in the waiting room. When the child was finally examined it was discovered he had a dislocated shoulder.

*'Discrimination against children with complex disabilities is a major problem.'*

*'Treat children with complex disabilities in the same way other children are treated. This discrimination must stop.'*

## **6. Communication between professionals**

Some parents gave examples of instances when a lack of communication between professionals had put their child at risk:

Children being discharged from hospital and the therapists in the community receiving no information about the care needs of the child.

A family referred to a tertiary centre for a neurosurgical opinion on brain surgery. They arrived at the hospital but no-one knew they were coming and had no information about the child.

A lady who has had more than one premature baby. The GP was not informed after any of the births.

A consultant who had difficulty reading the notes made by another consultant.

Professionals being unwilling to record incidents in a child's notes. The parent had to insist. For one parent whom this had happened to, the registrar was repeatedly denying a child was losing blood through his catheter. The parent made sure his named nurse recorded the blood loss that was visible in the drainage bag. Only then would the registrar stop denying the child's loss of blood.

An HDU nurse who did not believe the medication dose was correct despite numerous notes from the consultant. This led to a delay in giving the child medication and the subsequent need for additional medication.

## 7. The role of the parent

It was generally accepted that the majority of parents want to take an active part in the care of their child, but, it was pointed out that there are issues which need to be addressed:

Parents felt that they are often called upon to undertake medical duties, such as administering drugs, which would normally be undertaken by trained medical personnel. It was agreed that more training for parents should be provided.

Some parents also felt that they were often expected to be nurses, behavioural analysts, physiotherapists, speech and language therapists as well as parents and carers.

A particular issue in hospitals was that parents who are staying in hospital with their child are frequently left alone with the child and are not offered a break to visit the toilet or to go and get a drink or something to eat. It is often assumed that this parent is 'fine', but nobody checks. One parent told how in desperation she finally slipped out to the toilet, returning to find that her child was having a fit.

Parents also felt that where a lack of services (such as short breaks) puts them under strain and this could put their children in danger. A tired parent is far more likely to make a mistake or have an accident. Parents agreed that in many cases, things had to reach breaking point before anything was done.

A particular issue raised was how parents' health can be endangered by the fact that they are caring for children under circumstances which no professional would be expected to work. The examples used here were that of parents lifting children and also of parents whose children need a carer round the clock. If services will not provide a carer or if a carer fails to turn up for a night shift, the parents need to stay awake all night and perform medical duties and do the same the following day.

*'Actually the times that [my son] was probably most at risk was at night, when I was caring for him. I had about 4 years of unbelievable sleep deprivation when he woke frequently all night, needing care. For much of that time I slept on a mattress on his bedroom floor because it was not worth going back to my own bed. I kept a record of all his wakings and would present it to the Health Authority, but it took years for this to be taken seriously. I can recall getting really angry with [my son] in the middle of one night, also utterly despondent and too tired to get up when I registered he needed me again. It was like a form of torture, every night different from the one before, and often he needed my attention for extended periods... Health argued that [my son] didn't generally need medical assistance at night and Social Services said there was no point in installing a carer who would need to wake me for meds. Finally when [my son] started unpredictably going blue at his extremities, they decided we could have a nurse at night starting with one night a week. Slowly over the next years we got it up to 7 nights a week. My suggestion is that the strain to a parent of caring for a child with sleep problems should be better recognised. It is totally different from the daytime, when you don't have to weigh up your own needs against your child's in the same way. In my son's case the sleep problems were caused by reflux,*

*epilepsy, secretions, etc. It was a terrifying responsibility and I felt he was frequently at risk because I was just too exhausted.'*

## **8. Treatment and care**

Some of the parents raised examples where the treatment or care given, or not given, had put their child in danger. Examples included:

A home-ventilated patient developed a blocked tracheostomy which required emergency intervention. An alert had been issued to the hospital about the particular 'wet' ventilator-circuit the patient was using, but the knowledge that this had been withdrawn had not reached the community paediatric team.

A consultant who wanted to sign a consent form for a procedure without full checks for the condition having taken place.

After having a major operation a six year old began to scream hysterically. He told his parent his abdomen was swelling up. His back up line had fallen out so no-one could see if he was draining any urine out. When the parent informed the Clinical Nurse Specialist she said it was psychological. The child became more distressed and was standing up on the bed screaming. The parent called for a doctor but got no response. She then had to get the family care team involved who made the Clinical Nurse call the doctor. The Clinical Nurse was told that he needed to be drained as his bladder was filling up and there was no-where for it to go. If the parent had not insisted, the child's bladder could have ruptured and his kidneys could have been damaged.

A parent staying with a child woke up in the night and discovered the child covered in blood from her central line.

A lack of cots: children put in beds which were too big, didn't have side bars etc and which the child could have fallen out of.

Doctors who were not interested in treating the child as a whole, just one aspect. For one child this meant it took three weeks to discover she had a punctured lung.

*'Doctors do not use the correct technique to give anaesthetic into portacath (smaller syringe than 10ml which therefore gives too high pressure), no hand washing, gloves or aseptic technique, drugs not drawn up with filter which is advised to prevent microscopic particles of glass being drawn up. Basically dirty technique for any intravenous access never mind for central line. Medical staff do not seem to appreciate that proper technique for portacath use is necessary for a reason – nurses are much better at this but not many are trained in the use of portacath.'*

*'My son's exploratory bowel procedure went ahead even though he had been unwell with diarrhoea the previous week. It went ahead due to the pressure of theatre slots. He came out of theatre without fluids despite having a portacath. Soon after coming home he became unwell and starting fitting (this had never happened before) and became rigid. I tried to contact his consultant and then HDU. I was told to take him to A&E so had to take my 11-year old and all his equipment in my car. When we arrived they could see how distressed I was and how poorly he was. We were seen by many people and lots of phone calls were made with the argument of 'where' to send him and 'not too poorly for ITU'. He was barely conscious and fitting; nearly two hours after arriving*

*we went to ITU where they finally started fluids around 4am. He died in my arms at 5.20am. He shouldn't have died of dehydration.'*

Parents raised issues relating to the care of their child which did, or could have, put their child at risk. Some of these relate to procedures which are unwieldy; some of these relate to shortage of staff.

**Problems accessing the most appropriate hospital or ward:** Many disabled children are in and out of hospital frequently. Often they need very quick or specific treatment. A number of parents talked about issues of getting the right treatment at the right time being particularly difficult when a child has a rare or unusual condition or does not have a diagnosis.

These problems could be increased by:

- being taken to a hospital where the child is not known and which does not have the notes
- admission policies being changed to include an assessment even if the consultant had already made a decision to admit

*'All ventilated children used to go straight to the ward where they were well known by staff. A new policy meant we had to go to A&E first for assessment. It seemed such a waste of time when the decision to admit him had already been made by his palliative care consultant.'*

*'Going to our usual hospital feels like wearing slippers. Having to go to another hospital feels like wearing slippers on the wrong feet. [At the new hospital] staff hadn't responded to our daughter even when they could see she was upset: they didn't know her and she didn't know them.'*

**Transport to hospital:** Several parents were able to cite anecdotal evidence about waiting times for ambulances and felt that this was a major cause for concern. Some felt that their child's visits to hospital and thus their child's health were put at risk by transport difficulties to and from hospital. Several parents stated that their children were unable to use public transport and so travel by taxi (which is expensive).

Another parent whose child has a complex condition questioned whether an ambulance team would know how to deal with her child's medical condition.

**Staff shortages:** Several parents raised the issue of shortages of staff, particularly on wards. Most felt unable to leave their child for fear of what would happen.

*'They are always overstretched, particularly at night. On that occasion I had been meaning to go home to bed after briefing the night staff, but was told that the nurse on duty would only have time to check on him every hour. He was being sick every 10 minutes or so - how could I possibly leave him?'*

An example is a child who had had surgery to his hips, bladder and pelvis and was suspended from a gallows traction. His bed was next to the nurses' station so that they could keep a close eye on him. When the parent entered the ward one morning the child had twisted his legs around the traction and was screaming. He was lying in his own excrement. The ward sister was sitting at the nurses' station doing paperwork. When the parent confronted her

she said she was busy. The parent did not leave the child's side after this incident.

Another parent talked of the length of time that procedures take on the ward and how this meant that her son would be too late with his medication and would not get it at the same time as his feeds. This has a severely detrimental effect on his fits. The parent ended up drawing up his medication herself.

*'I couldn't blame the nursing staff for the lack of attention – there just weren't enough of them.'*

**Problems accessing medication:** Some parents highlighted that they had experienced problems obtaining medication. Sometimes the problems had occurred because they had needed medication on a Friday afternoon or over the weekend. Sometimes they were concerned that there needed to be a backup supply if problems occurred with their normal supply, e.g. pharmacist ordering a repeat prescription but being sent the wrong drugs by their suppliers: family unsure where they could go to get the right drugs in an emergency.

*'On the Thursday before Easter bank holiday weekend I was informed by the pharmacist that they could not fulfil his prescription until the following Tuesday. They had been given the prescription on the Monday. It took a lot of phone calls to sort out enough medication to last the weekend.'*

**Hand washing:** Parents felt that disabled children are so vulnerable and doctors not washing their hands before examining their children was a risk which unnecessarily put their children at risk.

*'Doctors don't wash their hands before they handle my daughter. Whatever the issue vulnerable children always get an infection in hospital. Parents as well – everyone needs to be washing hands. Consultants are the worst: they have their group with them and they walk from one child to the next. I hold off taking her into hospital for as long as I can.'*

## 9. Other issues raised by parents

**Information:** Several parents they felt they had lacked information about their child's condition, sources of support, and the treatments which their child would be having. Some wanted to have more time to talk to the professionals dealing with their child, and to be able to ask questions. This had caused them anxiety and they felt unequipped to look after their child.

*'When my child was born, I was led to believe he was the only one in the whole world with this condition. If it wasn't for my own researching methods, I would not have known about the support group that exists.'*

**Lack of therapy:** Parents talked about the unavailability of therapies that their children needed. For some this leads to deterioration in their condition and sometimes to further time in hospital.

One parent described how she had to fight for physiotherapy every time her daughter goes into hospital. If she does not have it she will not be able to get out of bed and this will lead to decreased mobility and digestive/bowel problems. This has been compounded by wards where there is nowhere to store her daughter's wheelchair so that she has to be nursed on the bed

further reducing her movement and mobility. There is also usually a lack of OT so that her daughter is then unable to feed herself because she does not have the right equipment.

**Family support:** several of the families raised the point that having a disabled child who requires ongoing treatment and may be in hospital for some time places a huge strain on the family unit as a whole. They talked about the exhaustion this led to and the problems they had had being able to care for their other children.

*'Nobody cared about how our family unit was surviving.'*

**Communication with disabled children and young people:** some parents felt that there was a lack of basic disability awareness amongst staff.

*'Training in how to treat people, particularly disabled children. They are individuals in their own right and deserve respect.'*

**Intimate examinations:** several parents mentioned that they thought intimate examinations and treatment for their children had been carried out inappropriately, without due regard for their children. Most examples were of girls being examined by male doctors or unnecessarily large groups of male doctors. Neither parents or children/young people were asked how the examination should happen or whether they were happy to have extra people in the room. Some felt that the presence of a female member staff would have helped. One parent talked of her daughter receiving no privacy while being treated: staff continued to walk in and out of the room.

*'Although this may not be exactly answering your questions I do feel it is relevant to the welfare of my child...In my opinion the procedure was extremely intrusive with a lot of male staff and doctors in the room observing. Although the procedure itself was very uncomfortable it was secondary to the fact that it was all so extremely undignifying to both my daughter and me. There should only be female staff present where girls are asked to get undressed and reveal themselves. I shall never forget that experience.'*

## **10. Young adults and transition to adult services**

As disabled children grow up there are particular issues relating to young people transferring to adult services.

Again parents felt there was a lack of awareness amongst staff relating to young disabled people, particularly those with learning disabilities. They felt that often the young person was ignored and staff failed to talk to them. As well as this they felt staff needed to continue to talk to the parents who are still experts in the needs of their children. They felt that often staff did one or the other when actually they needed to maintain good communication with both. Some disabled young people will never be able to explain their own needs.

*'For consultants in adult services not to be so puffed up and full of importance, and listen to the young adult's parents...'*

*'We have tried many things to try to make things better but it usually falls to us to be with her 24/7 to ensure she is not put in danger. Now she is seen as an adult it is even worse as they do not want to speak to us and we have even been told to wait outside while they deal with her even though she is not able to communicate her need to someone who does not know her.'*

*'In hospital parents and carers must be seen as essential parts of the whole package of care for the child/young person and must be accommodated and this should be seen as even more essential when the person turns 18 but still has the same needs as they did as a baby.'*

*'It's not that [daughter] can't understand – just that she can't communicate.'*

## **Summary**

The parents who took part in this consultation have children with a wide variety of different conditions and crossing a wide age range. However, the points they raised were remarkably similar.

Almost all the parents talked about the need for professionals to listen to parents of disabled children. Their experience of caring for their child is substantially different from that of a parent of a non-disabled child who unexpectedly needs health care for a condition which the parent knows nothing about. Parents of disabled children have an expertise in the health needs of their child built up from living with the condition constantly and having seen their child go through hospital admissions, surgery, treatment, medication changes and life's ups and downs. This expertise needs to be recognised. It is an invaluable resource which doctors can use to treat disabled children and young people better, more effectively and with fewer risks to their wellbeing.

Almost all parents also talked about the need for a greater level of disability awareness amongst professionals. By not understanding particular needs of disabled children they are being put in unnecessarily risky situations. Small changes and increased flexibility in procedures can make the difference between an appointment for a child with challenging behaviour being useful, or it being wasted and the child being put at risk in an unfamiliar environment. Likewise, more flexibility on wards could mean that nurses are better able to interpret the needs of disabled children with no speech thereby decreasing the likelihood of the child's needs being missed and a crisis occurring.

Parents felt strongly about the issues they have raised and some of their comments were strongly worded. They also had comments on excellent care which their children had received and which they appreciated greatly.

Some also gave examples of particular practice in health care which had improved the service their child received and decreased the risks which they have identified. They also made practical suggestions for how risks to disabled children could be reduced.

## Examples of good practice

Through the course of the consultation parents have raised examples of good practice which they felt demonstrated how services should be looking to minimise risk to disabled children and young people.

**Bristol Children's Hospital** was cited by several of the parents as a model of best practice.

*'My son was in Bristol Children's Hospital for a long time. Health care should be modelled on this centre. Safety procedures – EXCELLENT. Team work – EXCELLENT. Health care – BETTER.'*

*'Training students to FIRST listen to mum. They actually do this in Bristol.'*

**PALS:** One parent highlighted that the PALS service has been really useful to her and her family and have helped in situations where she has been unhappy with specific aspects of the hospital care. However, she find that when she talks to other parents of children in the hospital they are generally unaware of the PALS service and what it could do for them.

**Direct access to children's wards** available at some hospitals saving time and making the experience easier and less unsettling for children.

**Patient held records with emergency protocols** signed up to by the consultants have helped for some children and young people, particularly when they have very unusual care or treatment needs. However, some parents still find that A&E doctors still want to follow their own protocols which may not meet the very specific needs of a particular child.

**A 'Home Call Out' scheme** in Cardiff which prioritises GP visit for particular children.

**A dentist** who had spent a long time building up a disabled young man's confidence to the point that he allowed her to do a filling.

**A GP** who was prepared to come out to the car park to examine a disabled young man in the car to avoid the young man having to try and sit in a crowded waiting area where other patients found it hard to understand his bizarre noises and movements.

## Suggestions from parents

Parents had some specific suggestions for changes which they would like to see to increase safety for their children.

- Listen to parents: parents spend more time with their children than health professionals and can pick up on early warning signs when their child is in pain, or something is not right. If a parent is concerned – listen to them. If a parent says that their child is not behaving in a typical fashion – listen to them, just because they have a disability, they can still be acting unusual for them.
- Keep track of a child's notes, especially when more than one hospital or care setting is involved.
- Every family should be asked what support they need while their child is in hospital or receiving continuing care. All families should be entitled to the same – it should not matter where a family lives.



- Improve the planning when a child goes home from hospital especially if there are complex health needs.
- One lead professional or keyworker for the families to contact. Independent advocates should be available for families that need it – especially for families where there may be other barriers to communication such as language.
- Multi-agency meetings with all the health professionals involved so that they can share information with each other. It should be seamless between hospitals, across geographical boundaries and between children and adult services.
- Children's nurses for each local area in the community.
- Nurse specialists in disability.
- Children's nurses who can speak the child's language, use sign etc.
- Flexibility in rotation of staff to allow for staff to make use of their additional training and if they have become familiar with the particular needs of a disabled child, particularly for those with no speech.
- Mental health and learning disability trained staff in acute settings.
- Support parents who want to speak up on behalf of their child.
- Explain conditions, treatments etc so that parents can understand. Don't use jargon.
- If the health professionals do not know what has gone wrong be open and honest with parents.

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 Contact a Family  
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