

## **What do Human Rights mean for disabled children in the UK?**

When Contact a Family were asked if they would assist in finding parents to give their perspective at the conference we discussed how best to do this. We had to take into account the time we had to speak, how parents would feel about telling their stories in public and how to best inform the delegates about the range of problems parents face.

We decided that we would invite parents to tell us their stories. However we would have other parents tell those stories and we would not identify the children or the region in which they live. We made that decision as some of the parents we have spoken to in the past are concerned that any comments they make could have consequences if they were made public. We also knew that due to time limitations we would not be able to read out all the stories. We decided that we would however write these up so that delegates would have a copy of the stories.

We are not in a position to evidence these stories. We have no reason to believe they are anything other than true reflections on the parents' perspectives.

We wish to thank all those families who found the courage and time to share these with us.

## Parents stories for Human Rights of Disabled Child Conference

### Claire's Story

My daughter M is 10 years old. She was born with Down's Syndrome and consequently has learning disabilities and severe communication problems. Last year we received a dual diagnosis in that M is also on the autistic spectrum.

For the past two years I have been trying to get M to be seen by a clinical/behavioural psychologist yet this is being denied to her in our area.

I live in Northern Ireland. I have been in touch with MLA's and the Northern Ireland Commissioner for Children and Young People.

The reason I began this crusade is due to the fact two years ago Megan began to display severe self injurious behaviour in fact she pulled all her hair out. Her behaviour became what is described as "challenging" to say the least. . Because it was really difficult to find out why she was engaging in this extreme behaviour we wanted some outside help but there is no behaviour or psychology services for children under 12 in our area.

I was then advised to try Child and Adolscent Mental Health Service but was told she could not access this service because of her learning disability – there was a separate service for learning disability (the one that doesn't take them until they are 12!!). So reading between the lines if she had no disability she would have accessed this service! To me this stinks of a breach of human rights and discrimination.

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### Toni's Story

When Helen was about 3 and had only just learned to walk we were in the local play park. A parent came up to me and said Helen should not be allowed to play along with other children in the park. I was so taken aback I didn't know what to say. I hope things have moved on since then. Hopefully people are more informed about Downs syndrome now.

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### Dawn's story

I read your article re the above with interest as I have a 16 year old son with Down's Syndrome who has an avid interest in Bodybuilding, Gym and Wrestling.

As a 1<sup>st</sup> year student in Foundation Award working towards my degree as a Humanistic Counsellor, I am interested in promoting Equal Opportunity for Disabled members of the community and their Human Rights.

Whilst I do not have a specific story to help you, I have however noticed on several occasions the lack of understanding of a disabled child's needs.

I have found that when taking out a membership of a Gym for my Son the personnel involved with the running and instruction of equipment had a lack of the following:

How to communicate with someone who has a speech difficulty; (although my Son is very articulate, this does raise issues in understanding someone talking for the other person listening). Further, adapting training in the case of a disabled persons physical endurance and ability.

I feel that when someone takes up training for instance to be an 'instructor' of any kind, that deals with and necessitates communication, that person needs to be trained in how to communicate, not just for the abled person, but for all persons who are challenged in some way. I feel enough is not done to bring awareness of the difficulties these people experience, physically; intellectually and emotionally.

Whilst we are all aware of disabled persons, not enough is done to bring them into the 'reality' of non-disabled persons in terms of guidance for and meeting an individual's needs. Training should be 'across the board' in terms of any career which entails 'working' in the community. If disabled persons are to exercise their Human Rights and have access to Equal Opportunity, then further enhanced awareness for inclusion needs to be stringently explored in terms of training those able bodied members of society who at times have a responsibility to those who are not able bodied.

My ideas are that different forms of communication need to be learnt; More awareness needs to be taught in schools, colleges and universities in relation to diversity and the effects and impact this has on abled and disabled persons; training needs to be geared towards understanding abled AND disabled persons.

I am sure that there are many more issues that could be addressed in relation to the above, but this is my own personal experience and perspective when trying to include my Son in activities he enjoys, but because of the above reasons, I find myself worrying about the person on the other end understanding his needs!

I hope that I have not ramble on and that I have in some way made myself coherent in viewing my feelings and thank you for the opportunity to express my thoughts.

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### **Sam's story**

In May 2008 my son had an appointment with a community paediatrician .My son did not communicate with him as he has multiple disorders etc and has spent years being assessed etc

To cut a long story short we relayed a comment to the doctor that my son had said, and he perceived this as racist and lodged a complaint .My son said he did not like the doctor and wanted a white doctor .

To cut a long story short a risk assessment was done on my son, he was placed on the patient risk register all this was done without our knowledge or a chance to put our version of events across .

Before the doctor complained about us we put a complaint in about various concerns we had about him

Eventually we discovered that there was no working appeals system and they had placed my son on the wrong register .After 10 months he was removed only because of their error of using the wrong policy against my son .

For a period of five months my son was denied medical treatment and this was denied by

the trust .I have the proof in the form of a letter sent by the Paediatrician informing someone my son was suspended from access to services .

Almost two years on and we still do not have an apology and Sefton have yet to prove to me that they have tackled the issue of discrimination against people with disabilities .My case has been handed back to them by the government ombudsman which I find unfair .

My son was accused and found guilty of an act without any chance to defend himself and he was denied medical treatment which is against the law .I told the chief executive that he violated not only my sons human rights but his disabled rights . His response was that they had not.

### **Lynne's story**

Our 11 year old daughter has Angelman Syndrome. For those of you who have not heard of this, it presents itself as follows: Global Learning Delays; Epilepsy; Pronounced gait; Underdeveloped gross and fine motor skills; No speech and Doubly incontinent. It can also include curvature of the spine, several digestive problems, and a suspected link with Autism, amongst other things.

Because of her learning delays, she has the mental capacity of a toddler, and therefore it is extremely difficult to explain things to her.

We have asked her consultant if he would consider putting her forward for a hysterectomy, on the grounds that, apart from the fact that she will never have children, we do not want her to suffer monthly severe abdominal pains because of her periods unnecessarily, at the same time not being able to explain why she is in such pain. He agreed to look into it, and was sympathetic to my wishes.

However, the gynaecology department refused to take any further actions, due to the fact that it impeded the rights of the individual as she is unable to make the decision to go ahead with the operation herself.

### **How did that make you feel?**

We feel very let down, as we are acting in her best interests. We have nothing to gain from this procedure, apart from the fact that our daughter will be more comfortable every month. If there was a less intrusive alternative, without putting her on more drugs, we would jump at the chance. But we don't see how giving her medication that she has not given permission to have is any less invasive of her rights than having a surgical procedure, although we of course accept that there are potentially more risks involved.

Surely, if she is unable to make a decision for herself, she needs an advocate to act on her behalf, and who better than a parent, backed up by the child's consultant.

Yes, we accept that the rights of the individual matter. However, the backing of our consultant should surely have held some sway over the decision making process. We believe this to be a very blinkered attitude by the NHS and the law-makers.

### **What could have been done to prevent this or resolve it?**

A change in legislation is called for, to take each case on its own merits. If necessary, take it to a panel for them to decide; but at least do not make it a blanket ban on something that could markedly improve a person's quality of life.

### **Elizabeth's story**

I am a mother of a 10 year old boy with autism and learning difficulties. Apart from that, he has been diagnosed with a threatening and complicated heart problem which is difficult to correct. I have been studying for the past five years under very difficult circumstances because there was no one to take care of my child when I needed time to study. Children services in my area gave me a list of child minders to call. I called more than ten child minders and gave up because, the moment I mention that my son is autistic and has a heart problem, the child minder would tell me that she/he will come back to me. And that was the end of it.

Though I successfully achieved a Masters degree, I am unable to work because the jobs which I am being offered need someone flexible which I cannot do because my son has no one to look after when he is dropped from school. He has been attending an after school club but we had problems with the club because they told us that he needs one-to-one care. They consulted SENCO but their request was rejected. I felt my son was not receiving good treatment as he would come home unhappy and hungry and pulled him out. Surely, many mothers of disabled children want to work, but because there are no child minders nor clubs with inclusive facilities out there willing to take risks of child minding children with complex needs, they cannot. What makes it more difficult for me is that, I don't have my family here in UK since I am from ethnic minority. Is there anything that can be done to help mothers like myself get into full employment with confidence that their children are well taken care of. I wish his school could provide after school club from 3.30 to 6pm on a daily basis because I trust the staff and he loves his school.

### **Nina's story**

T, my 14 year old daughter has a neuronal migration disorder and temporal lobe epilepsy. She had been changed to a new anti epileptic medication as she was having side effects from the previous prescription. Once she had been on the medication for 3 weeks she had a total personality transformation and she became physically violent which resulted in a 3 week stay in the local hospital. As part of her transition into the home she was needing to be collected and taken to school (special needs school) on Monday and Thursday morning (she boards Mon, Tues and Thurs). When I contacted the home to school transport co-ordinator they refused to agree to her being collected from the hospital as it was not their 'policy'. Their policy was to collect from home. I explained that it was an essential part of her recovery program that she be re-integrated to the family and school slowly and that if the taxi didn't collect her I would need to go and collect her from hospital at 6am to get her dressed and home to be collected from home at 7.30am, and that this was not in her best interests to be up so early and having her routine disrupted. I also explained that this would cause distress to T and her siblings as T was still associating her home with the problems. They just continued to quote 'its not in their policy' then added that it 'wouldn't be very nice for the taxi driver' (who knows Teejan and has been transporting her to school for the last 12 months). Overall her human rights were breached for a policy which didn't apply, the council only has a policy for children with SEN being transported to MAINSTREAM schools, not SEN schools.

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### **Shona's story**

On 31<sup>st</sup> July 2008, our son M- who has Rubinstein Taybi Syndrome, ASD and severe communication difficulties (he is non verbal - and communicates by a mix of PECS and very few Makaton signs) was with a Council run Summer Play scheme on a visit to a local swimming pool when something happened and he fell very badly. The manager of the Pool rang us at 11.00 and said 'he has had a fall and won't get up - come and get him'

We went straight there and found M sitting in a pool of water, no blanket - obviously in shock - trembling, very pale and clammy with his right leg lying at an angle and his thigh swollen to 2-3 times it's normal size. I demanded an Ambulance be called - this had not been done even though it was now almost an hour since the 'accident'!

Neither Play scheme staff nor Pool staff could let us know exactly what happened - the support worker(who I had complained about two days earlier for leaving Michael alone!) said he 'just fell on his knees' (there were no marks on his knees - and no other injuries anywhere)

Play scheme staff had lost his Emergency sheet - which had been attached to the 'About Me' pack that I had completed. My husband had to detour to our home to fetch a copy of this which notifies Medical staff that in event of emergency Michael has trouble with anesthetics!

I went with Michael in the Ambulance. At hospital it was shown that Michael had snapped his Right Femur (thighbone) and emergency life saving surgery was needed.

He was in hospital for a month and then came home – but had to sleep in a hospital bed in the Dining Room for over a full year – as could not access his bedroom upstairs. He now has a ‘step climber’ so he can get to his own bedroom again – he has been sleeping there since November 2009.

Michael is now reliant on his wheelchair as cannot yet walk – he has painful Physiotherapy to help him regain his mobility and is trying very hard. His confidence has been shattered – he is very clingy and demands that one of us is always with him – his independence has suffered – he is reliant on us for all aspects of his care again – bathing, toileting etc.

He has missed out on so much, family gatherings, holidays and more – he cannot mix with friends out of school etc. In the long term we do not know how he will suffer because of this – he will almost probably have a permanent limp – his right leg is shorter than the other – he will probably suffer from Arthritis – we do not even know if he will fully regain the use of all his leg muscles. Surgeons report that his injury is not consistent with a ‘fall on to his knees!’ Michael now has nightmares too.

I made a formal complaint to the Council and they had a ‘supposed’ enquiry – this lasted months and the outcome was a letter saying that Michael had fallen and sustained an injury – that was it! No apologies – lip service!!

### **How did that make you feel?**

We are very angry. We trusted G Council to keep Michael safe and secure – they did not. They have completely disregarded him as a Human being. The Play scheme staff and the Pool Staff have taken full advantage of the fact that Michael is non verbal and so cannot tell us exactly what happened that day. The Council as a whole have now closed ranks – no-one will speak to us – no-one has even rang to see how he is getting on!

Michael's Human Rights of communication, right to future independence, right to play, right to be safe and secure, right to emergency first aid intervention and more have all been ignored.

I managed to get hold of the incident and accident reports from the day – they were full of inconsistencies – the lifeguards on the day had suspected a broken leg – the manager overruled them – the 1-1 support from Playscheme said something different in his statements as to what he told us at the time. The pool manager on the day told us he ‘did not know what happened as he was not there’ but he made a formal statement saying ‘he saw the whole thing’!! Nothing added up!

I asked several times about the Qualifications and training of the Playscheme staff and still have had no reply on this.

### **What could have been done to prevent this or resolve it?**

Staff on the Summer Playscheme should be properly trained – there is no evidence to show that they had any specialized training in certain aspects of disability – if the Council advertises an Inclusive Play scheme they MUST ensure that staff are experienced and qualified to at least Level 3 Standard. Staff must also have knowledge and experience of various non verbal communication methods. INDIVIDUAL risk assessments are vital for each child with extra support needs within Play schemes. The Scheme that Michael was on had generic risk assessments only. All paperwork concerning the extra support needs of the child MUST be read by ALL staff and adhered to at all times. With regards to the Swimming Pool staff – I would have expected the Manager to call 999 immediately – especially in view of the opinions of two lifeguards on duty that Michael's leg was broken. His injury was life threatening!

The formal complaint should have been properly dealt with – I now know that the procedure did not even include a ‘Serious Case Review’

### **Do you have any other comments?**

G Council have ignored many of Michael's Human Rights – he is a child – a child with extra support needs – but still a child. Because of their actions and their failures Michael will now suffer for the rest of his life. We are now taking legal advice against the Council.

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### **Lesley's story**

I was wondering if any parent had brought up the fact that the only Further Education College here won't provide anyone to do personal care for their sons and daughters when they are in College. Surely this must be an infringement on their human rights?. If the young person wants to access a course in the College then their parents have to pay for someone to go into the College to feed and change their children. This is usually paid for via their direct payments, I believe. So if you don't get Direct Payments or have money you can't access it.

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### **Jane's story**

My daughter has Asperger Syndrome. She has not, yet, got a diagnosis but she is on a waiting list to be assessed by the CDAT team. My daughter is a very intelligent and articulate girl. She is very good at all the academic subjects – the area she really struggles with is social skills.

She was attending a fairly small primary school with no previous experience of Asperger Syndrome. I tried my very best to help the staff at this school to understand how my daughter thought about things and what strategies to use when she got stressed. I told them that my daughter liked structure and that she would really benefit from having a timetable so that she would know what was happening next. In the four and a half years that she attended that school she was never given a timetable and their excuse was that they needed to be much more flexible than that because of the Curriculum for Excellence. The school relied very heavily on me and my daughter's Speech and Language Therapist (she was trying to help my daughter to improve her social skills) to sort out 'problems'. They called me in to the school on a regular basis because my daughter often refused to do things. As my daughter got older, things got worse. She was very unhappy and absolutely hated going to school. She was always viewed as a 'problem' child at the school because she had quite violent outbursts when she got very stressed and this was happening more and more often.

The school expected my daughter to fit in with the way they wanted to do things. They expected her to work successfully in groups. They expected her to enjoy team games and not to get stressed by all the noise and confusion that went on at break time. My daughter could not do these things. I told them time and time again that my daughter could not deal with lots of noise and that working with more than one person at a time was really hard for her. This did not make any difference and I felt as though they thought I was just making excuses for my badly behaved child as the head teacher said "You know, your daughter hasn't actually got a diagnosis."

Things got so bad that my daughter started being excluded from doing certain activities. She was stopped from doing P.E. because she had thrown a hockey stick in frustration and it had hit another child. Also, she was not allowed to take part in any concerts.

My daughter has now moved to a much better school that has an excellent head teacher who has had experience of working with children like my daughter. He understands that she thinks about things in a different way and that she is not deliberately being awkward or rude when she says exactly what she thinks. He gives her time to calm down after break time by allowing her to do some silent reading and he does not force her to work in groups. He allows her to take short breaks if she is feeling stressed (sometimes all she needs is the time it takes to watch the sand trickle through a sand timer). He has, also, talked to the other children about my daughter and is teaching them the best ways of dealing with her when she is stressed.

All these little things have improved my daughter's self esteem dramatically and she no longer sees herself as the 'problem' child. She actually enjoys going to school because she knows that things will be OK. This has made a dramatic difference to my life as well because I don't have to worry about her constantly when she is at school.

I am so glad that I moved my daughter to a new school – It has made a difference to all our lives.

I heard from a friend of mine, recently, that she had moved her daughter from my daughter's first school, as she was not happy with the way they were doing things, and they said to her "Oh, it's OK, you don't have to move your daughter now as that other girl has gone, so, everything will be much better now." ( They used my daughter's name). My friend said that, in her opinion, "Things were not better, in fact, they were worse."

If only all schools were as good as the one my daughter attends now.

P.S. I am, now, an Additional Support for Learning Classroom Assistant.

### **Jacqui's story**

My daughter has learning disabilities. She attended the nursery at the local primary school with support. She was due to go straight into the Learning Centre full time but the Principal for the Learning Centre told us she thought our girl would cope in mainstream with support. We were over the moon, thinking S was doing better than we could have thought. She moved into Primary school and with the same support assistant as before started in mainstream. We knew it was difficult, our daughter had no verbal communication and had challenging behaviour. A month later it was the first ever parents night. I was so proud, we waited to speak to her mainstream teacher with all the other parents in the room. When it was our turn we walked towards her desk. She put her hand up, palm out and said "stop right there, your daughter is a special needs pupil, she is nothing to do with me and shouldn't be in my class, go and speak to someone else". She said this loudly and all the other parents just stood and stared. We went to find the head teacher who told us it wasn't working and our daughter was to be returned to the Learning Centre. I should have taken my daughter out of that school there and then but I didn't and I regret it.

### **How did that make you feel?**

Heartbroken and humiliated. I realized then that the school was just box ticking with inclusion. Another parent told me there was no point complaining as the teacher was married to someone very high up in Education. I was too tired to fight at that point. My daughter went back to the Learning Centre and they never let her back into a mainstream class. A few years later I removed her.

### **Rachel's story**

My son is 4 years old. He has Cerebral palsy affecting all 4 limbs, meaning he is unable to sit or roll independently; he is registered blind, fed via a PEG in his stomach and is a wonderful boy who tries to communicate all the time by smiling and vocalising. He has a little brother who is fit and well. I'm his mum, and manage to squeeze a few hours as a nurse into the week while his dad, works as a local GP.

I feel I could write a huge essay about struggles and failures in meeting my son's human rights but I'll try to focus on a couple of areas and be concise. On the whole I must say we are served pretty well in that having worked in developing countries before I know we are unbelievably better off than many. I think on the whole I don't have a problem with stuff not being provided or services not being given but rather I get fed up with government and Health professional's committing to one thing and providing something that is substandard. In my mind if you don't feel we or S deserve your support or input I fully understand there is a limit to the public purse and S is anything but financially viable. However, if you commit in principle to providing a service, then do it; properly.

Firstly, one of our biggest concerns with children like S is feeding, an issue I feel both hits the right to life and right to healthcare. With both of us coming from a medical back ground our expectations and understanding of certain issues are often a few steps ahead, both a hindrance and a help. When one thing happens we can see where it is heading. S was fed artificially when first born but then discharged within 2 weeks breast feeding 'normally'. In hindsight his little brother fed completely differently and much more effectively. At 9 months he, had his first fit and over the ensuing few months fitting continued and feeding became a problem. At the time my husband was working as a Dr on the paediatric unit but even so we struggled to convince medical staff that his feeding was an issue.

My son wasn't born premature and was always a very good weight, looking both chunky and healthy. It was only with me fighting that he was seen by specialists in a tertiary referral hospital. The input was great

but difficult to hear. Unfortunately, after having a barium swallow, to assess his safety in feeding, their recommendation to never feed my son again was broken to me in a hospital corridor. No more cooking for my baby, no picnics, Christmas dinner, chocolate treats, birthday cake.....

The disabled world is very small and I have become involved in many mum's lives who have had children in various situations struggling with feeding. Unfortunately, in my area I think my experience is one of the best and proactive predominantly because of our knowledge and determination. There is no Speech and Language Therapist in our area qualified to assess and monitor feeding. Too often I have seen young children choke and struggle to maintain their nutrition. What is even more heart breaking, is the turmoil in a mother's heart as she desperately wants to feed her baby. This fundamental element of life and simple role of a mother becomes a huge stress. The conflict between not wanting anything to be wrong yet realising it isn't right is crippling. I have talked with many mothers and tried to encourage them to see the reality of a situation because unfortunately in my experience unless the parents initiate it the medical professionals don't step in to provide insight and potential solutions. I strongly believe this supporting role with specialists able to assess feeding and the effectiveness of swallowing should be established in every area (my understanding is this is sporadic and a postcode lottery).

My greatest gripe is that this situation simply would not happen if our children were not disabled. I fully understand their disabilities are central to this problem but no other mother would be sent away until their child had lost sufficient weight to warrant intervention. No other mother would be told to expect to spend an hour trying to get enough nourishment into their child at every meal time, every day. In any other situation this could be considered neglect as children are being chronically malnourished or persistently choking. It feels as though the bar of neglectful tolerance is significantly heightened for our disabled children. Professionals would rather wait for a parent to bring up problems rather than initiate dialogue and be responsible for supporting the emotional and psychological journey of the parent.

Ok enough of a rant. My second issue I'll just touch on - like I said there are just too many. We have tried and failed over the last 2 years to try and have our home adapted to accommodate our son's many needs. We are now moving house and paying for all adaptations our self because the provision of our local council is not only painfully slow but systemically flawed and chronically neglects the needs of the family. There is no vision of the bigger picture but simply ticking boxes and meeting basic needs without thought or insight into the impact on the family. Suffice to say I strongly feel the principle of right to family life becomes swamped by the legalistic and target driven focus of service providers.

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### **Anon parent**

I am the mother of a severely developmentally disabled 9 year old boy. I feel that the way the NHS operates is INSTITUTIONALLY discriminatory against disabled children. By this I mean the systems that are set up do not provide equal access to services- the vast majority of the staff we have encountered in the NHS have been very good.

I work in education, and we are very aware that for disabled children to have equal access, 'additional and different' provision must be made. We are also very aware of the requirements of the DDA. The systems that work in the NHS seem to have no idea of what this might mean.

For example, no 'additional and different' provision is made to counter the stress for disabled children and their parents or carers in overcrowded waiting rooms. There are no apparent systems where these children can have priority times, or immediate access to staff as they arrive on site. My son has no concept of time or why he is there, and as a consequence becomes distressed, violent and angry.

It is the sad truth that for a lot of families in our situation, we have to use the NHS more than most. The stress of taking my son to his appointments is often unbearable, so much so, that on some occasions I have cancelled important appointments.

This is quite simply denying him equal access to the NHS, and in that sense is an infringement of his human rights.

### **Lesley-Anne's story**

My little girl has learning disabilities and balance problems. But she loves to dance. She can't do steps like other kids or keep up but she tries her best and she just wants to do what the other kids do. At her primary school they had dance classes after school, all types of dancing. Each week my girl would get excited when she saw the other girls getting ready to go to this. A support assistant told me that one of the kids in the mainstream class had asked why my daughter didn't go because she loved dancing.

I sent a note in asking how she could join this group and if they needed me to come and support my daughter. The head teacher phoned me a few days later. She said that other parents had approached her to say they weren't happy about this because their daughters' chances of winning trophies would be jeopardized if my girl was in the team. She said that if I wanted to I could always insist but she would be worried that the mothers would tell their daughters not to accept mine, and did I really want to put my girl through that.

### **How did that make you feel?**

I cried all day. I felt as if my daughter had been victimized because she's different. I was disgusted at the other parents. It depressed me to think other mums could be so cruel. But most of all I was disgusted with the school. I did not entirely believe the Head Teacher. I think she didn't want my girl involved and used other parents as an excuse.

### **What could have been done to prevent this or resolve it?**

Assuming the Head Teacher was telling the truth she should have told the parents that this was unacceptable, immoral and possibly illegal. She should have seen this as an opportunity to prove that inclusion is more than a tick box for this council, going through the same gates is not inclusion.

And if that particular dance group was attended only by the children of ambitious, pushy and heartless mothers the school should then have looked at whether they needed to re-think their policy or have a dance group just for fun.

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### **Karen's story**

Our son was born with Bladder Exstrophy. This is a rare condition which causes the bladder to form externally and abnormalities in the pelvic bone and genitalia. Our son has no evident genitalia. He has had surgery to help with the bladder problems but he still needs to catheterize and he still has the major psychological problem of having no genitalia. We have other children and because of the size of our council house we applied for a grant to extend the house. We felt R needed his own room to allow him to catheterize in private and not have to undress in front of others. We were turned down as the Local Authority said we did not fit the criteria. They did not seem to understand the psychological impact of this condition. The cost for the extension was £35,000. We appealed and were unsuccessful. The whole procedure was draining. The council tried to force us to move to a different house, they didn't seem to care about the impact of moving areas on all my children.

I found the UNICEF Convention on the Rights of the Child. I took it to a solicitor and told him that I thought what the Council were doing was breaching my son's rights, I told him that every child has the right to a voice.

The case was taken in my son's name against the Local Authority and Social Services. It went to the High Court. They defended the action. We won the case.

They spent £85,000 defending that action when they could have spent £35,000 doing the right thing.

It was hard and it took a lot out of us, but we are glad we did it. I am telling this story so others know that using the Convention works.

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### **Nigel's story**

In 2001 our son was born. We never had a name for his condition but sadly he died when he was 14 months old. The Geneticists thought T's condition was linked to our genetics. They also thought if we had another child and it was a girl she would probably not be affected.

E was born in 2005 and within weeks it was clear that something was wrong. In the first year of her life she was rushed to hospital 33 times.

E requires around-the-clock care because of the following conditions: Global developmental delay; · Laryngomalacia (The soft, immature cartilage of the upper larynx collapsing inwards blocking the windpipe. As a result, E has to breathe through a tube inserted into an opening in her throat. She also has to be fed liquids only by another tube into her stomach); seizures and vision impairment.

It was hard enough coming to terms with all of this happening again without having the stress of trying to deal with DLA and Carers Allowance. It was clear E needed 24 hour care but it still took 4 months to get the DLA and Carers Allowance sorted out. And it feels as if it has been a battle ever since. It's not the people like the Paediatricians, they've been great, it is the system.

We needed a buggy for E, it took 3 months to arrive and when it came we were told we had to buy our own cover and hood. A few years later we needed a power chair, it took 12 months to sort out.

We applied for a grant to have an extension added to the house. We saw the plans but they did not build it as per the plans. Because of E's complex health problems it had been agreed the extension would be built in double block, they built it in single block. Soon the room was covered in mould and we could not let her sleep there. For 18 months we had to keep E downstairs and I slept on the couch beside her. Everyone agreed this was detrimental to her health and that what was needed was a proper 2 storey extension to the house. They said it would happen. This was 2007. Nothing happened but battles. Eventually an architect did the plans. OT were not involved. When the plans were done and they were sent to a builder to quote for the work the price was £105,000. The Local Authority said no, there were no funds. E was then taken into hospital again and this time the Consultant refused to allow her to be taken back to our home as he said it was detrimental to her health and well-being.

Since July 2009 we have been in rented accommodation, paid by the council at a cost of £1100 per month. The cost to extend our own home, which is lying empty, has now risen to £137,000. In the meantime our daughter is being bathed in a rubber dinghy filled via a hose pump from the utility room.

The stress on our family has been unbearable. We don't know what the future holds. We originally thought our little girl would not see his first birthday but she is a fighter, and we think she has the right to a good life. We have battled for everything and we know we will have to keep on doing it.

We believe that the fact that our daughter has a life limiting condition has been a major factor in the decision making. It's as if they are just waiting for her to die and don't want to spend the money.

All we want is to be home with an extension that allows E to have a room to herself, a room that is big enough to meet her needs as she grows.

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### **Debbie's story**

J is 11 years old. She has epilepsy but no specialists have ever been able to specify exactly what the underlying diagnosis for J is. Her last developmental check showed that she was behaving like a 15 month old toddler. She had no verbal communication, is doubly incontinent and spends a great deal of time in and out of hospital. She had brain surgery recently. She is a passive, lovely girl who likes having her hair

and nails done. She gets a lot of urinary infections. She doesn't pee little and often. Generally when she pees she has a full bladder.

For years her mum has battled to get her NHS to supply continence products which are suitable. J is quite a large child for her age. The continence department kept telling her that was all there was. Every time J peed the product would not hold the amount so she was flooded, soaking wet, needing change and still getting those infections. Her mum literally battled for over a year to get her local NHS to supply a better product. She took advice from Contact a Family. Eventually she got a better product. But it is not ideal. Because of all the infections her mum was advised that catheterizing J would be the best and safest option. Mum agreed and it has made a difference.

But...there is a big problem. Mum catheterizes J in the morning. J goes to school. But in mainstream schools there is no legal obligation on Education staff to attend to medical or personal care. So mum had to go up to the school to catheterize her daughter. Mum is a single parent with 24 hour responsibility for a child with complex health needs (J can have 30 fits a day). Mum asked if the school would catheterize J. The school explained that none of their staff were willing to volunteer to do this. So if mum did not go then J would flood, she would be soaked in her own urine and have to go through the indignity and hassle of complete changing again. Mum again asked for advice and was told that the responsibility lay with the NHS Board. She requested a meeting and put her case to a paediatrician. She was told that the local health visitors would do this. They haven't. They were told by a Senior Nurse not to, as she was of the view that J could manage all day without peeing. J has no understanding at that level. Mum can evidence that if J is not catheterized she will empty her bladder and not even the new product will hold that amount. Mum felt she was being emotionally blackmailed into going up every day to catheterize her daughter. She sought advice again and was referred to a Child Law Centre who told her how to proceed. She sent a letter to her NHS. She was invited to a meeting where she was told they had good news for her..they had staff who were able to catheterize J 3 days a week! Mum asked what J was supposed to do on the other 2 days - hold it in, no sorry tried that! The senior nurse was so annoyed with the mum she walked out. Mum was told by the Paediatrician that her reaction was unacceptable, she should be grateful and thank that nurse for being willing to arrange this.

Mum does not agree, she believes her daughter has the right to dignity every day, and that parents should not be expected to go to school every day and attend to their children. Mum is now taking legal advice.

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### **Tania's story**

We believe that our daughter has a right to an effective education. Unfortunately the current special needs system makes this virtually impossible, even for those parents with the education, intellect and stomach enough to fight for it.

A has a significant language impairment, dyspraxia, autism and learning difficulties. We realised very early on in her life that there were obvious communication and social problems. She was slower than her peers in achieving milestones and at interacting with others. We involved our GP and then a paediatrician. Eventually (through a friend) we discovered a specialist speech and language centre and managed to get her "in" for several sessions a week. Even though there were obvious problems - no one ever offered us any advice or support.

The statementing process took us over 18 months. Because A was not at school at this point, we couldn't get anyone from the LEA to visit her, so the caseworker and committee kept turning A's assessment down. Eventually we paid for private assessment and reports to be done which forced the LEA to assess her - the cost to us was over £1500. There then followed 6 months of arguments as she left the language centre and began school, over what quantified provision she needed. The LEA were unwilling to quantify exactly what help we could expect, stating that it would be "regular and monitored". I have since discovered (having been the SEN Governor at school) that in practice this means a visit once a term at the most! When we could not agree with the LEA we were forced to appeal to the SEN Tribunal in May 2000. We

represented ourselves and paid for a private speech and language therapist to give evidence as an “expert witness”.

We achieved the initial Statement of SEN following this appeal to SENDIST in May 2000. The Tribunal ruled in our favour and quantified her needs at the time, and Part 3 specified weekly speech therapy in school and 25 hours support from a Teaching Assistant. Despite the provision being detailed we continually had to chase the LEA as a lack of therapists and funding meant that almost 1 in 4 weekly sessions was missed. Compounding this, at each subsequent Annual Review, we found ourselves having to provide independent SALT reports as our LEA attempted to remove the provision.

We complained to the LEA and Dfes about the handling of the statement and lack of provision, all to no avail over the subsequent years.

In September 2006 we were forced to go back to SENDIST again as the LEA amended A’s Statement, removing the therapy, as she moved to Secondary School due to the local NHS’ policy of not providing in-school support at secondary level favouring the consultative model. Apparently all children in our area make a miraculous recover at age 11 and no longer require individual input from a qualified therapist! Our appeal was successful to the extent that the individual therapy remained on the Statement although it was changed to one longer morning every 6 weeks. The Tribunal asked that we look at this again in May 2007 at Annual Review to see if it needed to be changed based on A’s continuing needs. The Review Panel did indeed look at this again as requested and agreed a return to weekly therapy. This decision was based on 4 independent and highly regarded Therapists’ opinions. The LEA considered the request but refused to amend the Statement.

In April 2008 A received a diagnosis of Pervasive Developmental Disorder. We requested that the LEA include this on her Statement and the Annual Review in June 2008 concurred. The LEA did amend the Statement but placed it in Part 4. We appealed to SENDIST for the third time in March 2009. Once again the LEA requested removal of the speech and language therapy at the hearing. Again the Tribunal ruled in our favour retaining therapy and increasing the amount to four times a term for a morning session. They also included the diagnosis of PDD in Part 2, but provided no educational input in Part 3, despite this being part of our original appeal request. The Panel also left self-conflicting wording in Part 2 stating that A does not have an “Autistic Spectrum Disorder” and the next line then says that she does have a diagnosis of PDD – which IS and ASD! We appealed to first and second tier Tribunal but although we were informed that we were correct to appeal the wording, legal advice stated that the whole Statement would have to be thrown out if we continued with the higher appeal and we could effectively have to argue for everything on the Statement. We could not face this and so withdrew the Upper Tier Appeal in January 2010 leaving A with an ambiguous statement.

Overrunning this, were problems with the speech and language therapy. Our local NHS therapists felt that their professional judgement had been called into question too many times and therefore they refused to cover A’s statement needs. The LEA was forced to pay a private therapist to carry out the required time. This has actually worked very well and has been far more effective than in previous years. However we spent several months disputing how long a “morning” session was, with the LEA arguing for as little as 40 minutes! It currently stands at a couple of hours of a private therapist time 4 times a term.

Last month A attended Cambridge University’s Autism Research Centre as a volunteer for a study into teenage autism. She underwent a detailed series of tests under the supervision of Dr Michael Spencer. Dr Spencer subsequently wrote to us confirming that A “meets the criteria for a diagnosis of autism”. We have now asked the LEA to include this in Part 2 of the statement and an ASD support programme to be included in Part 3. Once again we won’t be holding our breath!

The House of Commons Education and Skills Committee report on Special Educational Needs (HC478-1) stated that “the SEN system is demonstrably no longer fit for purpose” and highlighted OFSTED’s identification that there is a “considerable inequality of provision”. We have had a “standard “response

letter from Ed Balls, offering nothing other than suggesting that we request re-statementing. Our MP has also spoken to the LEA on our behalf with little success.

We continually find ourselves in an impossible position. We have to fight for every piece of educational support that our daughter receives. It is exceptionally costly (the Sept 2006 appeal cost us £7000 and March 2009 around £2500) and wearing both physically and emotionally. Our problem is that, regardless of how much independent evidence we bring to bear, the LEA's decision is final and based solely on opinions of specialists appointed by the LEA. In effect all other professional advice can be ignored. A receives an education, but in no way could it be described as "effective" when every step has had to be fought for and even then, the NHS has been unable to provide the support ordered.

Our elder daughter has received an excellent education. She is at the other end of the spectrum and is on the "gifted and talented" register at school. This has provided her with extension activities recognising the fact that she may find some subjects boring or dull due to her intellect! This has not had to be fought for - cynically it could be argued that help is freely available as it improves exam results for the school.

Our only wish is for A to receive an equal education - one that helps her to achieve whatever her potential may be and does not rely on constant parental policing and an ability to stand up and argue the point.

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**Debbie's story**

My son R is 9 years old and is diagnosed with Asperger's Syndrome and ADHD. He was diagnosed at 6 years old, and in the same week was unlawfully removed from his mainstream placement and placed in a Speech and Language unit for further assessment. This was to involve him being taken to a school he had never been to before, with an Escort he had never met before and this, in their opinion, was the best thing for my child. This occurred in a situation where lies were told about the documentation used to support this action, and we were told if we did not co-operate reasons would be found to permanently exclude him from school. This occurred when we had a verbal diagnosis but \*\*\* Council decided to quickly remove him before he was formally diagnosed. They went against the decision of a Consultant Child Psychologist who was adamant that he belonged in a mainstream school with the right support.

When she complained against their unlawful action she was told that they, in the Education Department, decide what is best for the child. She wrote to them telling them that she was concerned about the long term damage which would be caused to my son as a result of their action. We had to get a solicitor involved to get him back into mainstream school. Since then he has attended a different school. But we have learned that instructions were put in place that he was to be automatically excluded from school if he got upset and had any negative physical contact with the teachers. He has since been excluded from school on several occasions and the school regularly disassociate his behaviours with his condition, telling us - it was not his autism, he knew what he was doing.

I have already been told by Enquire to query this as a breach of his Human Rights. I also have written evidence now in the form of Reports stating that, in Exclusion cases, his additional needs were not a factor, but no-one was qualified clinically to make that decision.

**How did this make you feel?**

Made me ill with depression and stress which has left me with many stress related illnesses. I feel that my child and I are victims of a system in which the Local Authority are trying to deprive my son of a suitable education and bully us into accepting their unjust system.

