



Northern Ireland
Assembly

Committee for Education

OFFICIAL REPORT (Hansard)

Special Educational Needs and Disability Bill:
Blind Children UK

24 June 2015

NORTHERN IRELAND ASSEMBLY

Committee for Education

Special Educational Needs and Disability Bill: Blind Children UK

24 June 2015

Members present for all or part of the proceedings:

Mr Peter Weir (Chairperson)
Mrs Sandra Overend (Deputy Chairperson)
Mr Jonathan Craig
Mr Chris Hazzard
Mr Trevor Lunn
Mr Seán Rogers

Witnesses:

Ms Michelle Bateson	Blind Children UK
Ms June Best	Blind Children UK
Mr Andrew Murdock	Blind Children UK
Mr Martin Walls	Blind Children UK

The Chairperson (Mr Weir): I welcome our witnesses and guests from the Northern Ireland branch of Blind Children UK. Its submission is in our meeting papers. In no particular order, the witnesses are Andrew Murdock, the policy engagement manager; Martin Walls, the service delivery manager; Michelle Bateson, who is the parent of a visually impaired child; and June Best, an educationalist and guide dog owner.

I ask you to make a short submission, and we will then pick up on any issues raised. I do not know who will lead off.

Mr Andrew Murdock (Blind Children UK): I will, Chair.

The Chairperson (Mr Weir): OK. By the way, June, what is your dog named?

Ms June Best (Blind Children UK): Alex.

May I ask Committee members to introduce themselves, because I do not know who is around the table? Thank you very much.

The Chairperson (Mr Weir): We will go around the table. I am Peter Weir, the Chair.

Mr Hazzard: Chris Hazzard, Sinn Féin MLA.

Mr Rogers: Seán Rogers, SDLP MLA.

Mr Lunn: Trevor Lunn, Alliance MLA. We met yesterday, June.

Mr Craig: Jonathan Craig, DUP MLA.

The Chairperson (Mr Weir): We also expect the Deputy Chair, Sandra Overend from the Ulster Unionists, to be back. If you hear a female voice among the Committee members, that is whose it will be. Paula, on my right, is one of the Committee staff, as is Peter, the Committee Clerk, who is on my left. Andrew, we are in your hands.

Mr Murdock: Thank you very much, Chair. Again, we thank the Committee for the opportunity to come to speak with you today. Blind Children UK is part of the Guide Dogs family. It is quite a new organisation in Northern Ireland, only being established in May of last year. The focus of the work of Blind Children UK is on habilitation services, which is quite a new concept for delivery in Northern Ireland. It is on that basis, as you will see from our written submission, that we dealt with only a number of the initial clauses in the Bill. That is because that is where our expertise lies, and that is where we see amendments to the Bill needing to be made.

I will pass over to Martin to talk a little bit more on that.

Mr Martin Walls (Blind Children UK): I will refresh and highlight some of the submission points.

Specification and quantification are important so that mobility, orientation and independence form a specific part of the Bill for blind and partially sighted children. In particular, those areas increase inclusion, decrease dependency on classroom assistants and enhance the information to parents, teachers, classroom assistants, learning support coordinators, educational psychologists and other therapeutic professionals who may be involved in the child's education.

Specific reference to habilitation assessment should be made through the Bill in statements, individual education plans and codes of practice. Those should be made by qualified habilitation specialists, which would put Northern Ireland education on a par with the provision that has been in place in England since 2014 and the provision that will be in place in Scotland from 2016.

Regard for the views of the child and parents is a hugely important principle of our approach in Blind Children UK in Northern Ireland, an approach that is designed to build on the resilience of parents and young people in developing independence and mobility freedom. We highlight the fact that recent research by Blind Children UK in Northern Ireland suggests that the fair contribution of parents to statementing relies on the careful use of language about specific needs of their children and should avoid, where possible, generic professional language that most people, outside of sight-loss professionals, are not versed in.

Collaboration between health and education will rely on a duty to cooperate by statute. Cross-professional collaboration is a primary principle of habilitation and is reflected in our approach with the qualified teachers of the visually impaired (QTVIs) in Northern Ireland. We are working hand in hand with them to deliver the service. That is a very effective working relationship. We regularly supply reports and school reviews, where asked for, to parents, teachers and QTVIs and add quality to the provision in the sector.

The habilitation quality standards are used by Blind Children UK across the UK to provide a framework for consistency and quality benchmarks to make clear when and how a service is provided, what service is provided and who provides that service so that parents and professionals are aware of what is expected. Adopting the habilitation standards in Northern Ireland would support the clarification of the offer and remove the unknowns for parents. Consequently, that would reduce the anxieties and stress experienced by parents concerned about the implications of sight loss in their children.

The habilitation input increases the sight-loss competence and confidence of classroom assistants and teachers, as I have already said, and it involves support of the classroom assistants moving forward in an empowering role rather than an overriding safety control role.

Our research found that collaborative pathways between health and education are patchy and lack any particular Northern Ireland standard. The Bill, though limited, is a potential mechanism for standardising what parents and children can expect from a 21st-century system of learning and support.

Michelle and June can speak from experience about early intervention and how important it is. On too many occasions, it appears that parents feel that they are left alone, and they will work on fear if they lack the insight of parents such as Michelle. Basically, we are talking about getting early intervention of habilitation and structured programmes to progress the child's movement, confidence, independence and social effectiveness and, arising from that, seeing the world around them. Our research found that parents feared constantly about their child being unsafe when walking around outside, using roads and buses and without adequate or sufficient training to move around in the classroom.

Habilitation addresses those issues by training the young person in all contexts, including school, home and public space. This capacity for independence transfers to a young person in later life getting to work, being effective in student life and managing their lives effectively. The cost of non-intervention is a huge burden on later care and the costs of benefits, over-reliance on ageing parents and the state. Habilitation can contribute to saving on the classroom assistant bill, increasing movement and coping and enhancing the effectiveness of the child through all school stages. Therefore, we commend that habilitation is specifically identified in statements, individual education plans, codes of practice, school reviews and plans for extra-curricular development.

Ms Michelle Bateson (Blind Children UK): I am mum to a four-year-old girl who is blind. Her name is Elodie. Four years ago, we took her to the hospital with concerns about one of her eyes when she was six weeks old. We thought that one was smaller than the other. Following a long, long day at the hospital, we found out that her eyes had not developed properly. She had small eyes. She had gaps in the back of her eyes, and, before she was one, both her retinas detached. Unfortunately, we were told that day that our little girl was going to be blind. We took her home, and I can remember being totally overwhelmed by the thoughts of what we were going to do. Probably the first thing that I noticed was that she did not move. She was a very quiet baby. She did not look at you when you came into the room. She did not wave her hands. She did not acknowledge you when she wanted to be picked up. Already, at six weeks old, our baby was probably falling behind. With children and babies, about 80% of learning and development is through vision. This was having a massive impact, even at six weeks old, on her ability to learn and develop.

At that time, I can remember being at home, and there was no support. There were no habilitation services in the Province. We were just lost. When she was about five months old, we found out about a clinic in Great Ormond Street. We took her there, and we were able to get an early intervention programme for her, which we took back. It was a specialist programme for parents, and this taught essential skills, such as reaching out, helping her with feeding and mobility. That was the beginning of habilitation for us. We did not really have a word for it then, but we knew that, as parents, we would be her best teachers. We needed to know what to do for her and the best way to do it.

When she was about one year old, I got ready to go back to work, and we began the struggle of looking for day care for her. We did go to a nursery that was happy to secure a place for her. When she was about one and a half, we discovered that other kids were moving on in their development, and she was struggling with the environment. She was struggling to move about safely. She was struggling to form relationships with other children. She did not see their faces and could not receive facial expressions. It was one of the most trying times for us; we felt that our child was not supported. Obviously, sometimes, she was coming home very distressed. She was in an early years setting, and one of the big things that we found was that, because it was a nursery, The Department of Education said that it was maybe a social services issue. Social services said that it was a nursery issue and that Education should be looking at it. We had no support. This went on for a few years, with me grabbing funding from small childcare partnerships and things like that to try to buy enhanced hours for her. Eventually, I got a direct payment. We had no support for our daughter in her nursery. I got a direct payment from social services, and I had to buy a classroom assistant and organise her support. We were very fortunate in that we were able to use and train that person to integrate the early intervention journal into the early years setting, so our daughter had early intervention from the age of 2.

That time was awful. I spoke to whoever I could; everybody said that it was somebody else's issue. We had a small child who needed to maintain her safety and mobility. She needed to learn all of the skills that you would normally learn through vision, such as feeding, dressing, taking turns and being able to select activities and even just stimulating the small bit of residual vision that she had at that time in order to use it effectively.

One big thing is that we are moving into a transition period for Elodie. She will be starting school in September. We have had a massive amount of habilitation input from Blind Children UK in getting her

independent and moving about. She is one of the youngest children in Northern Ireland to use a cane; she started using it when she was three years old. She uses it to move about from room to room. She uses it very effectively outdoors, and now, when she goes to school, she will be able to move from room to room and within the classroom like her friends. Again, it takes a lot of work for our daughter to be able to map her environment, to be able to learn a room and to know what the structure of the room is. A lot of education will be necessary for the people who will be working with her, her classroom assistant and teacher.

One big thing that we struggled with was that, when we were picking a school for our child, we had hoped that she would go to the school that our older son attended. However, the Education Authority felt that, as our daughter is a Braille user — she has been learning and reading Braille for the past year — that that did not need to be on the job description. It left us very upset that they were planning to employ somebody whom my daughter could read and write better than. We eventually had to move her to an integrated school. The person who we had employed at nursery, who was qualified in Braille and in all the mobility awareness, came across with her.

It left us in the position where we had two children in two different primary schools because of a lack of understanding of the very specialist needs of a blind child. I still struggle with that idea at the moment, that, come September, our children will not be together. That is because we had to make that decision to make sure that our child would not be lost again after the massive amount of input and work that she has had in her early years. The work has to be put in in the early years; there has to be early intervention and all of those hours and programmes on learning how to move, how to build confidence and how to make friends. She is beginning to form relationships, and that is a big thing. A lot of visually impaired children struggle with making friends. They tend to be isolated, so they develop behaviours that may not be socially acceptable. We have been working really hard on that.

From a family perspective, when Elodie was born and at the point of diagnosis, my understanding of blindness and visual impairment was that there was maybe a lack of sight and perhaps her hearing and touch would take over. Today, I know that being visually impaired has a global effect on development. It affects the ability to move, communicate and learn new things. Blind infants and children cannot learn by seeing and opportunities are missed. All of that incidental learning just does not happen.

Her catalogue of the world is so much smaller. We need so much work to be done on concepts. She may not recognise familiar animals that children might see in picture books. At school, when they are talking about cars or giraffes, my daughter will not know what those are. There is a huge amount of concept work, and probably, at best, she will receive one visit a week from a QTVI. The guidelines from the RNIB state that that should be 40% of a QTVI's time when a blind child is in mainstream school, because of the massive amount of braille work and the massive amount of analytical skill needed to adapt and modify the curriculum for that child.

The investment in those supporting Elodie is paramount if she is to have an equal chance to the rest of the children in the school. That investment needs to be in the classroom assistants, because they will deliver the programmes to the children as well. The QTVI will not be there from 9.00 am to 3.00 pm every day, so the other support personnel need to be upskilled to deliver the braille programme to her. That is it. Does anybody have any questions, or, June, do you want to go first?

The Chairperson (Mr Weir): June, would you like to make any additional comments or observations?

Ms Best: I do not actually need to say anything, because Michelle has said it all. I came up through the system as a person who was born with vision impairment, and I will quickly tell you what habilitation means to me.

I learnt everything naturally, because my parents decided to throw me out into the big wide world and let me fend for myself. I was a very clumsy child and did not realise that I could not see what everyone else saw. I managed the world and developed a sense of humour, but I used to go home and cry in bed. As a child, you know that you are very different.

One of the stories I want to tell you, which illustrates what habilitation is really about, is the fact that my grandmother and all of her family were totally blind. Unfortunately, I have that gene. I remember sitting on my grandmother's knee in a darkish room, because she never had lights on, and singing 'Twinkle, Twinkle, Little Star'. That was normal in our household, and I just took it, but I never knew what a star was. When I was three or four, I was sitting in a church school in Armagh and — I am aging myself now — I was doing 'Chicken Licken'. The sky fell on Chicken Licken's head, but I did not

have a clue that there was a sky up there. I had concentrated, all the while, on getting and moving around, to keep myself upright and to stop myself from bumping into things. Nobody had thought about telling me that there was a sky up there, so I hadn't realised.

Habilitation is somebody coming in and working with parents, teaching things that other children, who do not have visual impairment, acquire naturally. All the reasoning skills and cognitive development that you need for later on is done in your formative years. For years and years as an educationalist, I have gone on and on about the need for Health and Education to work together, because there is a big gap. We have let children down. I have said repeatedly at all-party working groups that I, too, as an educationalist and sensory support teacher have let children down, not deliberately but because it was the way of thinking at that stage. What happens is that we do not realise things, and there have been misconceptions, about blind and partially-sighted children and their capabilities. The fact is that we get very frustrated as children because we cannot see and do not have the reassurance of our mother's smile as she leans over the cot, or whatever, from an early age.

Going on from that, there are all the skills of learning orientation, being out and about, holding on to somebody and being with somebody, or, in my case, bulldozing into things because I was determined that I was not going to hold on to somebody. All of those things compound into low expectations. We have let our children down because Health and Education have not worked together and realised that there has been a big gap. I have given evidence before about the detriment —

The Chairperson (Mr Weir): One of the very familiar themes is the disjoint that is there and the need for much closer alignment and cooperation.

Ms Best: Early intervention is needed for employment at the end of it all. It will save money in the long run, because blind people will have the confidence to get out and about and use transport. Society will see more and more blind and partially sighted children going around like everybody else and taking their positions, so it is about changing the societal view as well.

Mr Hazzard: Thank you very much for the presentation, which was very thought-provoking indeed. I just want to make two points. What can habilitation bring to the Bill to improve and enhance it? You spoke at length, as have so many people when they come here, about the interface between the Departments of Health and Education. Some people have suggested that there is a need for a statutory duty to be put in place. Do you agree with that? What are your thoughts on that?

Mr Walls: You asked what rehabilitation can bring. I have tried to outline key issues for equipping young, blind and partially sighted children as early as possible. For that to happen, however, it has to be stated specifically on statements, and for that to happen, it has to be in the Bill. Equally, it has to be a collaboration with other professionals: educational psychologists, QTVIs and any other health professionals and therapists that are involved. We are on the ground working at that, but we do not have any statutory cover for that. In this day and age, it is important that we can at least be on a par with England and Scotland and say that all blind children should have a rehabilitation assessment by a qualified rehabilitation specialist as early and as close to diagnosis as possible. That is not an impossible statement to make in terms of the specificity that is required for the statementing process. People are asking for specifics, and that is very specific.

There is a broader aspect in terms of the habilitation standards. That is a much broader framework because it goes through all the transition stages. That will clarify the processes, who is involved and what parents can expect. One of the biggest issues that we are hearing — Michelle talked about it — is the fear that parents have. We did research, and it would break your heart to hear parents talk about their fear of their children being bullied or perceiving to be bullied and not getting on in life and not meeting their potential. That would break any parent's heart, but it would help to know that the specifics will be in place and that what parents can expect would be addressed.

The Velcro of classroom assistants for education is that they are used as a health and safety mechanism for getting around the school. That has major implications for disempowering the child in later life and for taking skills out that need to be independently acquired, but those are the big things that habilitation can bring.

You also asked about the interface between Health and Education. We did our research and found pockets of good practice, but they were only pockets, and they were reliant on individuals and their background and their attitude. We would say that without a statutory duty, that is not going to happen. There are major issues in terms of Health operating with Education. There is a basic structural one,

which is that there is, more or less, a single education process in the Education Authority. We can work across with all the QTVIs and have a fairly common approach because we can meet them all in one go. The system of health provision for sensory teams means that every trust seems to have a different mechanism or set-up and a different emphasis and set of goals and targets. That makes it very difficult for the parents; it is difficult enough for us to manage that, but it is a nightmare for parents. We would say that there needs to be a statutory duty to cooperate.

Mr Craig: I appreciate your story, Michelle. People like us cannot and do not have any concept of what it is like, and there no point in trying to hide that. I have been looking through all this material, and I see a lot of good stuff in the Bill, such as the need for a plan for each child, the need to review that plan and the need for a specific teacher to have responsibility for that area in the school. Not all schools did that; a lot of it fell to the principal. I also see that one of the governors is now going to be specifically responsible for that. All well and good, but what I do not see in there, and this puzzles me a bit — there has been a mention of the child being brought into the equation — is anything for the parents.

Ms Bateson: We really struggled. That was one of the big things when we were going to our school. We were not consulted at any point about what was going to be needed and what type of support our daughter would need from a classroom assistant. We were absolutely horrified. Going through the whole system from birth, early intervention, health provision and all of those professionals, the first stumbling block that I came across was in Education. Suddenly there was just a wall against me. I was saying that I had a child with a very particular disability and very particular needs, and no one would speak to me about it. People just went and did their own thing. As a parent, I felt invisible when it came to saying what we felt was best for our child and what we knew. I found that really upsetting.

Mr Craig: Would you agree with me that there is possibly a need there? The support plan is going to be put in place for your child. The experts are going to look at it. We have all of those experts within the school looking at it, whether it is the governors, the principal or the head coordinator. I just think that this is something obvious: whatever that support plan is, it should also be looked at in conjunction with not only the child but the parents before it is implemented. I have dealt with a case. Unfortunately, we have a neighbour who is sight-impaired. He is not blind. A lot of things were put in place for that child, and then when it came to the classroom, the sight-impaired child was sat at the very back of the class. You do find silly nonsense, whereas I feel that, if the views of the parents had been taken on board from day one, things like that just would not have happened. It is more of a comment. I think we need to look at that issue.

Ms Bateson: When I read some of the stuff in Elodie's statement, I thought, "I wonder whose child this is", because I did not see anything that recognised my daughter or that would help anybody who would be working with her. I did submit quite a bit to that, but quite a bit of it was ignored when we went to school.

Mr Murdock: One of the issues in relation to that is the use of language, which Martin referred to earlier. As I said, habilitation is still a relatively new concept in Northern Ireland, certainly among those potentially doing the different assessments. Martin has examples of working with parents where, if you ask the parent if their child needs help with mobility, the concept of mobility is more adult-orientated, so they say no, but if you ask whether their child needs help moving around and exploring the space around them, the answer is absolutely. I think there are issues around the language that parents are aware of and familiar with and that of the professions carrying out the different assessments at the different levels in the school. There is a whole piece of work to be done around that as well. We welcome the views of the child and the parents being taken on board.

Ms Bateson: One of my things is that Elodie can feed herself, but she needs help to select what food is available and to carry her tray. I think that, actually, that is not true. She can feed herself, but there is a lot more to that.

The Chairperson (Mr Weir): Things that you do not necessarily think of.

Ms Bateson: Yes, that is habilitation. Elodie will be taught to use her sensory efficiency. At the minute we are talking about smelling what is for dinner, so she is using a lot of other techniques to try to upskill herself to achieve independence.

Mr Lunn: Thanks for your presentations. I have just one small query. This is probably for you, Andrew. In your evidence, you say that article 26 of the UN Convention on the Rights of Persons with Disabilities requires a person with a disability to receive the habilitation support they need and for there to be quality standards and so on. Is that specific to people who are blind? It just says, "persons with disabilities".

Mr Murdock: That article refers to habilitation, and, from our perspective, habilitation is about the learning of new skills from a vision-impaired perspective. I think it would go beyond that with other disabilities, but, from our perspective, it is to do with vision impairment. It is the learning of new skills through habilitation rather than rehabilitation.

Mr Lunn: Habilitation is a new word to me, frankly.

Mr Murdock: It applies across all disabilities. It is a concept that we have adopted and are using and promoting. For us, it is very familiar. It might be associated more with visual impairment, but it goes across all disabilities.

The Chairperson (Mr Weir): Thank you for your presentation. It has been very useful to get some information on an area that many of us are not familiar with. You do not always engage your brain to realise what the implications of things are.

Mr Murdock: We appreciate that Blind Children UK and the services it offers are still very new to Northern Ireland, so we brought along some information leaflets this morning. Can we just leave them for members to take with them at the end?

The Chairperson (Mr Weir): Certainly.

Mr Murdock: Also, Michelle has very kindly provided an overview of the story from her family's perspective.

The Chairperson (Mr Weir): Do you just have the one copy?

Mr Murdock: We will send through a copy.

The Chairperson (Mr Weir): If you send through a copy to the Committee Clerk, he will circulate it. Thanks once again.