



Northern Ireland  
Assembly

Committee for Education

# OFFICIAL REPORT (Hansard)

Special Educational Needs and Disability Bill:  
Mrs Maria Treacy, Mrs Jane-Louise Kelly

24 June 2015

# NORTHERN IRELAND ASSEMBLY

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**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:**

Mrs Jane-Louise Kelly                      Parents of Children with Acquired Brain Injuries  
Mrs Maria Treacy                              Parents of Children with Acquired Brain Injuries

**The Chairperson (Mr Weir):** I welcome Jane-Louise Kelly and Maria Treacy. I know that you have been listening to the session and that you have a flavour of things. I invite you to make a short presentation. We will try to pick up any questions that we have. Thank you for your submission.

**Mrs Jane-Louise Kelly (Parents of Children with Acquired Brain Injuries):** Good morning to you all. Thank you very much for welcoming Maria and me to speak to you.

We are here in our capacity as mothers and carers. I am a carer for a child with a brain injury acquired from a grade 4 malignant brain tumour and its subsequent treatment. My child is now finishing his second year at grammar school and is finally benefiting from a full statement of special educational needs. My comments on the proposed new Bill draw on personal experiences of the system, watching other parents trying to navigate it and our observations of the gaps in understanding related specifically to acquired brain injury (ABI) that Maria and I have noticed in our process of advocating for our own children and for awareness of acquired brain injury among children in general. I am very aware that we do not have a code of practice to accompany the new legislation, so I can share only experiences based on proposed changes to certain clauses in the Bill and trust that what we share will be taken into account in the new code of practice.

Starting with clause 1, the views of the child are absolutely crucial. I am watching the process by which my child is learning to speak for himself, but that has been and continues to be a process of maturation beginning at age 9, when he was diagnosed, to the age of 14. It has been and remains fully dependent on his sense of physical well-being. Taking note of the child's views needs to be part of regular and open communication with the child and the parents or carers. Constant communication between the school and home is absolutely essential when you are dealing with a child with complex special needs because their needs change regularly.

One of the most important relationships in our experience has been the one built with my son's classroom assistant. She is a powerful advocate for his well-being, because she is watching him at every stage of the day and monitoring for fatigue, nausea or whether he is overwhelmed, all the while trying to help him to maximise his day. I challenge that, in clause 3, assistants should not simply be made "aware" of the child's special needs; that is just much too vague. They need and require training that is specific to the child's needs, with regular updating, so that they can do the best job they can when looking after them.

The most concerning part of clauses 2 and 4 is that, without advice and direction from the health and social care bodies, the Education Authority may not know to make arrangements for certain special needs or even to ask for help. That appears to be the case with acquired brain injury. Acquired brain injury is a very broad-reaching and complex term. I am summarising from a table that was produced by the Royal College of Paediatrics and Child Health when I say that its causes are varied, covering direct trauma to the brain from an external physical force; infection through, for example, meningitis or encephalitis; interruptions in the supply of oxygen to the brain due to, for example, near drowning or carbon-monoxide inhalation; malignant and benign brain tumours; vascular disorders, such as stroke; or metabolic disorders where the necessary nutrients do not get to the brain.

We wrote to the Department of Education in October 2014 with the help of the Bar Library to ask for clarity on the fact that we were told by the Minister of Education, John O'Dowd, that there were only 24 children recorded with acquired brain injury. The Department returned a response in which there was no mention of the complexity of acquired brain injury other than significant accidental injury or trauma. In the guidance for schools document, ABI is recorded under significant accidental injury, which is a subset of the physical special educational needs category that does not take into consideration the neurological impact of acquired brain injury. Sudden accidental injury can also include severe bone fractures, so the already inaccurate figure of 24 may even include children without brain injury.

When the education and library boards were requested by the Department of Education to consider whether a separate category for ABI would enable a more accurate figure to be collated, they advised:

*"the current system for recording SEN is predicated on the concept of special educational needs and their identification, rather than the medical diagnosis and naming of a particular condition".*

They also said:

*"that support for children with ABI will continue to be based on the identification of their SEN".*

That implies that the Education Authority waits for the special educational need to manifest according to its criteria before it reacts, regardless of a medical diagnosis.

My child eventually received two extra hours of additional teaching help per week in primary school, and it made all the difference in the world to him. A child who is the same age as my child, who was diagnosed at the same time with exactly the same type of brain tumour and treatment protocol, consisting of brain surgery, six weeks of radiotherapy and 55 weeks of chemotherapy — I will spare you details — received no extra help on returning to school, because the educational psychologists (EPs) found that he did not fall under the average intelligence limit, although he had been a child of higher than average ability prior to his tumour.

We hit the same barrier recently in the post-primary school when we asked for the reinstatement of the additional teaching help that my son received in primary school, which, for some unknown reason, did not follow on from primary school to post-primary school. It was removed without our knowledge. The request from the special educational needs coordinator (SENCO) was categorically refused by the school's educational psychologist on the grounds that my son's SAT results were too good. The SENCO decided to approach the request from a medical point of view, which I still do not understand, as we had already gone through that process in primary school. I started the process again of getting medical professionals' reports, even though I already had a file full of them from primary school. This time, though, we got a more directive letter from my son's oncologist in which he wrote:

*"following treatment, rehabilitation strategies must be adopted at an early stage and continued through. Evidence would clearly support [that] early intervention and preventive strategies within the educational environment offer the best opportunity for any survivor to achieve optimal academic achievement".*

The responsibility for my son's transition from the end of treatment to school life fell uniquely on my shoulders. The only reason that I eventually requested a statement of special needs for my son was because I was advised to seek one by a headmistress whose school we visited while looking for suitable post-primary schools. This was already many months into my son's difficult reintroduction to primary-school life. I did not know what a statement of special needs was until I heard that headmistress mention it. I was told categorically by several teachers and special educational needs coordinators (SENCOs) on the ground to prepare for battle, to refuse to take no for an answer and to make double and triple copies of everything. To gain help, I was initially given advice by a charity to navigate the veiled language and heavy administrative path. I did all the groundwork of contacting as many as possible of my child's nine professionals to get reports for his file.

The whole initial process took too long — in fact, it took a year from the end of my son's treatment — to get the help that he needed, mainly because the request for the process itself was not initiated in good time. The reinstatement of the additional teaching help that he had in primary school took another 19 months in grammar school. Both those gaps are very long in a rehabilitation process that:

*"should be adopted at an early stage and continued through".*

I believe that a comprehensive care plan, like a passport of care, recognised equally by all Departments and covering all the needs of an acquired brain-injured child should be drawn up from the moment of the medical diagnosis in consultation with qualified educational and medical professionals and should be followed and reviewed regularly throughout the child's development to adulthood and beyond.

On behalf of all children with an acquired brain injury, I demand that comprehensive training in the awareness, management and rehabilitation of acquired brain injury be introduced throughout educational institutions in Northern Ireland without delay. There are five rehabilitation centres in Northern Ireland for adults with acquired brain injury, but there are none for children. When a child breaks his leg, we put it in a cast and offer physiotherapy if necessary. When a child's neural pathways are fractured for whatever reason, what help are we giving them?

**The Chairperson (Mr Weir):** Thank you for that evidence, Jane-Louise.

**Mrs Maria Treacy (Parents of Children with Acquired Brain Injuries):** I have nothing —

**The Chairperson (Mr Weir):** Your presentation covered the area that I wanted to explore. I think it was very useful and very focused, and I congratulate you on that.

I will open it up to members.

**Mr Hazzard:** Thanks for the presentation. Before I go on to what you specifically raised, you both seemed very agitated at times during the last presentation and very involved in what was being said. Is there anything in particular that you would like to comment on? I do not want to put you on the spot, but is there anything in particular that you want to say?

**Mrs J Kelly:** Yes. The word "aspiration" was used. Frankly, that was the first time I heard it being used. I know that, from my experience, that is what I have been following. I have been following my child's dreams and aspirations, and that has been my motivation. I knew that he needed an intellectual environment for his school afterwards, but it feels as though you are pushing constantly against this really slow machine that looks at you and says, "Och, that is a bit of a shame. They have a brain tumour", rather than saying, "Right. Let's give them all the help they need so that they can be amazing human beings later on".

I really like the notion too that it is not a waste of money to give this so much time. It is not that huge an amount of time. He made massive steps with two hours of extra tuition per week. It made the difference between him going from being a low-average to an average child and to being an average to high-average child who was able to get into grammar school. The educational psychologist was able to see that progress being made.

There is just this idea that you fight for their life once they are given a brain tumour diagnosis and then you seem to hit the place where they are going to spend the most hours and the most productive hours of their day, because when they come home they are just so tired and exhausted. In their whole

rehabilitation process, you are giving them so much, and then you hit an education system that expects your child just to fit in to it.

**Mrs Treacy:** I will add that I think that the Committee and ourselves were privileged to hear from the Human Rights Commission and the Equality Commission. Michael in particular spoke really well for parents. He spelled out to us all that there is a duty on the Department of Education to provide special education but that there is no pathway for parents to understand the redress. I did not know the statementing process; I did not know how to defend my child. I am lost in the process, and I am tired, as a parent. This lady coined the phrase "project managed". I hate it. I hate being that project manager. I should not be that person; I have enough duties as a parent to three children without having to devote all my time to time-wasters and people who are unconsciously incompetent. Something that Michael said, which was very refreshing, was that there is hope out there and there are good practices. We were dismayed to hear that the code of practice will not be coming up for scrutiny. We would have loved that to be here today.

**The Chairperson (Mr Weir):** To be fair, we are saying that, at this stage, there is not a requirement, but that is not to say that there will not be something done to ensure that that will be the case.

**Mrs Treacy:** The last time we came to Stormont with a group of parents was back in November 2013. We brought with us a clinical psychologist — a specialist and expert — and a charity. All we got was lip service. The advisers explained to Mr O'Dowd that the ELBs told him that there were only 24 children in the whole of Northern Ireland with acquired brain injury. Can somebody please look at that and ask how that can be so, when the charity that attended knew of over 200 children that it was working with? How could it be, when the clinical psychologist knew of 1,000? How could that be? These children are lost in the system.

**The Chairperson (Mr Weir):** One of the things that we can do is press the Department to see whether there has been a wee bit of reassessment to see where we are on that.

**Mrs Treacy:** Yes, I think so. It came from the Equality Commissioner. You have to remember that these sets of parents, on the advice of Minister O'Dowd, went to see the five chief executives. There is a pattern developing. They said, "It is not our responsibility; it is that of the schools and the education and library boards". So, we pulled the five of them together. They are on good salaries, and we are not, because we had to give up our jobs for our children. We held an hour-and-a-half meeting. I have never seen as many tight-lipped chief executives in my life. I have seen it repeated. Dr Clare Mangan came to this Committee and shamed herself by saying, "Well, now, the responsibility lies with the school". Who does it lie with? Who do we have to go to?

After that, we went to the Bar Library. We have done research and networked with people in the area of acquired brain injury. It is not as though we are saying that it is a category that is more important than autism, Asperger's or ADHD. We are not saying that. What we are saying is this: why are we lost in school? Not one teacher in Northern Ireland is trained in brain development. When we say that, we are told, "Go back to John O'Dowd and ask him why not". Or, do we go to the education and library boards? If we do, we are told, "No. Sorry, that answer lies with DEL", but it is not here today.

What about the teacher training syllabus? We have appendices to one of her letters that identifies that the SEN training that a novice teacher gets depends on the student — I am going to call them "children", because they are maybe not in their mid-twenties yet — and on the college. We do not have a standardised teacher coming out with the same amount of special educational needs training. So, when I hear Michael speak, I think to myself, "We have been ignored as parents".

At a time in the Department's life when it is reforming special education, you would think that it would listen to parents. If it made the reforms that we are asking for, it should allow all teachers to have a better scope of identifying children with different SEN categories. Unfortunately, or fortunately, that was always based on the medical model. In the medical model, brain injury is permanent. Some people accept that. We are trying to move in and say that there should be an inclusive model. That is what the Bill is about. We are trying to get away from an attitude of people saying, "They can't move on", as Jane-Louise explained. They can. Neurological pathways can be developed. Treatment is support. That is what we are asking for.

The fact that we do not have a rehabilitation unit in Northern Ireland is a disaster. However, we want the schools to give rehabilitation. It is not good enough that teachers, classroom assistants, what were the old SENCOs, and their replacement, the new supported learning coordinator, or educational

psychologists do not have training. There is something wrong. When I hear Michael speaking, I think, "This is an equality issue that we have here. The Department of Education has ignored us". It is not only the Department of Education, however; the social cost that Michael spoke about is that these children do not achieve their potential, and, unfortunately, some will go on to earn themselves a criminal record, which is a greater cost to society. The evidence so far is that the Bill has loads of potential, but until we see the code of practice, I am sorry, I cannot get too excited — it will not be for my child.

**The Chairperson (Mr Weir):** You need to see the practical outworkings of whatever is put in place.

**Mrs Treacy:** Yes. I have to see it.

**Mr Hazzard:** In the document you gave us you touched on the unintended consequence of shortening the reduction in time and how that puts the pressure on to parents. That is something that I did not immediately think of. You were thinking that it is a good thing and that it might quicken the process, but it puts pressures on to parents. Maybe you would like to talk about that. From what you have seen, are there unintended consequences elsewhere that might put pressures on parents?

Finally, then, I believe that there is perhaps a role going forward for a specialised governor on a board of governors to deal with special educational needs. It is something that we can look at. What has been your experience with boards of governors? Have they been capable and willing to involve themselves in your process, or have they simply been another hurdle for you to clear?

**Mrs J Kelly:** On the question of boards of governors, I can say that have never met any. The process we had to go through to try to get my son into the right school for him, which was a grammar school, was very lengthy. It is all extremely stressful, because you are looking for the right school for your child but are not quite sure what their criteria are. One school told us that it did not think that he would keep up, and another school thought, "Yes, brilliant. Bring him in; we are ready for him." I was never given the details about why one board of governors would say no and another would say yes.

On timing, I was saying that I think that the process should be initiated from day 1. As soon as my child was diagnosed with a brain tumour, there should have been red lights flashing that it would give him some form of acquired brain injury. The experts should then have been called in to find out what type of an acquired brain injury, how he would be limited and what departments we needed to talk to so that we could make sure that he would get the rehabilitation and help he needed to overcome it. I think that, because it is not a visible, physical disability, it is harder for people to recognise.

Where the time is concerned, the language used throughout the whole process, from when you begin to ask for a statement, is so difficult to understand. You have so many documents coming to you. You get an amendment notice — I cannot even remember the other terminology — and it is the same document with maybe one word or name changed. It just feels that there is a lot of hiding going on behind many words. As a parent, you do not have the time for that. You are looking after a child with really complex special needs who requires your full-time help, and you are dealing with maybe nine professionals in a medical situation while trying to get your head around and understand the medical needs that your child has.

You would like to assume that you are going to be surrounded by professionals who know what you need. There is a moment of realisation when you think, "They do not get it; they do not understand; they do not actually know what to be doing". You end up having to do it yourself and to negotiate something that is really very heavy. You are also writing and chasing up reports so that things are seen in their full light. So, I would say this: make the process more action based.

**Mrs Treacy:** Can I just add, Chris, that the board of governors is a wonderful idea to strengthen the management of the school. Perhaps in later years the Education Authority will move funding responsibilities to the schools, which is possible. At least there should be a safeguard that there is a SEN person on the board of governors.

Moving on to the question of the barriers, we heard here that 81% of some statements do not get done in time. We are in the middle of this blame game. The next time you are at speech therapy, ask where they got that advice. We are in between, but we are lucky, because we already have a therapist. There are children out there with special educational needs who are not even in therapy yet, so there will be a long delay. I think that there is a three- to four-month delay in our trust for them to be seen by a speech therapist, occupational therapist (OT), physio or whatever.

With regard to the whole question about allied health professionals (AHPs) in schools and the statementing process and who delays what, I can tell you that I had my first statement for primary school. It was working well, but at the annual review the school realised that the next year the board of governors was not going to be able to have two classes of 16 for primary 2. The classes were going to have to amalgamate, which was going to discriminate, for want of a better word, against my child. She was not going to be able to manage, so they went to the EP and said, "Could you look at this? What will be the impact on her?" She did a fantastic report that was included in the annual review, so I thought, "Done deal". Not at all. I got a phone call from the board to say, "Do you know that any correspondence sent in on an annual review is only correspondence? Her recommendations will not change the statementing process. It is not on her statement". I said, "Do you mean that lady's comprehensive report is not going to be included?" The answer was no. The statement was already done, so I thought, "That is a bit of a learning curve".

We started in September, and it was evident that the child was not coping, so I asked for a multidisciplinary meeting — I thought that was a nice word — and I got one. An occupational therapist who had training and worked with adults with brain injury was on our team, and we were so lucky. She had worked with my child and came along, as did the speech therapist. One of the issues around the school day was that, in primary 1, play was kept to the afternoon and there was target learning in the morning when their brain was still alert and able to learn. However, the two primary 2 teachers wanted to do open play first thing in the morning, and the OT and speech therapist said, "That is not recommended for this child". They said, "We are not changing it". They were steadfast, so I spoke to a local councillor and said, "Where do I go from here?" That is the thing. Parents do not have anyone to turn to. The teachers could not even tell me. It was the teachers who were causing the problem. You talk about cooperation. I have spoken for the cooperation Bill, and I am all for it. You can have cooperation all day, but you may not have it in schools, because what happened there was that the advice of the medical people was not accepted by the teacher.

I then wrote to the board and asked for a statutory assessment. I should not have had to, because I had already had the advice and people had the meeting. That started in September 2013. It is now June 2015, and tomorrow night I might get a final statement. So, it has been two years of having drafts and sending emails. In fact, at one stage, I argued to get a new multidisciplinary meeting. I waited for six months, and, in fact, a lady from the board came to the meeting, and the new EP said, "Your child does need literacy support. I will organise that". Six months later, it was not organised. I wrote to them, and they said, "That was up to the school".

So, they have barriers. They are economical with the truth, they do not give the parents an easy time, they expect us to give up our jobs and not pay our mortgages, write to them, prime them, go and look for a QC to do a judicial review and come to you guys, instead of saying, "This is an unmet need. It has been highlighted in the evidence. There is a paper trail here. Let us just honour this child's needs". Instead, that lady from special education said, "We have a fear that we may over-resource one child". It was not them saying, "We will meet her needs". So, there is a mindset, and if Dr Clare Mangan is representing the new regional way of dealing with SEN, I fear that, with all the cuts to the budget and the fact that we still do not train teachers or educational psychologists and do not have a code of practice to discuss today, it will be very bleak out there, Chris. I am sorry for the long answer.

**Mr Lunn:** Thanks, ladies, for your presentation. You make a very powerful case, which, frankly, does not surprise me at all, given your circumstances. We share your frustration.

Let me touch on clauses 3 and 4. Jane-Louise, if I picked you up correctly, you said in your presentation that you thought that not everybody who was involved with your child knew about the acquired brain injury.

**Mrs J Kelly:** No —

**Mr Lunn:** OK, because the Bill makes it clear in clause 3 that the words "teach him", which presumably also mean "teach her", in the Education (Northern Ireland) Order 1996 should be substituted with the words:

*"be concerned with the pupil's education".*

That broadens it, and there is no doubt that there will be a duty on everybody involved in the child's education to be cognisant of all the facts.

**Mrs J Kelly:** Yes.

**Mr Lunn:** That is OK. You make the case, which others have made, for the need for cooperation between the Department of Health and the Department of Education. That is a big issue.

**Mrs J Kelly:** Yes. It is huge.

**Mr Lunn:** The Department seems to think that the wording in the Bill takes care of that. However, I take it that you are not quite satisfied. *[Laughter.]* The Bill's explanatory and financial memorandum states that clause 4 imposes:

*"a duty on the Authority to request help in all cases where it considers that ... a health and social care trust could help in the exercise of its functions."*

What would you like to see beyond that? Do you want something mandatory in all cases?

**Mrs Treacy:** Definitely.

**Mr Lunn:** There is an obligation there, even though it may have needed to be written down, on the health people to respond. Are you afraid that they may decide not to respond?

**Mrs J Kelly:** The Department of Health not respond? In my experience, it has responded and sometimes initiated the information but that has not been acted on by the Department of Education.

**Mrs Treacy:** Trevor, may I bring to your attention a strategy called the Regional Acquired Brain Injury Implementation Group — RABIIG — strategy. It was the brainchild of the Department of Health. The Department of Education was also involved, but it was not reciprocal. In August of this year, we believe that the Regulation and Quality Improvement Authority will come out and explain that it failed. It was a missed opportunity. Do you know why it was missed? The Department of Education did not have to reciprocate on the need to cooperate with the allied health professionals in delivering SEN. It did not have to do so. We have evidence that, when you leave it up to its own devices and do not have something monitored, the Department does not do it.

We think that that is down to a lack of knowledge. When you go to speak to teachers or educational psychologists and mention the word "brain", they go pale in the face because they imagine a child who is going to be attending a special needs school in a wheelchair. They see the physical side. Some 75% of children known to one trust go to a school in a mainstream setting. Therefore, yes, I totally welcome the fact that it has to be monitored. There has to be legislation to state that the Department needs to monitor it. We have not got such legislation, and that is why, in the past 30 years, too many children have been failed. It starts off in your first statement, as Jane-Louise said. Your medical advice is given, sometimes by a community paediatrician who may not be a specialist. Then, someone like Jane-Louise will go to her professionals and get the actual evidence from neurology, oncology, or whatever, but she will still not be listened to.

**Mr Lunn:** I am trying to slow you down. Are you saying — *[Laughter.]*

**Mrs Treacy:** It is a bad habit. Sorry.

**Mr Lunn:** I appreciate your passion on the subject. I do not mean to be rude. Are you saying that, in the past, there have been situations in which the Department of Education requested input from the health and social care trust but then ignored it or not acted on it?

**Mrs J Kelly:** When I was presenting at the beginning, I talked about a child who had exactly the same tumour as my son, and the same treatment protocol. My child received a statement of needs. The other child had a backup letter from the oncologist saying that most children experiencing that type of tumour will need some form of statementing. However, it was refused on the grounds that the child's educational psychologist would need to do a test to test his cognitive ability. Of course, he did not come out as below average, which seems to be a barometer, but that child was one who went from high ability to low ability because of his treatment.

**Mrs Treacy:** Trevor, the allied health professionals do a fantastic job when they are appointed to the child, and, as I said to Chris, when they work on therapy with the child. They provide excellent reports, go into the schools and do their very best. However, how does a teacher — a novice teacher — identify those children who have not yet been identified? You have to go back to the guidance. Jane-Louise spelt out how, in the Department's guidance, an acquired brain injury is not really mentioned. It is only mentioned under significant accident or injury. When you go to the new resource file that the Department has for the teachers, you get a full page. Whoopee. Rather than what you get for other SEN conditions, you get one page. However, it is not written in a language that says, "Look at the working memory in the first section", "Look at the communication", "Look at the cognitive impairment" or "Look at the child's personality and emotional disorders". Novice teachers will think that, by reading that one page, they will understand an acquired brain injury. You then get the health professionals coming in and saying, "You need to listen to my advice". They do not know, because they are unconsciously incompetent. Unfortunately, as that is the case, it is very hard for allied health professionals to come in and for their advice to be taken seriously. Not only is that present in schools but it is very evident when advice on my child goes to the special education panel. None of its members has training in the area either. They know only what they know. Our children are then put into categories in which the panel sees their primary need as being in.

At one point, I asked to get my child into a special unit for speech and language. Her diagnosis included an MRI scan that proved that she had a brain abnormality, so I was told that she would not meet the criteria unless we gave up her statement. I thought that that was so silly. A system has been designed that does not allow for cooperation.

One of the ways around that would be for the schools to be opened up and allied health professionals and educational psychologists were allowed to be in the schools — to be resident. The novice teacher who does not get her answers from the resource file or has not had the opportunity to get the training could then pull in an OT who says, "Look at this child's handwriting", "Is her nervous system working properly?", "Is it something to do with her development?" or "Should we get in an educational psychologist or a clinical psychologist?" The teacher cannot get an opinion, so the child has to go through what, at the moment, is a five-stage statementing process. If allied health professionals and educational psychologists were in schools, there would be saving. Moreover, the length of time taken to get advice would be reduced, as they would already be in the school. It would also assist with the number of statements. Only 16,000 children have statements compared with the 70,000 with SEN. If the allied health professionals were in schools working with those children, perhaps Dr Clare Mangan would not need as many statements.

The Education Authority has caused that anomaly. Why? It has set aside time-allocated educational psychology slots to schools. I have a second child who has been seen by allied health professionals. There is not a medical diagnosis, but there is a suspected case of dyspraxia. I went to the school and asked for an educational psychologist's report, but I was told, "No, we have used them all this year". What alternative route do I have? The only one is to write to the board and exercise my right as a parent to have my child statutorily assessed. I probably will get rejected and will then go for appeal. Unfortunately, the Education Authority is causing the issue and creating the barriers. It blames the allied health professionals for the delay, but I do not see that as being the issue.

**Mr Rogers:** Thank you very much for your testimony. You are speaking on behalf of parents of children with ABI and have expressed the frustrations of a lot of parents out there around getting some attention for their child with special educational needs. The Bill talks about being child-centred. We know that the problem with the system up until now has been that it is very much resource-driven. If the resources were there, you might be lucky to get treatment, and, if it were for a speech therapist, you might get an appointment in six months' time or whatever.

I was particularly concerned at the mention of the term "cost-neutral" in the previous presentation. That seemed strange. If we are to deliver a proper child-centred approach to special educational needs, it will cost money. OK, less money might be needed in the justice system or whatever other systems that the children are in. Do you have concerns that the Bill is not really any more child-centred than what we have had up until now?

**Mrs Treacy:** It is run as a business, and the system has to conform.

You are absolutely right to say that there need to be resources, but the resources are not just in the form of classroom assistants. A lot of it is about training. We have looked globally at how other Governments have handled a new education system model, particularly for children with acquired brain injury. Australia and parts of America lead on it. Europe sadly falls way behind — we are off the

scale. We went to the Department of Education and told it that this was an opportunity and that it could be the legacy of the reforms: that we could give educators, with their co-peers — the allied health professionals — the chance to learn about neurodevelopment and how a child develops. We were not invited in, and that has not happened.

The first International Conference on Paediatric Acquired Brain Injury is coming to Liverpool in September. At it will be the leading experts from throughout the world. One lady doctor who will be there, Dr Ann Glang, has produced a model that has been up and running for about 11 years in different states in America. It is that type of lady that we would like the Department of Education to speak to in an advisory capacity and ask her what we need to do. The model that she presents will help all SEN categories. She recommends that you need to take this away from the clinical environment, go to school and bring in the child who is involved in the case. She also recommends that the parents, the classroom assistants, the school nurse, the principals and the SENCO — all the stakeholders who are working with that child — need to be trained over a period. Sadly, what we are seeing here is a quick fix — a sticking plaster — in which educational psychologists go to an opening session on what ABI may look like. That is not a multidisciplinary process. It is not training from which people can learn.

Acquired brain injury is only emerging as a condition in Europe. It is there and has been there for many years. We need a model. We do not have a model, but the spin-off of that model is where the spending could occur. If you want to take a blueprint from America to see whether we could adopt it, that could be one. That is what happens — we look across the water. Even if we look closer, to England, Bristol has a training centre for training on acquired brain injury. We do not have that in Northern Ireland. The multidisciplinary team in Cambridge has three health professionals and one peripatetic teacher. In Northern Ireland, the Department of Health funds the Children's Acquired Brain Injury Consultation Service. That is headed by Dr Eunan McCrudden. He is a leading clinical psychologist in acquired brain injury in Northern Ireland and has part-time OTs and speech therapists. The service is not nearly what it should be.

The Department of Education is supposed to use his service for consultation, but it does not fund it — it is not co-funded. If it were co-funded and both had ownership of it, we would have peripatetic teachers and educational psychologists involved. That would bring it all together. We would probably suggest looking at a new building for that and for that organisation to be taken from a hospital out to a school of excellence, where we can develop how we manage children with acquired brain injuries, because the injuries are so complex. In unravelling their complexity, the spin-off for learning for other teachers is better than what we get at the moment, which is, "Your child presents like a child with autism, so let's use that strategy".

When I asked a neurologist at the very start of this journey how I could explain the condition to a non-medical person, I was told, "Just say that your child is like a child with cerebral palsy. Just say that it is like cerebral palsy". However, it is not.

We want to get away from this doublespeak, we want to say what it is and we want to give you the most cost-effective way of dealing with it. There is a real opportunity here in September. Dr Mark Linden, at Queen's, has also done lots of research in Northern Ireland about how little educators know about traumatic brain injury, which is a subset of ABI.

We have the resources and could be the leading Education Department in Europe rather than the last to take it up. This is the time to do it, because in 30 years' time I will not be here to give you this speech. *[Laughter.]*

**The Chairperson (Mr Weir):** We may not be here in 30 years' time either. *[Laughter.]*

**Mr Rogers:** Given your experience of acquired brain injury, is it possible that, with the proper intervention, children could be operating quite well at two or three years behind their chronological age?

**Mrs Treacy:** Such children have a patchy profile.

**Mr Rogers:** Clause 13 refers to children up until their nineteenth birthday. However, children with acquired brain injury would benefit from having that extended until they were 21 or 22 years old.

**Mrs Treacy:** Yes, because children's brains do not fully mature until their early twenties. I had something silly said to me by an education adviser. I did not know that it was silly the day that she said it, but she said to me, after my child had suffered two episodes of hypoxia, "We normally find that children who suffer that catch up after a few years". If she had been trained, she would have known that, once children have an episode that affects their brain development, you will not know the deficits. They perhaps do not manifest themselves in primary school. They could occur in secondary school or beyond. That is why we have asked for legislation to cover children up until at least the age of 21. That would give those children who have not developed according to their chronological age a chance. It would also allow the frontal lobe — the front part of the brain — to develop. When that part of the brain develops, there is a risk of headaches and personality disorders. Only then might we know whether a child had an injury or infection early in childhood. Unfortunately, GPs and hospitals are not coding that, and, as a result, those children are not being tagged. Quite often, no one is making the connection with a child's medical history. There is actually a publication in which the connection is not made.

In the red book that parents are given when a child is born, we are asked to methodically keep records of their vaccinations, but we are not told that their neurological development is precious and needs to be recorded. If a child has something such as swine flu, in five years' time, we may see loads of teenagers who had swine flu in primary school and may have got a brain injury from it but were left undiagnosed. Unfortunately, they may get a diagnosis of ADHD or be just seen as adolescents with behavioural difficulties.

**The Chairperson (Mr Weir):** Jane-Louise and Maria, thank you very much for your evidence. It has been particularly helpful to get evidence from people on the front line, who have that direct, personal experience. That has been valuable. Thank you.

**Mrs Treacy:** We wish you well. Thank you.