

11th May 2015

Mr Peter McCallion
Clerk to the Committee for Education
Room 375a
Parliament Buildings
Ballymiscaw
Stormont
BELFAST
BT4 3XX

Dear Mr Mc Callion,

**Response to the Special Educational Needs and Disability Bill
by Independent Parents of Children with Acquired Brain Injuries**

1. In 2013 Mrs Maria Treacy and Mrs Jane-Louise Kelly were members of Northern Ireland's first parent support group (Talking Heads) for carers of children with **Acquired Brain Injury** (ABI). As independent representatives of parents caring for children with Acquired Brain Injury in Northern Ireland we would like to comment on the SEND Bill. Sincerely we apologise for this late submission and express our concern that although we have been engaged with the Minister of Education, the Head of the Special Education Team, Ms Frances Curran and previously the Chief Executives of the five Education and Library Boards on educational provision for children with Acquired Brain Injuries, we were neither informed nor asked to respond to the SEND Bill.
2. We are of the opinion that the Department has a duty to ensure proper provision is made for the education of children with ABI, a duty, we believe, it is currently failing to discharge. If we were given the opportunity we would certainly like to meet with the Committee for Education to give an oral account of our findings with regard to this SEND bill.
3. On the 10th March 2015, at the second stage of the bill Mr O'Dowd stated;

"..the basis for the existing framework dates back to 1986. Although the Education Order 1996 and the Special Educational Needs and Disability Order 2005 made some important changes to the inclusive aspects of that framework, I need to recognise and overcome the barriers imposed by the framework initially developed some 30 years ago."
4. We strongly welcome the much needed reform to the legislative framework of Special Education. We are conscious of the time and effort it takes in the process of deeming a bill 'good legislation'. There is however a missed opportunity with this SEND Bill in its current form. Although there is apparently a conscious move to overcome barriers imposed by the framework, it is of greater concern to us that there are crucial issues **not**

being addressed. If this review process has been ongoing since 2006 why have key matters been left unanswered by this SEND Bill? For example it is difficult if not impossible to comment on the potential outcome of this Bill without having the reformed **SEND Code of Practice** and further details of the **revised Statement process**. More time and consideration need to be allocated by the Committee so these essential details are presented for consultation. This incomplete method makes it impossible to draw finite conclusions on this Bill. The importance of **Inter-departmental cohesiveness** has not been addressed by the SEND Bill. It is not possible to compartmentalise SEND into one department. It is cross-departmental, and co-operation between departments is vital for the delivery of an education system designed to unlock a child's full potential. Children with ABI are the perfect example of a population of children that demand a high standard of co-operation between all governmental departments (DE, DHSSPS, DoJ, DCAL, DEL, DSD). How would this SEND Bill achieve the mandatory co-operation required without legislating on the participation/responsibility of the Department of Health and Social Care to fulfil the joint delivery of special education?

5. The Department of Health and Social Care and the Department of Education are intrinsically linked in the provision of special education. Already they work jointly towards providing a multi-disciplinary approach that is child and young person-centred by promoting inclusive education for pupils with SEND. On the issue of SEND these two departments coexist, motorised by **separate executive funding** and an array of domestic and international legalisation to govern their actions. To get the best delivery of children's services and co-operation these two departments need to be formally united by this reform. This bill should set up a legislative framework in **collaboration with the department of health** initially.
6. The reforms to the SEND education have failed to tackle the practical problem of a **growing percentage of children and young people with SEND** and the increasing **pressures placed on both departments** to manage their limited resources and reduced budgets. The plan should have included sharing resources and pooling budgets. The reform process should have drawn conclusions about the role of all professionals involved in delivery of SEND and provided a clearer structure designed to optimise the best utilisation of resources. With increased demands how do teachers and allied health professionals teach and deliver therapies all the while juggling growing numbers of pupils with SEND, new legislation, ongoing SEND/inclusion monitoring (PLP, IEP, Statement, Annual Review)? Disturbingly with the increasing workload they will need to prioritise tasks while trying to meet the educational and clinical needs of these children. It is alarming that the role of the Educational Psychologist has not been reviewed in this process. Over the past 30 years EPs have provided an essential service to Special Education. CASS is an integral service for schools but its future involvement is not stated in this reform. Likewise the role of other agencies like Surestart, CAMHS, ACE and voluntary organisations are not clearly recognised. It is evident the Bill addresses the role of the Boards of Governors and Learning Support Coordinators but the resourcing and role of all other professionals and agencies involved is not clearly stated.

7. This SEND Bill will not build a better system of education or provision for children with ABI. **The Department of Health made the same mistake** when it commissioned the Regional Acquired Brain Injury Implementation Group (RABIIG) to improve children's brain injury services based on a system of reciprocal goodwill to be established with the department of Education. RABIIG boasted that;

"Improved linkages with the Education Sector and a better understanding of the effects of ABI will lead to improved outcomes for children of school age."

[Brain Injury: Service Standards and Quality Indicators 2010 Report, RABIIG: Page, 2]

This RABIIG strategy failed as there was no legislative framework between the departments to deliver better joined services for children with ABI. This was a real opportunity for good practice in providing children with ABI improved special education, sadly it turned into a missed opportunity. Later this summer (August 2015) a recent review of RABIIG by the Regulation and Quality Improvement Authority (RQIA) will be published and it is likely to highlight how this was a systematic failure. If this is evident in the RQIA report it will be too late to prevent the same mistakes reoccurring through the reintroduction of this Bill as it stands.

8. Assessment of SEN for children with ABI is heavily **dependent on clinicians** providing the initial diagnosis, medical advice for the Statement and identifying therapies required (*e.g. Speech and Language Therapy, Occupational Therapy, Physiotherapy, Behavioural Therapy and Psychology Services*) so that the child is fully empowered to engage in an inclusive educational setting. The contribution of the health professionals is paramount at every stage of education, including pre-school level, yet this Bill fails to restructure the 'framework' to enforce legally binding co-operation in a cross-departmental fashion. Instead the framework is as weak as it was thirty years ago as inter-departmental co-operation remains based on reciprocal goodwill between the Departments of Education and Health.
9. This Bill is failing to remove barriers for **children aged 0-4 with SEND**. It does not protect this most vulnerable stage of special education by failing to implement a comprehensive early intervention and identification of children with SEND or suspected SEND. The child's Red Book (*completed by parents, health visitors, doctors and health professionals*) entitled "My Personal Child Health Record" advises parents to 'contact your Health Visitor or GP' if they are concerned about the developmental issues. Early SEND identification is heavily reliant on parental observation years prior to school age. The Bill does not target raising parental awareness or a sharing of this responsibility with the Department of Health. Early intervention and identification of SEND should be targeted at pre-school age. As the Department of Education has not been involved in providing advice to parents in the red book, this is also a missed opportunity. The education of parents/carers on global developmental delays and expectations for a child to pre-school age should be met by both departments. From experience we have witnessed how health visitors and GPs appear to have no access to support children with suspected neural developmental concerns. This Bill does not break down the silo mentality that continues to exist with each department working separately nor does it contribute to early intervention prior to capturing SEND at the pre-school stage.

10. The **pathway between Health and Education for pre-school age with SEND** is not established by this Bill. Signposting parents towards early intervention for pre-school age children, is not being adequately addressed in this SEND reform. Better screening and awareness need to be developed for parents, health visitors and GPs to ensure early identification and the necessary input of support for the child. Access to pre-school settings for children with suspected SEND needs is not fully met by this Bill in terms of resourcing changes and Capacity Building for pre-school settings.

Clauses:	Parents of ABI response:
<p>1 Duty of Authority to have regard to the views of the child</p>	<p>We welcome this reform but are aware that the mental and cognitive capacity of the child needs to be taken into consideration, particularly for children with ABI. They may require competent and caring support to be able to fully express what it is that they want said.</p>
<p>2 Duty of Authority to publish plans relating to its arrangements for special educational provision including a description of the resources and support services available</p>	<p>Without the New Code of Practice it is difficult to judge if the Authority will have an improved guidance on categorizing pupils with SEND suitably, particularly children with complex SEND, common coexisting conditions and disorders that overlap. Childhood ABI is a classic example of a condition that has many presenting problems that are interlinked. With more than one presenting problem, placing that child into the right SEND category or categories is awkward. Specialised Clinical and Educational Psychology input is required to ensure the representation of pupils with specific SEND is truly reflective, only then the Authority can more effectively plan arrangements for SEND provision once the ratio of SEND categories is understood. This comes from the revelations made by the Minister of Education (18/11/13) that the 5 ELBs informed him there were 24 pupils in Northern Ireland with ABI. This is a grossly inaccurate figure and miscalculated prevalence, which adversely affected the ability of the Authority to duly allocate provision for children with ABI.</p>

<p>3 Duties of Boards of Governors in relation to pupils with special educational needs</p>	<p>Increasing the role and duties of the Boards of Governors is ambitious as these positions are normally held by volunteers who will require a level of training to appreciate SEND and the legislative reforms. This clause is commendable as it seeks to raise awareness among all staff to safeguard children on the schools` SEN registrar. The movement from IEPs to PLPs could be beneficial but it needs more consideration as the detail of its application in the Code of Practice is not available and as a result again it is difficult to judge the significance of this change to supporting children with SEND. It is imperative that the LSC has adequate SEN experience/desirable qualifications and training. Teachers taking the post of LSC will require training on; (a) new SEND reforms (b) relationship between the LSC & Board of Governors on SEND (c) associated legislation. It is preferable that the LSC is a teacher from senior school management level and that the Board of Governors can protect the time the LSC will require to fulfil their duties. For SEND to be safeguarded, the LSC needs to be respected by their colleagues and what is understated in this proposed Bill is the importance of the LSC`s relationship with other professionals, parents and pupils.</p>
<p>4 Duty of Authority to request help from health and social care bodies</p>	<p>This need is still defined as a request for help. Only with mandatory interdepartmental co-operation will the services from HSC be guaranteed. The Department of Education and Health need to be obliged to provide all support on request, rather than recipients of their services having to rely on an ad hoc relationship of goodwill.</p>
<p>5 Assessment of needs: reduction in time limits Appeals</p>	<p>Reduction in the number of days can increase the pressure on parents to seek advice and make representation for appeal. In special circumstances this clause needs to be flexible for parents dealing with complex issues.</p>
<p>6 Appeal following decision not to amend statement following review</p>	<p>This is a positive reform as too often new SEN requirements identified at annual reviews are not considered or recorded as an issue worthy of amending the child`s existing statement. The right to appeal is beneficial to ensuring the process of monitoring and reviewing SEND by annual review is productive.</p>

7 Child under 2: appeals against contents of statement or failure to make statement	This reform is a welcome development as it offers some protection to pre-school school children with SEND.
8 Mediation in connection with appeals	Who is responsible for explaining the mediation process to the parents? The appointed mediator must be independent and suitably knowledgeable. It will be welcomed if parents do not incur the cost of this mediation service.
9 Rights of child over compulsory school age in relation to special educational provision	This is a positive and much needed development for young people with SEND so that they are enabled and empowered to continue their educational career by participating in decisions which impact their future. Clarification is required on how young people with reduced mental capacity will be fully supported. Is it only parents who can take responsibility to exercise this right for the young person or a “significant other / representative” such as a Social worker?
10 Rights of child over compulsory school age in relation to disability discrimination claims	Every young person should have the right to post 16 education. We welcome this clause and would like that it ensures ‘ all ’ young persons with SEND ‘ will ’ have the opportunity to explore further opportunities in education over compulsory school age. Employment and education opportunities for children with SEND post 16 years of age is sadly underprovided for. It is essential that provision of SEND provision continues to at least 19 years of age although we see the need for children post 19 with SEND to be equally supported in continuing their educational career. The language of care should be completely understand and shared all by educating institutions.
11 Appeals and claims by children: pilot scheme	Childhood Acquired brain injuries are effective from birth up to age 25, since the developing brain does not finish maturing until that time. This means that the deficits of a brain injury occurring in the younger years may not present until later in that child’s development. Policy intent of this Bill should cater for young people up to the age of 23 years old which goes much further to meeting

	the needs of children and young people with ABI than the current proposal of ending at 19 years old.
12 Appeals and claims by children: follow-up provision	This is welcomed, but the pilot scheme is going to take two years and will only include children of compulsory school age, not current post 16 years of age young people with SEND who are not included in the pilot scheme. The aims and objectives of this pilot scheme need revised before being implemented.
13. Definition of a child	It is a welcome development to view a child up to the age of 19 years old however we would strongly advise for education purposes that this be extended to 23 years of age for the reasons we have highlighted above.

We hope that this response from concerned and implicated parents, attempting to improve SEND provision for all children and young persons with ABI, will be beneficial to the Committee of Education in its review of the SEND bill.

Yours sincerely,

Maria Treacy & Jane-Louise Kelly

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