

Committee for the Office of the First Minister and Deputy First Minister

Children's Services Co-operation Bill Response pro forma

For your convenience the Committee has prepared the attached pro forma to assist in responding to the main clauses of the Bill. The Bill can be found at <http://www.niassembly.gov.uk/assembly-business/legislation/current-non-executive-bill-proposals/childrens-services-co-operation-bill-as-introduced/>

Please respond by Friday 27 February 2015 to committee.ofmdfm@niassembly.gov.uk.

Organisation Name	In 2013 Mrs Jane-Louise Kelly and I were members of Northern Ireland's first parent support group (Talking Heads) for carers of children with Acquired Brain Injury (ABI). As representatives of parents caring for children with Acquired Brain Injury in Northern Ireland we collectively support and welcome this Children's Services Co-operation Bill.
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I wish for my organisation to be considered for oral evidence sessions in relation to the Committee's scrutiny of the Bill: Yes please

Clause	Comments (200 words)
<p data-bbox="174 188 369 212">1. General Duty</p> <p data-bbox="174 268 526 292">Please provide comment on:</p> <ul data-bbox="174 347 548 1034" style="list-style-type: none"> <li data-bbox="174 347 548 603">• The six specified outcomes relating to the well-being of children and young people as listed in the 10 Year Strategy for Children and Young People 2006 - 2016 <li data-bbox="174 659 548 874">• The duty on Northern Ireland Departments to co-operate with each other in order to further the achievement of these objectives <li data-bbox="174 930 548 1034">• The mechanism in place for amending the specified outcomes 	<p data-bbox="566 228 2047 483">We recognise how children with Acquired Brain Injury (ABI) are ignored. The aim of this 10 Year strategy was to create a better world for all children. Yet today children with ABI are living in a society which fails to respect their rights due to the incompetence of Northern Ireland Departments to deliver services for children with ABI. This strategy was to improve the health and well-being of those with a physical or sensory disability, yet it did not produce significant improvements in the provisions to Children’s ABI Services thus far.</p> <p data-bbox="566 531 2047 746">In 2008, the Minister for Health, Social Services and Public Safety commissioned a review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland, from which an Acquired Brain Injury Plan was developed. Since the release of the Acquired Brain Injury Plan, the Regional Acquired Brain Injury Implementation Group (RABIIG) has been working to progress the recommendations.</p> <p data-bbox="566 794 2047 1137">In 2015 the RQIA undertook a review of the implementation of the Brain Injury Action Plan across HSC trusts and progress in developing services to meet the needs of children who have suffered a brain injury. The pending results of this review will highlight how the Department of Health failed to deliver a satisfactory level of Neurological Paediatric Provisions. Therefore if prior strategies, plans, implementation groups have failed in the past to secure improvements it will take a much more robust mechanism to amend and deliver the necessary outcomes so desperately required for these children. We believe this bill has the potential to achieve this.</p>

Clause	Comments (200 words)
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<p>2. Co-operation Report</p> <p>Please provide comment on:</p> <ul style="list-style-type: none"> • The requirement for OFMDFM to publish periodically a report on the progress of departments towards achieving the specified outcomes • The requirement for other Northern Ireland Departments to cooperate in the preparation and publication of the report 	<p>It is impossible to compartmentalise children's needs into one Department. It is cross-departmental, and co-operation between Departments is vital for the well-being of all children. Children with ABI are the perfect example of a population of children that demand high standard of co-operation between all government Departments (DE, DHSSPS, DoJ, DCAL, DEL, DSD).</p> <p>But it is possible and logical that one department continues to report on progress of executive departments' commitment to co-operation, as OFMDFM holds the policy lead they should be tasked with overseeing co-operation across all departments and agencies to achieve the specified outcomes periodically.</p> <p>Realistically there has been challenges in delivering the 10-year strategy for children and young people but investing further in <u>Delivering Social Change (DSC)</u> should better support children with ABI. The journey has started in challenging the difficulties that many families find themselves in. In comparison, the speed at which Paediatric Neurological Services have been modernised is at a snail's pace.</p> <p>Presently brain injury is incurable but treatable by employment of an extensive competent Inter-disciplinary team which in turn commands cross-department co-operation for all children's services. (This could be done by adding / expanding to the Children's Acquired Brain Injury Consultation Service Team (CABCS) and transforming it from a health multi-disciplinary team to an Inter-disciplinary team.</p> <p>It will come apparent to government how children with ABI have been disadvantaged historically as the definition of brain injury and implementation of care was exclusively derived from a <u>medical model</u> yet to responsibly meet the needs of children with ABI requires adaption of the <u>social model</u> which is complementary and beneficial to all children with a disability not just those with ABI. Medical advances mean more children survive brain injury with better prognosis. Public perception of childhood brain injury is typically of children with severe disabilities but increasing these children have complex hidden disabilities (including lack of inclusion) attend mainstream/ grammar schools, few require home schooling or transfer to a special needs school. This myth needs dismissed by awareness training, delivered cross all departments.</p>
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Clause	Comments (200 words)
<p data-bbox="174 177 479 248">3. Sharing resources and pooling funds</p> <p data-bbox="174 300 479 363">Please provide comment on:</p> <p data-bbox="174 419 479 751"><input type="checkbox"/> The enabling power which will permit Northern Ireland departments to establish pooled budgets and shared resources to achieve the six outcomes in clause 1</p>	<p data-bbox="501 177 2011 308">In England and beyond where there has been examples of cooperative working, particularly by pooling of budgets, costs have reduced, efficiencies gained and the delivery of services for children has improved.</p> <p data-bbox="501 355 2011 571">For the benefit of all children in Northern Ireland we support the sharing of resources and pooling of funds. Faced with a severe lack in funding in the provision of children’s ABI services accompanied by the lack of public awareness of ABI and scarce existence across children’s services of trained professionals or experts with ABI knowledge and availability of skill framework calls for uniting all resources.</p> <p data-bbox="501 619 2011 879">Currently the pathway or transitions for children on their life journey evolves around provisions provided between a number of departments (DE, DHSSPS, DoJ, DCAL, DEL, DSD) however for children with disability and particularly ABI this ad-hoc approach is damaging. Children with ABI sadly not been supported to reach their full potential. The current government structure encourages silo mentality by enabling powers to pool and share valuable resources will break down that silo mentality.</p> <p data-bbox="501 927 2011 1058">From a parent-lead perspective it would make common sense that all necessary professionals working in children’s services share in the process, combine resources, pool budgets to strive for a better achievable outcomes for children services.</p> <p data-bbox="501 1106 2011 1366">Allied-health professionals should be allocated to schools, teaching staff would gain from the permanent timetabled presence of these professionals onsite along with shared resources for the benefit of pupils. For example, Speech Therapist (SLT) could continually liaise/advise teachers not just for pupils with SEN but concerns for any pupil. Both could share resources; e.g. communication flash cards could be used by the pupils and their teaching staff as part of their IEP’s in classrooms and not kept by the SLT for use only in clinics.</p>

Clause	Comments (200 words)
<p>4 Children’s Services Planning, Please provide comment on:</p> <ul style="list-style-type: none"> • The requirement for the Health and Social Care Board to review and publish a children and young people’s plan, including: • Content, Review mechanism, Co-operation between public bodies • The public bodies listed at Clause 4 (7) • The duties placed on the HSCB particularly with regard to monitoring and reporting 	<p>The current planning of children’s services is falling short. A systemic example of failure will be highlighted by the RQIA later this summer when their findings will be published on the outcomes of RABIIG and it’s Brain Injury Service Standards and Quality Indicators report which proposed in 2010 targets like;</p> <p style="text-align: center;"><i>“Improved linkages with the <u>Education Sector</u> and a better understanding of the effects of ABI will lead to improved outcomes for children of school age.” [page,2]</i></p> <p style="text-align: center;"><i>“Links will be made as appropriate between Community Brain Injury Services, other <u>statutory bodies</u> and voluntary organisations (e.g. Education, DEL, Cedar, Headway & the Children’s Brain Injury Trust).” [Page 6]</i></p> <p>It is likely that the RQIA will conclude what parents of children with ABI have uncovered that the brain injury action plan was not delivered to plan. The RQIA may serve an improvement notice on the HSC Board but will this resolve future planning for ABI Children’s by the HSBC?</p> <p>This Bill would promote cooperation at policy and operation levels. Departments, agencies and relevant partners should work together to plan, implement and monitor the appropriate policies. Children and Young People's Strategic Partnership (CYPSP) is an example of where agencies have cooperated well but based simply on goodwill. Agencies within HSBC had a responsibility to engage with others but those agencies did not have the reciprocal duty to cooperate in return. Clause 4 seeks to strengthen the principles of the CYPSP; indeed, the agencies outlined in clause 4 are already members of the CYPSP.</p>

Do you have any suggested amendments to the Bill? (200 words)

Listen to children with ABI and their parents, as children have rights and parents are in the best position to advocate for children with ABI.

Do you have any other comments? (200 words)

Policy Intent, outcomes and operation

Childhood Acquired brain injuries are sustained from birth up to **age 25**, since the developing brain does not finish maturing until that time. **Policy intent** of this Bill should cater for young people up to age of 23 years old which goes much further to meeting the needs of children and young people with ABI than the current transitions to adult services at **age 18**.

Currently;

- Educators (teachers, Educational Psychologists, SENCO's, school Nurse, class assistants) **do not receive ABI training**.
- Those involved in Youth Justice and Restorative Youth Justice are **ill-equipped to identify** alleged young offenders with undiagnosed or diagnosed ABI, hence a large number of youth offenders gain criminal records and custodial sentences instead of receiving support and diagnosis of brain injury in appropriate cases.
- Hospitals, Emergency Departments and GP's **do not record/ code incidences** of paediatric; concussion, head injury, primary and secondary brain injuries, meningitis, swine flu, stroke, hypoxia or receives radiotherapy, chemotherapy and neurosurgery. Health or education staff don't instantly identified these incidences as potential risks of resulting as acquired a brain injury later in the child's life (up to age 25) as deficits become apparent later with brain maturity.
- Incidents and statistics of **childhood ABI incidents and prevalence** is not readily available to Executive Departments. Hence funding does not match demand as the extent of the problem is unknown.
- Undiagnosed and diagnosed cases of Childhood ABI don't have a **specialised assessment unit, pathway or transition plans** between or within departments.
- The Education and Library Boards also **fail to record ABI in school aged children**, as there is no ABI category in the SEN Code of Practice to record these children. The ELB's advised the Minister of Education (2013/14) that there was a total of 24 children with ABI in the whole of Northern Ireland, **a gross under-estimation**.
- Special Education don't recognise or categorise pupils with ABI as they don't know the actual definition of ABI. Awareness building and rollout of training is required.

Basically with inter-department cooperation this bill will provide an array of professionals **working with children with a better understanding of ABI** which will raise public awareness of the condition help identify, support and manage suspected cases of ABI.

What is it like for parents when government departments fail to co-operate?

As one mother said;

*“ I have become a **project manager** instead of caring for my child or resuming employment I spend my day safe-guarding my child from an accidental medical error in hospital appointments, as the oncologist, neurologist, ophthalmologist, haematologist and so on don't effectively share notes, the left hand does not know what the right hand is doing. As for Education Statements, no-one took the responsibility to initiated that process or even explain it to us before my son returned to school”.*

Parents are lost, with no **pathway** from hospital to home/community and finally a return to school. It is simply not signposted and is dependent on, **how the brain injury was acquired**, which **clinician**, which **trust**, which **ELB** you reside in. Some children leave hospital without discharge meetings, SEN for children with ABI are not correctly assessed as the expertise is not available, and a multi-disciplinary approach is not forthcoming. Educators don't receive training in ABI. Some confess they don't even know what the ABI term stands for and are nervous when talking about the brain as they are uncomfortable due to their professional incompetence.

Agencies like **CAMHS/ACE/CDC** have refused to offer psychology support to children with ABI as they don't have the training or expertise. Physiotherapists, Occupational Therapists, Speech Therapist, Clinical Psychologist cannot offer the necessary support due to lack of training and therapy is time-limited although the child requires ongoing support.

The **Children's Acquired Brain Injury Consultation Service** Team is a starting point to offering inter-department support across health and education, but it's thinly spread and under resourced, not jointly funded.

The fact there is no **Children's Brain Injury Rehabilitation Unit** in Northern Ireland leaves our children and parents at a huge disadvantaged compared to adult brain injury provisions.