

Developing Services for Children and Young People Living with Acquired Brain Injury: Good Practice, Opportunities and Challenges

Virtual Conference NI 2021
Summary Report



This summary report will include the following:

Sharing Good Practice

3



Sharing the Challenges of Service Delivery

4



The Lived Experience of Families

5



Lessons and Learning

6



Conference Conclusions

7



Conference Recommendations

8



Introduction

Brain Injury Matters and Psychological Services within Belfast HSCT hosted the Children and Young People Acquired Brain Injury (ABI) conference: Developing Services for children living with Acquired Brain injury: Good practice, opportunities and challenges on the 10th of May 2021.¹

The purpose of the conference was to consider the range of services currently available and to highlight how services might be improved to best meet the needs of children and young people living with an acquired brain injury. Through a combination of expert presentations, case studies and panel discussions it was intended to showcase best practice across the health, education and voluntary sectors, highlight areas for development and the challenges facing both practitioners and families.

The conference was targeted at practitioners, clinicians and voluntary sector partners working in the field of acquired brain injury and on the day attracted some 130 participants.² The conference opening address was offered by the Minister for Health in the Northern Ireland Executive, Mr. Robin Swann, with inputs from experts drawn from the fields of education, mental health, clinical psychology and social work. A key element in the design and delivery of the conference was the lived experience of children, young people and their families reflected in presentations and the panel discussions.

The conference report below summarises the key contributions offered on the day under a number of themes of good practice, the challenges of service delivery, the lived experience of families and lessons and learning. In turn these have informed the conclusions and recommendations offered to support the development of services.

The quality and range of the presentations, the level of attendance, participation and the feedback offered in the conference evaluation³ all point to a very successful conference. As with all such events a key challenge is what happens next, how can we collectively build on the momentum and learning to better serve those children, young people and their families living with an acquired brain injury?

On behalf of Brain Injury Matters and Psychological Services within the Belfast Health and Social Care Trust we would like to thank you for your participation in the conference and seek your continued support in building a regional framework of integrated services meeting the needs of children, young people and their families living with an acquired brain injury.

Gordon Gough
Chair Brain Injury Matters (NI)

Dr Sarah Meekin
*Consultant Clinical Psychologist
Head of Psychological Services*

¹ See Conference Programme at www.braininjurymatters.org.uk/children-and-youth-services

² See Appendix 1 for the list of participants and sectoral attendance

³ See Conference Evaluation report at www.braininjurymatters.org.uk/children-and-youth-services

Sharing Good Practice



The conference presentations highlighted examples of the range of services which support children and young people living with an acquired brain injury. This included services within health (Children's Acquired Brain Injury Consultation Service; SHSCT Community Brain Injury Team), education (Educational Psychology Service) and the voluntary sectors (Brain Injury Matters, Child Brain Injury Trust). The presentations highlighted examples of good practice, partnership working and the progress that has been made in service delivery for children and young people with ABI since 2016 (See Appendix 3 for details of recent local reviews of brain injury services for children). Summarised below are some details from the various presentations.

The Children's Acquired Brain Injury Consultation Service (CABC's) was commissioned as a specialist training and consultation service. It provides support to services/teams across statutory sectors and also 3rd sector working with children and young people with an ABI. The service is staffed by clinicians from disciplines of clinical psychology, occupational therapy and speech and language therapy, with a whole-time equivalence of 1.0. The presentation noted the range of services that are accessed by children following on from ABI, also referencing the fact that some services are becoming involved with children quite some time post injury.

A new pilot training programme has been established via a partnership between the **Education Authority's Educational Psychology Service** and **CABC's** delivered to Special Educational Needs Coordinators (SENCO) in primary and post primary schools looking at brain development, ABI and its impact, meeting needs regarding ABI in schools and return to school after ABI.

Brain Injury Matters in partnership with Psychological Services within BHSCT delivers evidence based support for children and young people with ABI (0-18) and their families regionally. The Family First Programme provides a family focused model of intervention that is bespoke and tailored to family needs around the ABI. Professor Chris McCusker (University College Cork) presented an external evaluation of the programme demonstrating clinically significant improvements in the quality of life for the children, siblings and parents who had been involved with this programme.

Brain Injury Matters also presented their initiatives and social activity programme for young people, siblings and their families. These programmes, by focusing on social engagement and connections, facilitate interaction for young people and families living with an ABI. Their peer mentoring programme emphasises the expertise that comes with direct experience of having lived with an ABI and supports, develops and educates young adults with an ABI to become peer mentors to younger persons (13-18 year olds) who have recently become aware of their ABI diagnosis. The Family First Portal offers online support for families where they can access a variety of resources, activities, and information documents and communicate on a one-to-one basis with their practitioner and connect with other families involved with the service.

An acquired brain injury at any time is a significant occurrence, but its impact during the teenage years can be even more impactful, given the developmental challenges associated with this stage in relation to identity formation. **The Southern Health and Social Care Trust Community Brain Injury Team** discussed this in detail highlighting in the form of a case study co-presented by Dr Salisbury and Rory Keenan, a service user who had become involved with this service in his teenage years. Their collaborative and moving presentation focussed upon Compassion-focused therapy (CFT) and how this formed the basis for promoting his mental and emotional well-being following his brain injury. CFT is extensively used across mental health services to encourage people in developing compassion, both for themselves and others, as an essential component of well-being. The presentation indicated how a well-evidenced mental health therapeutic approach can have a comparably impactful following an ABI.

Sharing the Challenges of Service Delivery



Arising from the presentations and associated discussions a number of challenges in ensuring timely and appropriate service delivery were highlighted. These challenges are summarised below.

Awareness and understanding of ABI

Supporting children and their families requires an awareness and appreciation of the systems around the child and young people, family, community, school, services and the broader community context. Research clearly evidences the need to holistically consider the challenges facing children, young people and their families.

An ABI can be sustained in many ways and can have a variety of impacts, partly dependent on the stage of the child's development. These factors have implications for how the needs of children, young people and their families can and should be met by services. Similarly, all professionals who work within services accessed by children and young people who have sustained an ABI need to have some appreciation of how an ABI could impact on children's engagement and understanding.

Education of those working with Children and YP with ABI in education

We know that education plays a key role in a child and young person's life. The international and local literature evidences the need for greater understanding, awareness and implications of a child and young person's injury on them within the school setting. The **Education Authority** in partnership with CABC have developed a pilot training programme for SENCO's in schools regarding acquired brain injury. This needs to be monitored and evaluated with a view to ascertaining what will be of greatest assistance to educators and children and young people with ABI in the school setting.

Accessing services

The **CABC** services reflected on the challenges around the timing of support for children and young people and difficulties accessing services, both in the short term and in the longer term given that the injury-related needs of children and young people can change in the wake of an ABI.

There is no dedicated head injury liaison nurse, in-patient, post-acute, rehabilitation service or specialist community services for children and young people with an acquired brain injury. The independent, external evaluation of the Family First service indicated how this service is meeting unmet need, as unlike within adult services, there still remains no centrally commissioned statutory service for children and young people. The service has also evidenced how it has improved the lives of children and young people, while supporting the whole family unit. However, funding for this service comes to an end in July 2022 and, without further funding, the service will cease to exist.

Brain Injury Matters identified that a regular challenge relates to children who have sustained brain injuries and are subsequently referred for advice and support via voluntary sectors services without a contemporary assessment of their cognitive and/or adaptive functioning. The provision of such a clinical assessment falls beyond the remit of a voluntary sector provider like Brain Injury Matters, and the absence of such an assessment can delay appropriate/indicated supports being provided to children and their families. Expertise to provide such clinical assessment exists within regional specialist services, however, it is less clear whether the same level of involvement is available within local community paediatric services.

The Impact of the Pandemic and Need for Better Coordination of Services

The global pandemic has significantly impacted on service delivery, with impacts on mental health (for children & families), access to statutory services curtailed and significant disruption to education. The **Child Brain Injury Trust** highlighted the ongoing impact that this has had for children and young people with ABI and their families. Coupled with insufficient services provision for those children prior to the pandemic, this has been greatly exacerbated with a rise in difficulties in relation to behaviour, sleep, mental health and wellbeing.

The Lived Experience of Families



The parents' panel, facilitated by Professor Siobhan O'Neill, provided a moving and very powerful insight into the experience of families living with children and young people with an acquired brain injury. The parents, who had volunteered to share their respective stories, were asked to offer their experiences, challenges and aspirations for the development of services. While each experience was unique, reflecting individual circumstances, the timing and nature of the child's injury and geography, a number of common themes emerged. Equally, while the parents' panel acknowledged the support provided by the statutory and voluntary sector providers and by individual practitioners and clinicians, their experiences point to a range of issues and unmet needs within current service provision.

Issues and Challenges

- Coming to terms with a life changing condition is extremely difficult and has given rise to many different and ongoing challenges over the years.
- Delays/inaccurate diagnoses.
- A lack of post discharge advice and support from statutory services.
- The absence of appropriate and timely support in relation to mental health implications of brain injury.
- A perceived lack of coordination of services between statutory and voluntary providers.
- Significant gaps in rehabilitation service for the 14-18 age group, especially outside Belfast.
- Parents and carers lack information and understanding regarding acquired brain injury and its implications and meaning for their child and the whole family post injury.
- Meeting the injury-related, new onset, needs of the child/ young person following their brain injury, including access to timely assessment.
- Lack of understanding of the child and young person's needs within the school environment and how to manage that need.

Aspirations for Service Development

- Greater awareness and understanding of what an acquired brain injury is, and the devastating impact it can have on the family. This awareness needs to be evident in the general public and particularly within the health and education sectors.
- A Key Worker/Liaison clinician dedicated to working intensively with the child and the family from diagnosis, rehabilitation and providing on-going support for the child and family living with an acquired brain injury.
- Increased support at the early stages and ongoing to help families accept and adjust to the diagnosis.
- Rehabilitation service for the 14-18 age group, especially outside Belfast.
- Support for parents and families ongoing from statutory and voluntary providers working more closely together.
- Greater access to mental health support for the child, young person and for the whole family.



Lessons and Learning

The range of presentations, discussions and the very impactful experiences offered by the families provided an overview of the current landscape of service provision and support as well as detailing unmet need. Lessons learned are summarised as follows:

- There are excellent examples of good practice and of collaborative partnerships within the health, education and voluntary sectors. These models need to be resourced and sustained.
- There are some excellent examples of evidence based models that have supported not only the child but the family e.g. the Brain Injury Matters Family First Model.
- The voluntary sector play a vital role in health and social care service delivery. However, as evidenced by Brain Injury Matters their input is curtailed by short-term/temporary/non-recurrent project funding.
- Ensuring the voice of the child, young person and family is heard and is central to service design and delivery.
- There are adverse effects on families and carers supporting a child or young person with ABI and consequently access is required to the training and family focused support.
- Children and young people with ABI including their families have limited access to services that support their mental health and psychological wellbeing.
- There is a need for greater awareness raising and education for clinicians and practitioners in both the health and education sectors to understand the implications of a child or young person's injury.
- The need to consider the changing, evolving and emerging needs and their impact on a child with ABI and the response of health, social care and education services.
- There is a need for a more seamless provision of services across Health and Education and the Voluntary sectors.



Conference Conclusions



This conference proceedings and discussions are congruent with the Department of Health Children and Young People Strategy 2020-2030 with stakeholders from health, education, the voluntary sector and parents coming together to share their experiences and vision of what the future should hold for children and YP with ABI.

We know that some children and young people, like those with ABI, face greater adversities and barriers to well-being and therefore more effort and support are required to improve their well-being. By working together effectively, we can provide better services that are joined up and not allow any child or young person to fall between the gaps.

It is also important to highlight that the majority of children do not live in isolation but as part of a family. Any issue affecting a child can have an impact on parents, carers, siblings and the wider family. Conversely, an issue with a parent or carer can have an impact on the children in a family. We must therefore be mindful of the need to adopt a child-centred and family focused approach where appropriate and possible, in the best interests of the child.

The conference clearly highlighted some examples of positive collaborations and projects between Health, Education and the Voluntary sectors while identifying some good examples of evidence based models of working that have supported not only the child but the child's family and the wider community networks. However, it is very clear from the conference proceedings and the feedback received that there remains limited provision and unmet needs in the services available for children, young people with an acquired brain injury and their families.

The broad consensus and themes arising are summarised below and it is interesting to note many of the findings echo those of the Acquired Brain Injury Conference held in Belfast in 2016, indicating that while progress has been made there is clearly much more to do. This point is also reinforced by review initiatives and policy set out at Appendix 3 which highlights the limited progress and current absence of any clear strategic focus or targeted resources to support children and young people living with an acquired brain injury.

There is further work to be done in relation to a shared understanding, across the general public and various services, as to the causes and consequences of an acquired brain injury in childhood. The scale and nature of the problem is not fully appreciated by statutory bodies, who are therefore not in a position to plan and provide appropriate services. There is a need for easier access to services to facilitate early intervention both after the injury has been sustained; and when subsequent problems arise.

Access to training for educators to assist children with an acquired brain injury is limited as is the provision of services throughout the child's school career and beyond. There is a need for children's service clinicians and practitioners to have a common and shared understanding of the long term implications of childhood acquired brain injury which should be built into the training curricula and professional development of clinicians, educators and social workers across settings.

The need for better communication between health and social care agencies, education and voluntary partners is essential which in turn will improve cross-disciplinary working. A simple but effective approach may be to utilise a link worker to help children and families navigate the various systems they encounter. There is a need for additional resources to ensure service provision for children and young people living with an acquired brain injury and their families is appropriate, timely and supports a seamless model of regional delivery and support.

⁵<https://www.education-ni.gov.uk/publications/children-and-young-peoples-strategy-2020-2030>

⁶ABI Conference Belfast 2016

Conference Recommendations



Arising from the paragraphs outlined above the following summary recommendations are offered.



Awareness: The extent and potential impact of acquired brain injury is not widely understood by those working with children and young people. **We therefore need to educate those both within Health and Education to understand the implications of a child or young person's injury and to understand the longer term implications of this injury on the child and their family.**



Intervention: The early intervention and provision of appropriate services, can significantly improve the long term outcomes for children and young people with brain injuries and so avoid the high costs both for them and society that are otherwise being incurred. **We need to develop a dedicated in-patient rehabilitation service and specialist community services for children and young people with ABI with more access to services that support mental health, and psychological wellbeing.**



Collaboration: Health, Education and the Voluntary sector and other public bodies concerned with the provision of children's services must work collaboratively together to ensure the needs of children and young people with ABI are met efficiently and cost-effectively. **We need to ensure a more seamless provision of services across the Health and Education and Voluntary sectors.**



Family: Ensuring the voice of the child, young person and family is heard. Support for the families of children with an acquired brain injury should be acknowledged and the subsequent detrimental impact this has on family outcomes should be recognised (e.g. physical and mental health, income, family cohesion) and factored into intervention programmes. **We need greater consideration of the impact on families and carers, access to the training and family focused support they might need.**



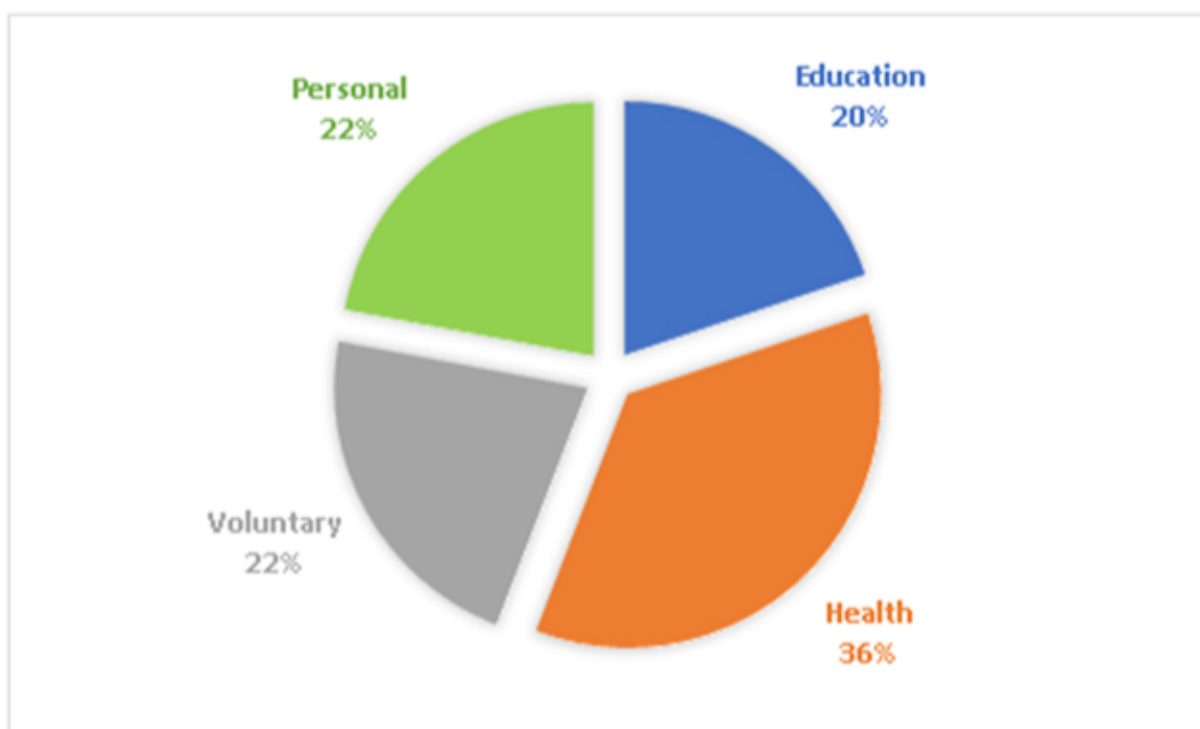
Resources: In order to implement the above recommendations, there is a clear need for additional resources to ensure service provision for children and young people living with an acquired brain injury and their families is appropriate, timely and supports a seamless model of regional delivery and support.

Appendix 1

Conference Participant Summary

The conference had **130 unique visitors** on the day with over **200 additional viewings** online after the conference ended.

Over one third of participants on the day were from the **health sector** while one in five visitors worked in **education**. 22% of participants worked in the **voluntary sector** with the remaining 22% watching the conference for personal reasons.



Of those health sector participants working for Trust areas in Northern Ireland:

- 42% were from the Belfast HSCT
- 5% were from the Northern HSCT
- 21% were from the Western HSCT
- 16% were from the Southern HSCT
- 16% were from the South-Eastern HSCT



Appendix 2

A 20 year Context of Service Provision in Northern Ireland for Children and Young People with ABI

2003 – “Services for Children with Acquired Brain Injury, Getting it Right in Northern Ireland”. Northern Ireland Traumatic Brain Injury Forum & DHSSPS Seminar.

The seminar identified

- A need to establish a residential rehabilitation centre for children with ABI in Northern Ireland.
- Much greater investment in training and support for agencies helping those children who are living at home.
- A gap in acute and community health care for those young people aged between 13 and 18.
- Concerns about ensuring that education services and especially schools are supportive and inclusive of those who have suffered from ABI and are returning to school.

Nigel Williams Northern Ireland Commissioner for Children and Young People, commented that while there was “first class regional acute services for children with ABI in the province, there was a real issue about what happens when children are no longer in intensive care, and especially when they are ready to return home”.

2008 - Minister for Health, Social Services and Public Safety (DPHSSPS) commissioned a Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland⁷.

The review found that there was a sense of isolation of elements of the service and insufficient coordination of care for the commissioning and provision of services. In addition, there was little evidence of the performance management information needed to inform commissioning or strategic planning. It was also noted that there were particular issues regarding how the needs of children and older people with acquired traumatic brain injury were being addressed. The review identified a need a for an action plan - DPHSSPS Acquired Brain Injury Action Plan 2009⁸.

The Action Plan included specific recommendations in relation to:

- Service Redesign
- Quality Improvement
- Improved Support for Individuals, Carers and Families
- Effective Engagement and Partnership Working

The themes and actions were delivered by a series of work streams of which included Children's Services. One of the key outcomes required was to develop a regional standardised ABI Community Care Pathway for Children.

2010 - The Regional Acquired Brain Injury Implementation Group (RABIIG)⁹

This was established to make improvements to health and social care services provided to users and carers of brain injury services. It was jointly managed by the HSC Board and Public Health Agency, and its membership included representatives from the five HSC trusts, statutory bodies, voluntary organisations, service users, parents and carers. RABIIG established The Acquired Brain Injury Pathway for Children & Young People

2013 - RABIIG was stood down. The responsibility for brain injury services, and taking forward the outstanding actions from the brain injury action plan, formerly the responsibility of RABIIG, was to be incorporated within the Physical and Sensory Disability (PSD) Strategy and Action Plan 2012-15.

(Continued on next page)

Appendix 2

2015 - The Regulation and Quality Improvement Authority Review of Brain Injury Services in Northern Ireland¹⁰

This review identified on going issues re services for children and young people with ABI

- There were no specific children's brain injury services, with children being cared for within the relevant specialty of children's services.
- It was difficult to identify the drivers for providing the strategic direction, or how service improvement specific to brain injury could be initiated. Within children's services there were no specific policies, procedures or protocols that aligned to the brain injury standards; the brain injury care pathway for children and young people was the only specific document. It was unclear to the review team as to how extensively this was being used, if at all.
- Key members of staff were identified in each trust who had taken a particular interest in children's brain injury, and their drive and enthusiasm was the impetus for making a difference in the level of care being provided.
- There are no dedicated facilities for children's inpatient rehabilitation or post-acute inpatient rehabilitation in Northern Ireland. The only service for children's inpatient rehabilitation is within the Belfast Trust. Paul Ward within the Royal Belfast Hospital for Sick Children was highlighted as not being a suitable environment for neurology patients. The provision of therapy interventions was also highlighted as an area of concern. Both these areas need to be appropriately addressed within the new children's hospital.
- In the community, children are cared for by the general children's community teams; however, they had no specific brain injury skills. Advice and support is available from the Children's Acquired Brain Injury Consultation Service.
- Overall, good working relationships were reported between the voluntary and charitable organisations and the trusts. These relationships need to be maintained and developed for the benefit of children and their families.
- The provision of an appropriate service for children with extremely challenging behaviour or with complex needs was a significant gap.

2016 - Acquired Brain Injury Conference: Costs and Consequences

Issues arising from the conference were

- Better Awareness of ABI in those working with children and young people with ABI
- Magnitude: ABI is under-represented as a condition and is frequently misidentified as other neuro-developmental disabilities
- Intervention: The need for early intervention (through schools, community, criminal justice system) and provision of appropriate services which can significantly improve the long term outcomes for children and young people with brain injuries and so avoid the high costs both for them and society that are otherwise being incurred.
- Collaboration: the need for all departments and other public bodies concerned in the provision of children's services must, as a matter of urgency, work collaboratively together so as to ensure the needs of children and young people with ABI are met efficiently and cost-effectively.
- Rights: Departments and other public bodies need to consider the United Nations Convention on the Rights of Persons with Disabilities (UNRPD) and United Nations Convention on the Rights of the Child (UNCRC) as they apply to children and young people with ABI.
- Family: The lack of appropriate and effective assessment and support for the families of children with ABI should be acknowledged and the subsequent detrimental impact this has on family outcomes should be recognised (e.g. physical and mental health, income, family cohesion) and factored into intervention programmes.

¹⁰Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland - September 2008

⁹Acquired Brain Injury Action Plan – July 2010

⁷<http://www.hscboard.hscni.net/download/PUBLICATIONS/ACQUIRED%20BRAIN%20INJURY/Pathways/Acquired-Brain-Injury-Pathway-Children-and-Young-People.pdf>

¹¹<https://www.rqia.org.uk/RQIA/files/3e/3ec2d69e-689e-4eac-802d-98ed6c14ee8b.pdf>