

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



Virtual Conference NI 2021
10/5/2021
9am – 4.30pm

Introduction

On behalf of Brain Injury Matters and Psychological Services within Belfast Health and Social Care Trust (BHSCT), we welcome you to our Children and Young People ABI conference: Developing Services for Children and Young People Living with Acquired Brain Injury: Good Practice, Opportunities and Challenges.

Acquired brain injury (ABI) is a complex condition, with injuries varying widely in terms of origin, severity and longer-term impact. The challenges children, and their families face after sustaining an ABI have been the subject of international debate over the last 15 years. Many children will be left with no physical indication of their injury, but are at risk of experiencing difficulties in terms of their thinking, their functioning in activities of daily living and their emotional experiences.

These issues may only become apparent after return to everyday life at home or school. Importantly, as the brain is still developing throughout childhood and adolescence the impact of an injury sustained at this time may not be known for a number of years. In addition, numerous studies demonstrate that children following an ABI are at risk of underachieving in education, developing mental health and mood difficulties and are disproportionately represented in the juvenile (and adult) justice populations.

In 2015 Brain Injury Matters entered a partnership with the Department of Psychological Services of the Belfast Health and Social Care Trust, to develop a service to work with families to support and empower families to meet the challenges of supporting their child with an acquired brain injury. The Family First Service is a secondary prevention service, with an aim to intervene early with children and young people to support long term outcomes, and hopefully prevent these from escalating.

The service landscape in Northern Ireland for children with ABI has not changed since inception of this programme. Unlike for adults, there is no dedicated post-acute, regional rehabilitation service for children with ABI, nor are there any specialist community brain injury services for children. The needs of children with ABI are currently met by a small number of statutory and voluntary players.

Conference Aims

The aims of today's conference are about:

- Highlighting current good practice within NI
- Promoting opportunities for the development of services
- Sharing the challenges of delivery
- Exploring the lived experience of families

Conference Outcomes

We hope this event will offer you an opportunity to think about how we can improve the quality of life for those affected by brain injury, addressing needs in services, and showcase some of the work in the Health, Education and Voluntary sectors.

We hope to enable professionals to gain a deeper understanding of the impact of ABI on children, young people and their families.

Furthermore, we hope to enhance the understanding of services that are available to families, statutory and voluntary sectors as well as identifying some of the challenges and how potentially these can be overcome in the future.

Programme

8.45 - 9.00

Log on

9.00 - 9.20

Opening Comments

Mr Joe McVey, CEO, Brain Injury Matters

Mr Gordon Gough, Chairman, Brain Injury Matters

Dr Sarah Meekin Consultant Clinical Psychologist Head of Psychological Services BHSCT

9.20 - 9.30

Opening Address

Mr Robin Swann, Minister for Health Northern Ireland Executive

9.30 - 10.00

“Acquired Brain Injury in Childhood: contexts & considerations”

Dr Eunan McCrudden, Consultant Clinical Psychologist, BHSCT

“It takes a village to raise a child”. This phrase acknowledges the roles played by people across the community in influencing a child’s development. We all know and recognise the pivotal role in a child’s development played by their parents/caregivers and their siblings. An additional, though maybe less visible role, is played by the other contexts that influence a child’s development. Such contexts can include interactions with extended family, neighbours, friends, teachers, health & social care professionals, service commissioners and politicians.

This reality is no different after a child has sustained an acquired brain injury (ABI). Indeed, following on from a significant injury new contexts might become prominent and established contexts might change or become less available. Fundamentally, the child’s development post-injury will continue to be influenced by the contexts they find themselves in. In this presentation some time will be given to thinking about our local contexts, in terms of services, educational experiences and family perspectives. Reference will be made to where changes have been occurring in these contexts, and how these might be influencing children who have experienced an ABI.

10.00 - 10.30

“Supporting Services: The role of the Children’s Acquired Brain Injury Consultation Service”

Dr Katie Burns, Highly Spec Clinical Psychologist

Charis Wylie, Speech & Language Therapist

Children’s Acquired Brain Injury Consultation Service (Children’s ABCS)

This presentation aims to highlight the work of the CABS service, explain how it interfaces with other services that support children with a brain injury and their families, and discuss the goals for service development post-pandemic.

10.30 - 11.00

“Childhood Brain Injury and Education in Northern Ireland”

Dr Ruth Nesbitt Educational Psychologists Education Authority
Dr Maria Martin-McKeever Educational Psychologists Education Authority

The Educational Psychology Service (Education Authority) and Children's Acquired Brain Injury Consultation Service (CABCS, Belfast Health and Social Care Trust) formed a working group in February 2020, with the aim of developing training and resources for schools in Northern Ireland. Today's presentation will outline the rationale for the EPS and CABCS partnership, provide a brief summary of the training and overview of initial feedback from participants, and discuss how the working group plans to extend the support and training available for schools.

11.00 - 11.15

BREAK

11.15 - 11.20

“An Introduction to Children and Youth Service - Family First Project”

Ms Bridget Smyth, Head of Children and Youth Services, Brain Injury Matters

11.20 - 11.50

“Working with Families: Practical Strategies used by Children and Youth Service”

Meg Irwin, Family First Practitioner
Catherine Quinn, Associate psychologist,

Family First Project, Children and Youth Service Brain Injury Matters
Meg and Catherine will take you on an experiential journey enabling you to understand and experience some of the difficulties experienced by children and families with ABI. They will discuss a case study to illustrate some examples of strategies CYS use.

11.50 - 12.20

“What happens when we bolster family resilience? Family First outcomes for the child, family and service networks”

Dr Chris McCusker, Senior Lecturer in Clinical Psychology
Consultant Clinical Psychologist / Neuropsychologist
University College Cork

Family First is an innovative programme which aims to improve outcomes for the child with acquired brain injury, by bolstering family resilience. In this talk Chris will outline and discuss the outcomes we have seen across the first 5 years of the project. Specifically, gains were observed in child competencies (social and school) and family resilience, together with reductions in behavioural difficulties and distress in both the child and family. In addition to these positive family outcomes, we found impressive project reach, capacity building and filling a gap in statutory provision. Future directions are considered.

12.20 - 13.15 LUNCH

13.15 - 13.45 **“Social & emotional impact of brain injury services during a global pandemic”**

Gerard Anderson, Head of Brain Injury Services, Child Brain Injury Trust

Paediatric brain injury support services across Northern Ireland have evolved and developed over the years, however, none have anticipated a global pandemic and the future needs of families impacted by acquired brain injury. Gerard will explore the evolving needs of families across Northern Ireland and future considerations for the development of effective family support services.

13.45 - 14.15 **“Empowered Engagement: Adolescent Independence & Participation in ABI Services”**

Suzanne Turner, Speech and Language Therapist Youth Matters Project, Children and Youth Service Brain Injury Matters

In this talk Suzanne will share lessons and successes from the Youth Matters Empowerment Programme in engaging adolescents with 1:1, family and group services. The opportunities & challenges related to remote delivery in response to the pandemic. The success of the Youth Steering group in promoting the autonomy of the youth members, involving them in the decision making process, developing a supportive dynamic in an online group scenario and creating opportunities for peer social interactions. How the service is continuing to empower young people through the creation of the mentoring programme in collaboration with the SHSCT.

14.15 - 14.45 **“What Are These Three Circles Anyway?” Life and Learning After Acquired Brain Injury Using Compassion Focussed Therapy**

Dr Bernadette Salisbury Consultant Clinical psychologist and Service Manager of the Acquired Brain Injury Rehabilitation Team in the SHSCT.
Rory Keenan

Brain injury can bring about a sudden and traumatic change in our lives. This presentation will examine ways in which traumatic events affect us and give examples of strategies to increase wellbeing following adversity through sharing a young person's personal journey towards acceptance and resilience.

14.45 - 15.00 BREAK

15.00 - 16.00

The lived experience of ABI: The voice of the families

Elizabeth Downey, Gemma Rankin, Jacqueline Quinn and Sarah Moon with Professor Siobhan O'Neill Interim NIMental Health Champion

Elizabeth, Gemma, Jacqueline and Sarah will talk with Siobhan O'Neill about their experience of having a child or YP with an ABI, what has been helpful, their challenges and what additional supports they need.

16:00 - 16:30

Closing Remarks – Capturing the themes and key learning of conference

*Dr Eunan McCrudden, Consultant Clinical Psychologist, BHSC
Mr Joe McVey, CEO, Brain Injury Matters*

Speakers

Joe McVey

Chief Executive Officer, Brain Injury Matters

Joe McVey was appointed as CEO of Brain Injury Matters in January 2019. He has worked extensively in regeneration and development in local government, the public and third sectors. His areas of interest are governance, leadership and organisational development. Joe is an Honours graduate from the Queen's University of Belfast and holds a Master's in Business Administration and a Master's in Business Improvement. Joe is actively involved in the voluntary and community sector and is currently a Trustee of the the Golden Thread Gallery and the V.S.B Foundation. In June 2015 Joe was appointed to serve as a commissioner with the Equality Commission for Northern Ireland. In 2010 Joe was awarded an OBE for services to the voluntary sector.

Gordon Gough

Chairperson of Brain Injury Matters

Gordon was appointed Chairperson of Brain Injury Matters in 2017. He is past CEO of Enterprise Northern Ireland and has over 20 years experience in international business consultancy. He now runs his own consultancy business, specialising in small business support. He is also a Governor of Southern Regional College and a member of the BBC Children in Need Northern Ireland Committee. An MBA graduate from the Open University, he also holds an MSc in Human Resource Management and is a Fellow of the Institute of Consulting and a past Chairman of the Northern Ireland branch.

Dr Eunan McCrudden

Consultant Clinical Psychologist, Belfast Health and Social Care Trust

Dr Eunan McCrudden has worked with children and their families following ABIs since 2010 when he started working at the Royal Belfast Hospital for Sick Children (RBHSC). In 2011 He contributed to the regional review of acquired brain injuries services. Between 2012 and 2018, he led the Children's Acquired Brain Injury Consultation Service (Children's ABCS) a service-facing-service, building capacity within children's services to meet the needs of children following ABI. Dr McCrudden has also built partnerships with the non-statutory sector and, between 2015 and 2020, provided BHSC's representation within the Family First Service, a partnership between Brain Injury Matters and BHSC. Since August 2018 Dr McCrudden has been employed as clinical lead within BHSC's adult community brain injury rehabilitation team where the impact of ABI in childhood continues to feature in his day-to-day work.

Robin Swann *Minister of Health, Northern Ireland Executive*

Robin Swann was appointed Minister of Health in the Northern Ireland Assembly on 11th January 2020.

A father of two young children, he was first elected as an MLA for North Antrim in 2011.

Before his appointment as Minister, he held a number of posts including Chairman of the Public Accounts Committee, Chairman of the Employment and Learning Committee, Assembly Commissioner, as well as Party Leader and Chief Whip of the Ulster Unionist Party.

He is an active member of the Kells & Conor Community Association and has served as a Board member of the Volunteer Development Agency in Northern Ireland.

Dr Katie Burns *Highly Specialist Clinical Psychologist Children's Acquired Brain Injury Consultation Service (Children's ABCS)*

Katie Burns completed her Doctorate in Clinical Psychology at Queen's University in Belfast in 2008. Having developed an interest in working with children with complex medical conditions, and their families, on qualifying she took up post as a Clinical Psychologist at the Paediatric Psychology Department in Royal Belfast Hospital for Sick Children. As well as working with the regional CABCS service, Katie also works within the Paediatric Neuropsychology service in Royal Belfast Hospital for Sick Children.

Charis Wylie *Speech & Language Therapist Children's Acquired Brain Injury Consultation Service (Children's ABCS)*

Charis Wylie is the Clinical Lead Speech and Language Therapist for Neurology and Neurosurgery at the Royal Belfast Hospital for Sick Children. This role includes providing swallowing and communication assessment and treatment for inpatients as well as time within the regional Children's Acquired Brain Injury Consultation Service (Children's ABCS). The Children's ABCS is a multi-professional team designed to support existing services and to recognise and respond to the needs of children and young people after an acquired brain injury.

Dr Ruth Nesbitt *Educational Psychologist Education Authority NE Region*

Dr Ruth Nesbitt is an Educational Psychologist working in the Ballymena area of the Education Authority. Dr Nesbitt completed her Doctorate in Educational Psychology training at Cardiff University in 2012 and then began working as an Educational Psychologist for Warwickshire County Council.

Since beginning with the Education Authority in February 2014, Dr Nesbitt has worked with pupils and schools who have experienced traumatic events, including Acquired Brain Injury, as part of the Critical Incident Response Team, as well as providing support and assessment through direct casework.

Dr Maria Martin-McKeever

Educational Psychologist Education Authority SE Region

Dr Maria Martin-McKeever is an Educational Psychologist in the SE region of the Education Authority. She qualified in 2019 and previously worked in the NE region. During her training on the Doctorate in Educational, Child and Adolescent Psychology (DECAP) course at Queen's University Belfast, Maria completed elective placements with Paediatric Psychology in the Royal Belfast Hospital for Sick Children/the Children's Acquired Brain Injury Consultation Service (CABCS), and Brain Injury Matters.

As part of her role within the Educational Psychology Service (EPS) Maria has been involved in an ABI working group, which has been a collaborative project between the EPS and CABCS. Her role in the group has included co-delivering training to school staff on ABI.

Bridget Smyth

Head of Children and Youth services, Brain Injury Matters

Bridget graduated from Queens University Belfast with BA Hons Sociology, Postgraduate Diploma and Masters in Social Work 2002 and Postgraduate Diploma in Systemic Practice. Bridget is also a qualified mediator. Bridget has had extensive clinical practice as a social worker and systemic practitioner in a range of Family and Childcare settings North and South of Ireland, both in the statutory and voluntary arena. Bridget brings a wealth of experience in working in the field of child protection, family support, trauma, and the application of evidence based practice in working with children, young people and families. Bridget joined the Brain Injury Matters in 2018 and is the head of the children and youth service.

Meg Irwin,

Family Practitioner, Family First Project, Brain Injury Matters

Meg Irwin is an Early Years specialist and joined Brain Injury Matters' Family First team as a Family First Practitioner In late summer 2017.

Meg has had many roles in my professional career covering over 35 years working with children and families in a range of organisations within the statutory, private and voluntary sectors including working as a cardiographer, nurse, teacher and lecturer, assessor and play therapist. In addition to her role as a Family practitioner working part-time with Family First, Meg also work independently as a Play therapist facilitating Therapeutic and Filial-based play skills alongside parents and carers in a variety of settings with the aim to empower, equip and enable children and families. These skills have been extremely valuable in her role within Family First to enable her to work holistically in support of the family's needs. Throughout her career she has also delivered an extensive range of training including first-aid, ante and post-natal care for parents, ASD awareness, child development, behavioural management, sensory awareness, creative and sensory play for parents and professionals and baby and toddler yoga with parents. Meg's core beliefs relate to working to empower children and families to live as independently as possible and achieving their own potential.

Catherine Quinn

Associate Psychologist, Family First Project, Brain Injury Matters

Catherine graduated from Queen's University Belfast with a BSc (Hons) degree in Psychology in 2015. She then achieved a Distinction in her Master's degree in Applied Psychology (Mental Health and Psychological Therapies) and has worked in a range of clinical settings in the statutory and voluntary sector since. Catherine has particular clinical and research interests in various areas including mental health, attachment, trauma and acquired brain injury. Catherine has been a valued member of the Family First Team since September 2017.

Dr Chris McCusker *School of Applied Psychology, University College Cork*

Chris McCusker is director of the Doctorate in Clinical Psychology at University College Cork. He is also a practising clinical psychologist and paediatric neuropsychologist. He is past chair of the Division of Clinical Psychology in Northern Ireland and the Northern Ireland British Psychological Society. His research has focused on (a) understanding the determinants of outcomes for children with chronic illness and their families and (b) designing and evaluating psychological interventions which improve outcomes for children by strengthening the resilience of the family. This has been across paediatric specialisms including congenital heart disease, acquired brain injury, epilepsy, cerebral palsy and neurodevelopmental disorders. He has published many papers in this area and is author and joint editor of the seminal book *Congenital Heart Disease and Neurodevelopment: Understanding and Improving Outcomes*, McCusker and Casey (2016). He is the external evaluator of the Family First project in Northern Ireland.

Gerard Anderson, *Head of Brain Injury Services, Child Brain Injury Trust*

As Head of Brain Injury Services for the Child Brain Injury Trust, Gerard manages a national team of brain injury support coordinators based in 19 major trauma centres and specialist hospitals across the UK. Gerard has been involved in several projects that have led to changes in the type of support provided to children pre-surgery in one of London's busiest major trauma centres, through to the development of traumatic brain injury support services in the A&E department of one of Europe's busiest children's hospitals.

Gerard has worked in the field of disability for many years, working with children and young people with neuro-degenerative and progressive neurological conditions as well as acquired brain injury. Gerard has a strong belief in the importance of educational and emotional development of children and young people and by focusing on supporting early years, can avoid long-term social, emotional and physical impediments that can affect a person throughout their adult life.

Suzanne Turner, *Speech and Language Therapist, Youth Matters Project, Children and Youth Service, Brain Injury Matters*

Suzanne graduated from the University of Sheffield in 2016 with a First Class BMedSci Honours degree in Speech Science alongside three graduate awards. She joined Brain Injury Matters first as a volunteer befriender back in 2011, when studying at QUB and later as a staff member in 2018. Suzanne has professional experience and interests in trauma, mental health and human behaviour. Suzanne also facilitates meditation sessions and is a qualified fitness instructor with a holistic approach to health and wellbeing. In her independent Speech and Language Therapy practice Suzanne works primarily with adults with acquired brain injury and progressive neurological disorders

Rory Keenan

Rory sustained an acquired brain injury aged 16 years following Encephalitis, an inflammation of the brain. He currently works as a quantity surveyor and has a strong interest in advocacy for people affected by brain injury.

Dr Bernadette Salisbury

Consultant clinical psychologist and service manager of the Acquired Brain Injury Rehabilitation Team in the SHSCT.

Bernadette is a consultant clinical psychologist and service manager of the Acquired Brain Injury Rehabilitation Team in the SHSCT. She has worked with and supported people affected by brain injury for the past 17 years. Bernadette has a keen interest in adjustment following brain injury using therapeutic approaches such as Compassion Focussed Therapy (CFT). Bernadette leads an interdisciplinary team of professionals including social work, occupational therapy, physiotherapy, speech and language and clinical psychology in the Southern Trust offering rehabilitation after brain injury.

Professor Siobhan O'Neill

Interim NI Mental Health Champion

Siobhan O'Neill is a Professor of Mental Health Sciences at Ulster University, and Interim Mental Health Champion for Northern Ireland. Her research programmes focus on trauma mental illness and suicidal behaviour in Northern Ireland, and the transgenerational transmission of trauma. She is now on a mission as the Mental Health Champion to improve the mental health of the people of NI by promoting evidence-based services and care for those who suffer from mental illness and suicidal thoughts.

As Interim Mental Health Champion for Northern Ireland, she will advise and assist in the promotion of mental health and wellbeing through all policies and services throughout the province. Her role is as a public advocate for mental health, and to be a voice for those otherwise voiceless. Her goal is to communicate the collective voices of people with lived experience and their families and carers, and to advocate for communities impacted by mental health inequalities.

Elizabeth Downey

"My name is Elizabeth, I am married to John and have 2 daughters, 3 cats and one dog! My oldest daughter is 15-years old and has an acquired brain injury as a result of a rare and complex brain tumour. She also has autism, mental health difficulties and developmental coordination disorder. At the age of 11 she had brain surgery to partially remove the brain tumour in Great Ormond Street Hospital London. We received excellent medical support but what we also needed was a service to help us adapt to this new way of life. BIM bridged this gap in a way that no other service known to us at that time could have done. BIM helped us to learn to accept a life that now includes an acquired brain injury yet also challenging us to move forward from it. I will be forever grateful to have BIM in our lives."

Sarah Moon

"My child Matthew is age 7 and he has Hemiplegic Cerebral Palsy (caused by stroke). Matthew's condition affects all the limbs on the right side of his body. Matthew lives in Fermanagh with his family and is a fun loving and energetic boy.

Matthew attends many practitioners, regular clinics and reviews all over NI for his medical needs. Brain Injury Matters has helped us all understand the impact of living with an ABI and therefore has helped us tailor everyday life to allow us all to get the best potential from our day without feeling hindered by the ABI. We feel much more confident and empowered in working with the additional needs that have arisen from the ABI and really 'owning' and accepting the condition and whatever it may bring. We have been able to pass on knowledge we have gained to our child's school and any other caregivers and family members so we are all optimising what we do for Matthew to help him reach his own potential."

Gemma Rankin

"My daughter Lola suffered a TBI on 6th March 2020 whilst out walking with her horse on a country road. She was discharged after 5 days in hospital with no medical follow up despite ongoing debilitating symptoms, reporting her CT as NAD and MRI with micro haemorrhages. We were lucky to get advice to self-refer her to Brain Injury Matters for their amazing advice and support. Lola suffered awful TBI symptoms but we had been reassured on her discharge this was normal.

Finally I spoke to her GP who referred her for an urgent Neuro Consult, her CT and MRI were reviewed and changed, accurately reporting a fractured skull and contusional haemorrhages. In July '20 Lola finally began a Neuro Rehab plan which is ongoing, she is doing amazing and although not able to ride her horse yet, she is well on the way thanks to her amazing Neuro OT and team behind her. I find it hard to accept it's over a year and Lola is still on her recovery journey. We left hospital with nothing but a discharge letter wrongly advising after a few weeks rest and recovery Lola could resume as "normal", which most importantly for Lola meant riding again... it was so far from the truth and reality of what lay ahead. Never did I realise this was long term and life changing for Lola, but she has been patient, strong and quietly determined throughout – she reminds me how lucky we are to have her here and how amazingly well she is considering what she has come through."

Jacqueline Quinn

"My name is Jacqueline. I have a 15 year old daughter Roisin, who had a life changing stroke in 2019. This has been a major adjustment for Roisin, her 4 siblings, my husband and I. Roisin's ABI has impacted her physically, emotionally, academically and socially. She has required input and support from numerous services to support her rehabilitation.

We commenced working with Brain Injury Matters in September 2019 this has supported Roisin with her confidence, self-esteem and provided her with opportunities for social interaction with peers. Roisin is the treasurer on the Youth Matters Steering Group, a role in which she is really thriving and has provided opportunities to interact with peers online."

Dr Sarah Meekin

Consultant Clinical Psychologist

Head of Psychological Services Belfast Health and Social Care Trust

Dr Sarah Meekin is a Consultant Clinical Psychologist and has been Head of Psychological Services in Belfast Health & Social Care Trust for 10 years. Sarah has an interest in developing psychologically informed systems and psychologically evidenced interventions, and champions the need for both a psychologically informed workforce and for specialist psychological therapists to deliver care and support, at varying levels of intervention.


Dr Meekin has specific interest and expertise in the importance of a psychological perspective within physical healthcare and experience in working across Paediatric and Adult Physical Healthcare systems, providing both clinical interventions to patients and families, and supporting staff working within physical healthcare environments. She also has a specialist interest in bereavement and grief and the prevention of additional distress and trauma by preventative actions.

Dr Meekin has been actively involved in the delivery and development of staff support systems throughout her clinical career and currently chairs the Regional Workforce Wellbeing group.

Keep in touch

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