

RECOMMENDATIONS OF THE EXPERTS

Acquired Brain Injury Conference: Costs and Consequences Held at Belfast on 11 March 2016

The experts all agreed upon the following set of 6 Recommendations for the Departments of Education, Health and Justice:

- 1. Awareness:** The extent and potential impact of ABI is not widely understood by those working with children and young people (e.g. on cognition, social functioning and communication).

Action: *Establish educational programmes & build them into the training curricula of clinicians, educators, police, prison officers, social workers, magistrates and the judiciary.*
- 2. Magnitude:** ABI is under-represented as a condition and is frequently misidentified as other neuro-developmental disabilities (e.g. Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Personality Disorder etc. The current figures from the Department of Education, Northern Ireland indicate there are less than 29 children with ABI where research from other regions of the UK suggests this figure should be around 1100 (Hawley et al, 2003).

Action: *Identify the incidence and prevalence of ABI amongst children and young people in Northern Ireland & make that data available for those involved in planning and implementation*
- 3. Intervention:** The early intervention (through schools, community, criminal justice system) 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.

Action: *Develop interventions to address the broad range of deficits related to ABI, with systems established to monitor alterations in functional deficits over time.*
- 4. Collaboration:** Departments and other public bodies concerned in the provision of children's services must, as a matter of urgency, work collaboratively together (whether or not under the auspices of the Children's Services Co-operation Act (Northern Ireland) 2015) so as to ensure the needs of children and young people with ABI are met efficiently and cost-effectively.

Action: *Develop systems for sharing information, including an ABI register to track interventions and performance*
- 5. 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.

Action: *Assess current support for those with ABI for compliance with UNRPD & UNCRC and build them into future decision-making*
- 6. 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.

Action: *Carry out regular reviews of family needs by healthcare and social services with respite care being made available*

THE BELFAST ACQUIRED BRAIN INJURY CONFERENCE

About the Conference



An Acquired Brain Injury (ABI) is any injury to the brain following birth, which therefore covers illness or medical conditions (e.g. meningitis, brain tumours, hypoxia) and trauma (e.g. road traffic accidents, sports injuries, falls, assaults). It is a chronic, life-long condition.

The purpose of the Conference was to raise the profile of ABI in Northern Ireland, recognising that it is a frequently misdiagnosed condition, which nonetheless has very significant consequences for the children and young people affected by it and who must try to cope (often with little or inadequate assistance) with the difficulties it presents (e.g. poor concentration, mental fatigue, impaired memory).

The conference was opened by the Honourable Mr Justice Stephens, current President of the Queen's Bench Division and former Chairman of the Medico-Legal Society of Northern Ireland. It brought together experts on ABI in the fields of special education, neuropsychology, youth offending and neuro-disability from the USA, England and Northern Ireland.

The Northern Ireland Commissioner for Children and Young People (NICCY) input to and chaired the panel debate following presentations made to conference. NICCY is the statutory body whose mission is 'to safeguard and promote the rights and best interests of children and young people' in NI.



KEY POINTS FROM THE EXPERTS

Professor Ann Glang, Director, Centre on Brain Injury Research and Training, University of Oregon and Research Professor at the University of Oregon, presented on - *“Childhood Brain Injury: Advancing Best Practices in the School Setting”*:

- Early school-based intervention in working with children with ABI is vitally important in improving long-term outcomes.
- There is a general lack of training for educators to assist children with ABI and a failure to appreciate the significance of failing to provide appropriate services over the child’s school career and beyond.
- The under-identification of support services leads to the persistent myth that there are very few children with ABI.

Dr Mark Linden, Lecturer in Health Sciences in the School of Nursing & Midwifery, Queen’s University Belfast, presented on - *“Acquired Brain Injury in Northern Ireland”*:

- There is an overall lack of understanding from lay and professional people in Northern Ireland on the causes and consequences of ABI.
- The scale of the problem is not appreciated by statutory bodies, who are therefore not in a position to plan and provide appropriate services.

Professor Huw Williams, Associate Professor of Clinical Neuropsychology and Co-Director of the Centre for Clinical Neuropsychology Research at Exeter University, presented on - *“The Role of Traumatic Brain Injury in Crime”*:

- Health initiatives need to be provided to: (i) identify neurodevelopmental factors in children and young people that may lead to social exclusion (e.g. from school/college/work); and (ii) develop neurorehabilitation programmes linked to education and training.
- Awareness training needs to be provided to Police, Prison Officers, Probation Workers, Lawyers, Magistrates and the Judiciary on how children and young people may have delayed maturity due to neurodisability.
- There should be screening for adversity and neurodisability issues at key points in the Criminal Justice pathway.
- Efforts should be made to ensure that sentencing, rehabilitation & resettlement of children and young people takes account of factors such as: (i) immaturity; (ii) poor memory; (iii) communication problems and dealing with instructions; (iv) impulsivity and socializing.

Dr Nathan Hughes, Marie Curie Research Fellow, Murdoch Children’s Research Institute, Melbourne and Senior Lecturer, School of Social Policy, University of Birmingham, presented on - *“Recognising and Responding to the Criminalization of Paediatric Traumatic Brain Injury”*:

- There needs to be recognition of the various ways in which functional deficits in cognition, social functioning and communication might inadvertently become criminalised by a criminal justice system that (whether in the police station, in the courts or in delivering interventions) assumes normative levels of functioning.
- Criminal justice professionals and any interventions need to take account of / be responsive to functional difficulties in order to effectively engage children and young people with ABI so as to address the underlying causes of offending.

Dr Eunan McCrudden, Clinical Psychology Department, Royal Belfast Hospital for Sick Children, presented on - "*Case study of Brain Injury and Service Involvement*":

- There is a need for children's service professionals to have a common/shared understanding of the long term implications of childhood ABI which should be built into the training curricula and professional understandings of clinicians, educators and social workers across settings.
- There needs to be easy access to services to facilitate early intervention both: (i) after the injury has been sustained; and (ii) when subsequent problems arise.
- Services need to review whether the pathway documents that set parents' expectations over the interventions for their children with ABI are meeting those expectations.
- Better communication between health and social care agencies and education is essential and cross-disciplinary working should be improved, if necessary using link workers to help children and families navigate the various systems they encounter.

ABOUT THE EXPERTS AND THEIR RESEARCH

Professor Ann Glang is a Research Professor at the University of Oregon and the Director of the Centre on Brain Injury Research and Training at University of Oregon. She began her career as a researcher in 1987 after receiving her PhD in Special Education from the University of Oregon. Combining her interests in Special Education with her commitment to the principles of effective instruction, she has designed and studied interventions developing effective strategies to help teachers and families support children and adolescents with brain injuries. As the parent of a child with physical disabilities, she brings the unique perspectives of researcher, educator, and parent to her work. Since 1987, Dr Glang has secured and directed or co-directed nearly 30 federally funded research projects focused on individuals with TBI, including both descriptive and intervention research projects. She has published numerous articles in refereed journals, edited two books on her work with children with TBI, and co-authored five manuals for educators serving children with TBI. In addition, she has led the development of a range of SBIR-funded health education programs, including Brain Injury Partners, an intervention to train family members of children with TBI in advocacy skills, and ACTive, a concussion education program for youth sports coaches.

Professor Huw Williams is an Associate Professor of Clinical Neuropsychology and Co-Director of the Centre for Clinical Neuropsychology Research (CCNR) at Exeter University. He was on the founding staff team of the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation in Ely and Visiting Scientist at the Cognition and Brain Sciences Unit in Cambridge. He has honorary positions with the OZC and the Royal Devon and Exeter Hospital's Emergency Department. He has published papers and books and held grants in a range of areas of Clinical Neuropsychology - particularly on neuro-rehabilitation. His current projects include: (i) Emergency Dept: tracking effects of Mild TBI and Acute Stress Disorder on Post-Concussion Syndrome, Computerised Neuro-cognitive testing of MTBI patients to predict outcomes, epidemiology of MTBI and areas for reducing injury, modeling of TBI in fatal accidents to improve road safety; (ii) Sports: video-analysis and bio-engineering models of concussion in rugby, DTI/VBM neuro-imaging of elite concussed rugby players, neuro-cognitive testing of University rugby players; (iii) Crime: affect processing in young offenders; audit of Linkworker services for TBI in young offenders; improving access to psychological therapies in adult offenders. He was guest editor of the Journal of Head Trauma Rehabilitation on Brain injury and Crime in young and youth offenders. He is the past Chair of the Division of Neuro-psychology of the British Psychological Society, and is currently vice Chair of the DON Policy Group and Chair of the BPS working group on Neuro-disability and Offending Behaviour. He established, with Child Brain Injury Trust (CBIT) and Lord Ramsbotham, the Criminal Justice and Acquired Brain Injury Group (CJAABIG). He has had advisory roles with various organisations, including England RFU (2014).

Dr Nathan Hughes is a Senior Lecturer, School of Social Policy at the University of Birmingham and is currently Senior Visiting Fellow at the Melbourne School of Government, Melbourne University. Until recently he was the Marie Curie Research Fellow with the Murdoch Children's Research Institute at Melbourne. His research considers the explanations apparent in emerging understandings in the developmental sciences for patterns of offending among young people with neuro-developmental impairments, and young adults, aged 18-24 years, and the implications for reform to policy and practice.

Dr. Mark Linden is a Lecturer in Health Sciences in the School of Nursing & Midwifery, Queen's University Belfast. His research involves the exploration of social inclusion in childhood survivors of brain injury. This includes a range of contextual factors that either help or hinder inclusion. These include the cognitive, social and environmental challenges that these children, and their families, deal with on a daily basis. As part of this work his research explores the use of technology as a tool for rehabilitation. He is currently investigating the prevalence of TBI in young offenders at Hydebank Wood College, NI in a project titled 'Offending behaviour in young adult survivors of traumatic brain injury (TBI).' (PhD student Conall O'Rourke).

Dr Eunan McCrudden obtained his Doctor of Philosophy (PhD) in Psychology from the Royal College of Surgeons in Ireland in 2008 and his Doctorate in Clinical Psychology (DClinPsych) from Queen's University, Belfast in 2009. He is a chartered member of by the British Psychological Society (BPS) and a registered practitioner psychologist with the Health and Care Professional's Council (HCPC). Clinically he has worked working with children with acquired brain injuries, and other neurological presentations, since he qualified. He attained a Post Graduate Diploma in Clinical Paediatric Neuropsychology from University College London (UCL) in 2014. He is employed to provide clinical psychological input to the regional neurosciences and neuro-disability services in the Royal Belfast Hospital for Sick Children. He also leads a regional, multi-professional outreach service assisting core services meet the needs of children (and families) with acquired brain injuries. As well as having specialist clinical experience in the field of neuro-psychology, he has conducted research and published peer-reviewed articles regarding neuro-developmental disorders in scientific journals.