

Child and Adolescent Neuropsychology (CAN) Research Group

Paediatric Neuropsychological Interventions - Implications for service development

Workshop held on Thursday 25th June 2015, University of Exeter, U.K.

This workshop was the first in a series of three focused on the development of an adoption, implementation, and maintenance plan of neuropsychological interventions for paediatric acquired brain injury in the NHS and educational contexts.

Overview

In the UK a child injures their brain every 30 minutes. Paediatric acquired brain injury (pABI) can affect cognition, emotion, and behaviour, which can impair the child's ability to cope with everyday life and gain future independence. Despite these long-term difficulties, children with pABI do not automatically receive specialist education, often returning to mainstream schools with little or no additional support. Furthermore, although some specialist NHS services do exist in the UK, children are often discharged from services before any neuropsychological effects of pABI manifest themselves (e.g., some cognitive functions mature later in childhood, causing difficulties to present years after injury).

Aims

1. Facilitate engagement between key stakeholders involved in local and national clinical and educational provision.
2. Identify examples of best practice, and develop a collaborative strategic plan for the delivery of neuropsychological interventions in the South West.
3. Establish a collaborative network of key stakeholders to contribute to the development and implementation of such a plan, and a platform for future work.
4. Provide a platform for all delegates to enhance their understanding and contribution to local and national clinical and educational policies.

Summary

Outcomes

1. Establishment of a platform and network to inform and influence clinical and educational policies for Children and Young People, particularly those with pABI.
2. Identified areas for strategic focus across clinical, educational, and research domains.
3. Identified and planned targets for focus of next workshop and maximisation of engagement and dissemination.
4. Professional development opportunity for delegates interested in understanding and contributing to local and national clinical and educational policies.

Summary of Talks

The workshop included presentations by Prof Tamsin Ford (Medical School, University of Exeter), Prof Brahm Norwich (Education, University of Exeter), Dr Catherine Gallop (CEDAR, University of Exeter), Dr Anna Adlam (CAN/CEDAR, University of Exeter), Dr Richard Tomlinson (RD&E), Dr Ayla Humphrey (CPFT) & Dr Suzanna Watson (CPFT), Associate Prof Julie Mytton (University of West of England), and Ms Sarah Haworth (parent of a child with ABI).

Please see copies of the presentations attached.

Identified Themes

Following the presentations, delegates worked in small discussion groups to identify and discuss key themes:

(1) Care pathways

The need for a shared/agreed definition of acquired brain injury (ABI) was identified as a key challenge to improving consistency and access. It was recognised that there is currently inconsistency in services. In addition, services are subject to considerable change, and there is a need for greater clarity around accountability and access. The broad spectrum of potential impacts of ABI was recognised, as was the need for greater awareness and understanding of ABI, even within clinical services. In particular, the potential longer term consequences of ABI were identified as something that merits greater awareness and recognition. A significant contribution to the inconsistency of families' experiences is that care pathways are reliant on the knowledge of the healthcare professional a child first sees, which can vary considerably. Access and provision also varies considerably based on geographical location. Services were recognised to be structured around what is already available, as opposed to being client-led and structured around children's needs. Additionally, there is frequently an assumption that schools will provide rehabilitation. Collaborative working and communication were identified as being of huge importance, as was the inclusion of NHS, private sector, and third sector/charitable organisations in this. The sharing of knowledge and communication, which can be facilitated through workshops such as this one, and the establishment of good communication networks were all highlighted as important foci for future work.

(2) Generating evidence of need

The question was raised as to whose needs must be considered. Within a public health framework, it is important to consider commissioner needs, felt needs of the parents/family and child, perceived needs by clinicians, healthcare professionals, and education services, and demand (who accesses services), which are all likely to differ. At a commissioning level, neuropsychology and neuropsychiatry service specifications are clustered within neurodisability services. The preference for simplicity, clustering, and a clearly identified objective to take forwards were highlighted. Demand will influence commissioning. It was noted that as there have not historically been paediatric neuro-rehabilitation services, the level of input will need to increase, which raises a question around incentivising this. The families accessing services will only reflect a proportion of those with needs, and there is a question as to how to assess need, and the numbers with unmet needs/not accessing services. Clinicians will be aware of what they perceive to be the needs of those accessing services, but there are a number of questions around how best to measure these needs, and what the needs of those not accessing clinical services are (e.g., families/children reliant on voluntary sector support). The use of dashboards raises questions about which outcomes are most important and for whom – family experience and the needs of parents and children must be recognised within this. However, family needs can be individual and variable, whereas commissioners are likely to favour standardised outcome measures. The need for a core national set of outcome measures was identified. Teachers and SENCos may feel under-supported and wish for more specialist training around ABI.

(3) Neuropsychological assessment and intervention

Within clinical settings, the disparity between public and private sector services was identified. Accessing and navigating these provisions and achieving agreed synchronicity was discussed. The challenges associated with providing assessment without the availability of potential interventions poses clinical challenges, and the question was considered as to whether the recommendations following such assessments should reflect what is realistic or what would be

ideal for the child. Child specific education and training for SENCOs was identified as an important area for future work, as was the establishment of agreed minimum standards of provision across the board. Interdisciplinary working, and engagement with research were identified as ways to maximise provision within current constraints.

(4) Education services

The question of identifying ABI was recognised as an important one. It was felt that it would be helpful for schools to be notified about children identified with ABI and provided with information about what should be done or where they can seek information. Reciprocal workshops with schools were proposed as a valuable way forward, and it was recognised that it may be difficult to narrow down the foci of training given the breadth of challenges this population can face. The training and scaffolding of reflective practice, information seeking, and metacognitive ways of working for SENCOs was also identified as a valuable future step. It was highlighted that teachers want to learn (e.g., THRIVE project), but may also feel overwhelmed by the amount they are currently expected to take on from their own resources. The identification and sharing of information, and optimal use of all available resources were identified as important to improving educational support structures. It was identified that teachers and SENCOs will benefit from opportunities to build up their knowledge and understanding of ABI, and highlighting transdiagnostic process, and knowledge cross-overs may be helpful to this. The use of planned review was highlighted as a valuable approach, as was the use of out-reach services. An identified shared goal is to work towards continuity from hospital, to school, to home.

Future Directions

- The workshop highlighted a shared desire to improve communication and collaboration amongst those working to support and improve care for families and children with ABI. The importance of increasing the involvement of families and, in particular, of young people with ABI in this work was universally recognised, and this will be a key focus for the upcoming workshops. Such engagement will be invaluable to collaborative work to identify appropriate outcome measures that will reflect the needs of families and children, whilst also meeting the needs of commissioners.
- An agreed definition of what the minimum standards of provision is a central target to be taken forward within this work, and will be essential to establishing a strategic plan for the network.
- Education services, commissioner engagement, and health economics were identified as core areas for focus within this work. These will be taken forwards within two future workshops (to be arranged).
- There was a shared appreciation of the value of establishing regular workshops and a collaborative network to support and foster interdisciplinary communication and support across different sectors and areas of expertise. Work is underway to set up an email network, and set out a framework to take this platform forwards. The South West Neuro-Rehabilitation meeting was signposted as an opportunity in the near future for further communication and collaboration around this work.

2016 Update

- The University of Exeter have funded the CAN group (Dr Anna Adlam, Dr Jenny Limond, and Dr Catherine Gallop) to conduct a scoping project to identify the neuropsychological rehabilitation needs of children with ABI and their families living in Devon. This project involves working with commissioners, clinicians, service providers, and families and children.
- The University of Exeter are also funding the CAN group to pilot a paediatric neuropsychological intervention research-led clinic with four local families.
- Focus groups (funded by the British Academy) have been completed with local children with ABI, parents, clinicians, and teachers to identify neuropsychological rehabilitation needs and intervention design.