WORKSHOP REPORT

Helping children and young people cope after a parent's brain injury

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Workshop summary

This workshop aims to provide an up-to-date discussion of the impact of parental brain injury on children and young people and identify emerging best practices to support them.

Globally, acquired brain injury (ABI) is a leading cause of disability, and is the leading cause of death and disability for people aged under 40 in the UK. ABI significantly impacts the injured person but also alters the lives of family members – including children and young people. While the impact of ABI on adult family members is well-recognised, the impact on young people is often overlooked. The focus of services, professionals and non-injured family members is, not unreasonably, on the injured parent. Children and young people are left feeling stressed and worried, lacking information, and grieving the loss of the parent they knew before the injury. Evidence on the longer-term impact on young people is emerging and indicates that they experience higher incidence of mental health difficulties, worse school performance and poorer social relationships than their peers, signalling an urgent need for early intervention.

This workshop brings together experts working across disciplines (psychology, nursing, social work, allied heath), with community organisations supporting families affected by ABI, to discuss how the challenges of developing and delivering evidence-based interventions to support children and young people affected by parental brain injury can be overcome.

Workshop aims

This interdisciplinary knowledge exchange workshop aimed to bring together researchers, professionals working in neurorehabilitation (nurses, occupational therapists, psychologists, medics, psychiatrists, social workers), and experts by experience (including parents and young people affected by parental ABI) to share good

practice in supporting children and young people when a parent has an acquired brain injury. More specifically, it aimed to improve the support available for children and young people, and their families, when a parent sustains a braining injury by:

- identifying the key challenges experienced by children and young people and their families;
- understanding the barriers that professionals and families in offering the right support at the right time within the contexts that they work and live;
- showcasing existing good practice in supporting children and young people and their families;
- identifying priorities and opportunities for co-developing practical strategies to improve the wellbeing of children and young people and enhancing the existing research evidence-base that would support them.

Emerging themes

The workshop consisted of opportunities for focussed discussion and a set of varied presentations – from professionals talking about how they support children and young people to visit an injured parent in acute hospital settings, to a charity presenting a book produced by people with brain injuries to describe their emotions and experiences, to researchers sharing the results of studies showing the long-term impact of parental ABI on children and young people. Emerging themes from the workshop include:

Under-recognised impact on children and young people – Collectively participants recognised the enormous and often detrimental impact on children and young people when a parent sustains a brain injury. They acknowledge that this impact is felt in the short-term immediately following the injury but also evolves over time as young people struggle to adapt to their changed family circumstances and continues into adulthood as reflected in poorer outcomes across education, employment and adult relationships. Despite this, support for young people is patchy, inconsistent and fragmented across different services and support systems which are often focussed on rehabilitation and care for the parent with the injury. There is an urgent need to raise the visibility and necessity of better meeting the needs of children and young people, and hidden costs of failing to do so.

Upskilling services/organisations in child-focussed care - Specialist practitioners who have expertise in providing psychological support to children and young people shared a variety of ways in which such support can be embedded in existing healthcare pathways and services. A key barrier to uptake of these strategies and techniques for non-specialist services, third sector organisations and professionals focussed on adult care is both a lack of knowledge and low confidence in supporting young people, and a fear of traumatising the child and/or alienating parents.

Developing high quality resources for parents/families – Workshop participants were inspired an encouraged by the resources and practices which were already being used across different services, and which were shared in the workshop. They wanted high quality resources to be made more widely available to professionals supporting families, and directly to families themselves. Our lived experience participants emphasised that resources and support were hard to access, and the availability was patchy across different geographical areas. They felt it was important to be able to access resources directly to help the children and young people in their family as well as being able to access more specialist support when needed. Professionals were also keen to be able to access high quality resources to help them support children, their parents and their wider families.

Bringing together practitioners, researchers and stakeholders to secure funding to innovate – People who attended the workshop were clear that further research and innovation was needed to find better ways to support children and young people and their families when a parent has a brain injury. They also emphasised that this required close collaboration between a range of different professionals who are tasked with supporting families, third sector organisations, policy makers, researchers and people with lived experience to be able to innovate in ways which are fit for purpose and meet the needs of families.

Participant perspectives

The workshop attracted thirty-eight participants from across a range of different professions, charities, private sector organisations, and included people with lived experience of being a child of a parent with a brain injury or parenting children in the content of parental ABI. Participants valued the mixed format of presentations and discussions and the opportunity to be inspired by meeting others who "*who share the same passion about working with children whose parent has had a brain injury*".

The content of each of the presentations was motivating and accessible, however, what was most valuable for me, was the discussions in small groups around the challenges and the opportunities in working with a family system around ABI; and the possibility of beginning even in a very small way.

It was particularly valuable to hear how others are working in this area - both in research and in practice - and also to hear the perspectives from experts by experience. The workshop gave me a broader understanding of some of the key barriers to meeting the needs of children and young people and the entire family.

Next steps – outcomes

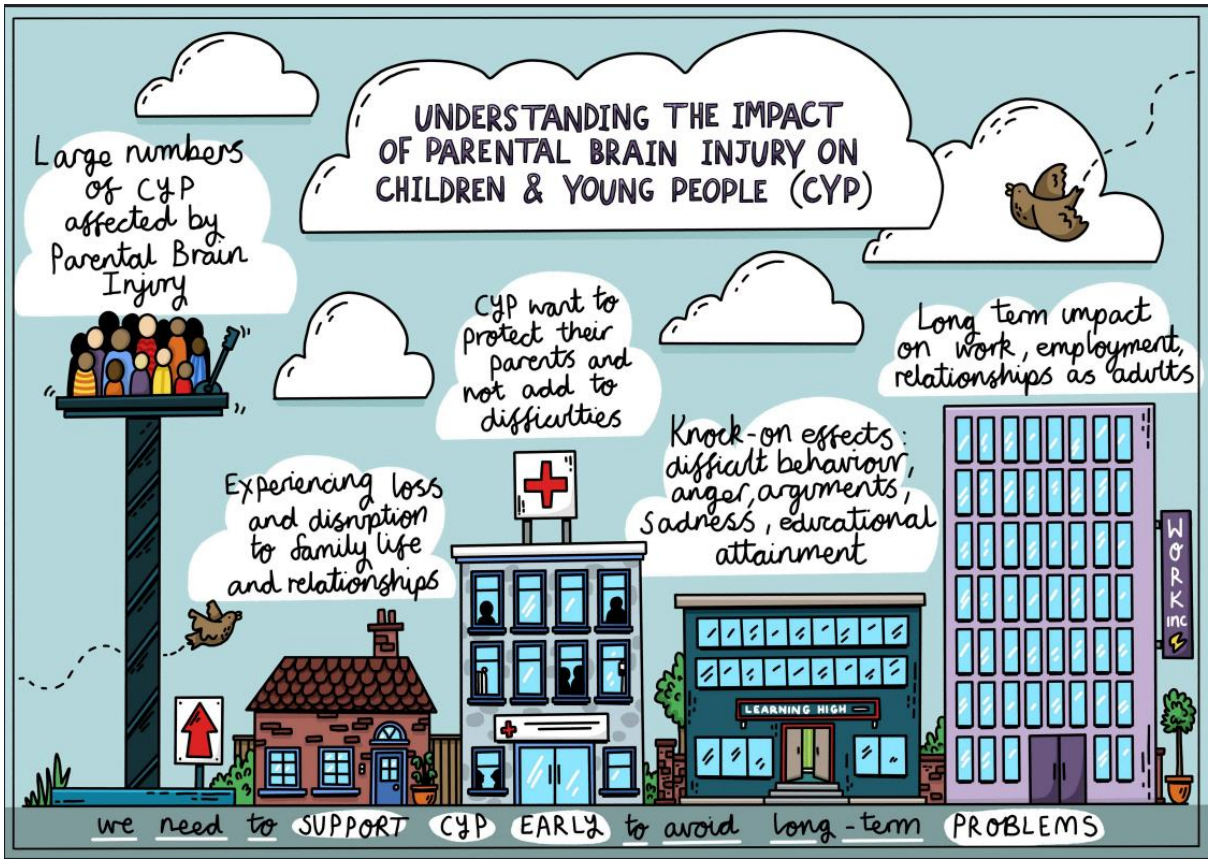
This workshop generated a clear set of outcomes and a shared appetite for collaborative working to realise these outcomes together:

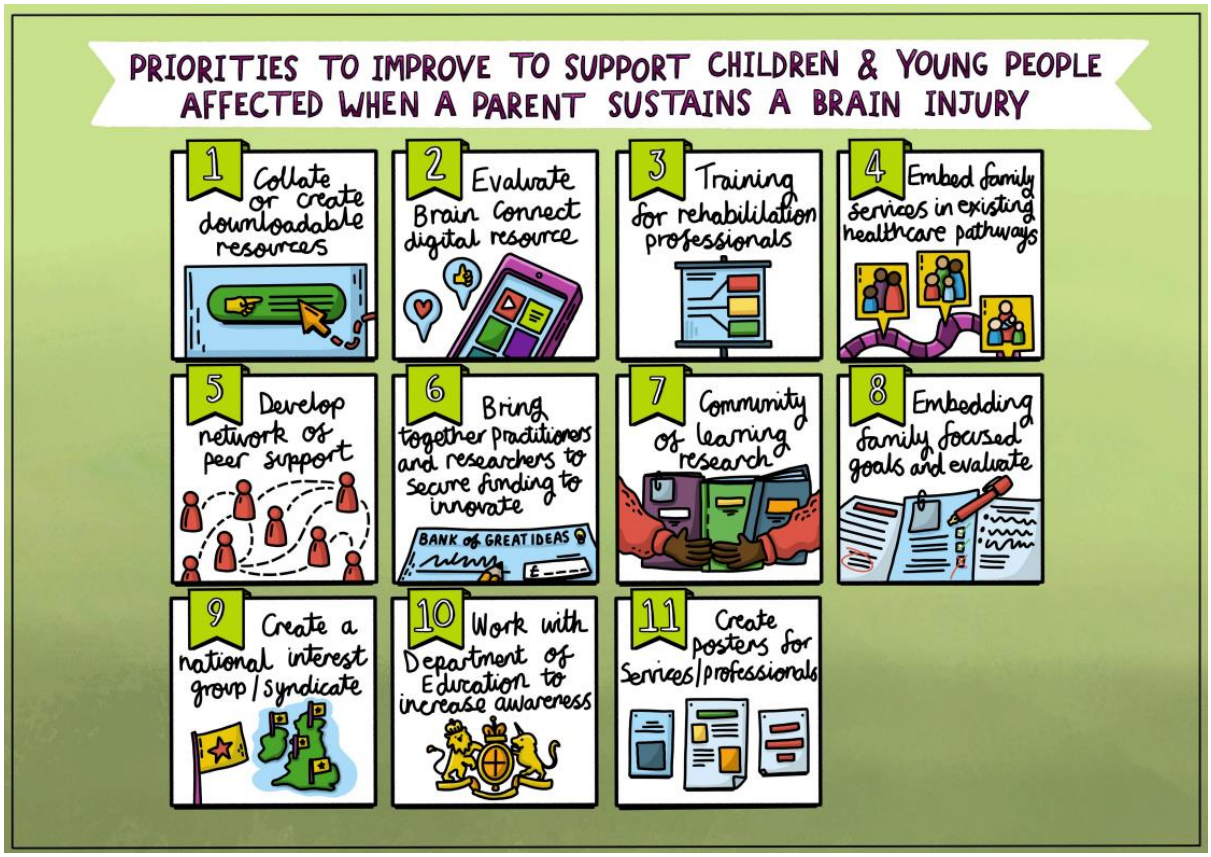
- Establish a network of multidisciplinary researchers, health and social care professionals, community organisations and experts by experience who are interested in supporting the wellbeing of children and young people affected by parental brain injury.
- Produce lived experience commentary on the workshop and the key themes that emerged from the workshop to underpin funding applications and publicity.
- Generate a set of images from the artist's live scribing during the workshop which captures the key messages from the workshop and can be shared via our presenters, partners and our newly established network to raise the visibility and necessity of enhancing support for children and young people impacted when a parent has a brain injury (see examples below).
- Write a Letter to the Editor at the *Neurorehabilitation Times* to profile the needs of children and young people to an audience of multidisciplinary professionals involved in supporting families following a brain injury.
- Develop a grant application to submit to the NIHR Research for Social Care programme.

Acknowledgments

Thank you to the Institute of Advanced Studies at the University of Surrey for sponsoring and supporting the event. Thank you to all our inspiring speakers who shared their knowledge, expertise and examples of good practice, and to all our workshop participants who contributed to the rich and lively conversations in our discussion sessions.

Particular thanks go to Charlotte Cheatle who provided administrative support and excellent technical support when we had to switch to an online event at short notice, and Annalees Lim (annaleeslim.com) who supplied the beautiful live scribes and artwork for the event.


UNDERSTANDING THE IMPACT OF PARENTAL BRAIN INJURY ON CHILDREN & YOUNG PEOPLE (CYP)
Large numbers of CYP affected by Parental Brain Injury
CYP want to protect their parents and not add to difficulties
Long term impact on work, employment, relationships as adults
Knock-on effects: difficult behaviour, anger, arguments, sadness, educational attainment
Experiencing loss and disruption to family life and relationships
LEARNING HIGH
WORK inc
we need to SUPPORT CYP EARLY to avoid long-term PROBLEMS


PRIORITIES TO IMPROVE TO SUPPORT CHILDREN & YOUNG PEOPLE AFFECTED WHEN A PARENT SUSTAINS A BRAIN INJURY
1 Collate or create downloadable resources
2 Evaluate Brain Connect digital resource
3 Training for rehabilitation professionals
4 Embed family services in existing healthcare pathways
5 Develop network of peer support
6 Bring together practitioners and researchers to secure funding to innovate
BANK of GREAT IDEAS
7 Community of learning research
8 Embedding family focused goals and evaluate
9 Create a national interest group / syndicate
10 Work with Department of Education to increase awareness
11 Create posters for services/professionals