
Brain Injury Matters Virtual Panel Discussion 2021

Wednesday 29th September
Evaluation Report



Introduction

Moving out of the Covid 19 pandemic Brain Injury Matters has been engaged in a process of looking to the future, trying to reflect on what we have learned and how we might respond .This has contributed to the development of a “Vison 2025” statement ,challenging us to think what type of an organisation we wish to be, what services do we need to be delivering and what might the future of services look like.

To widen the debate we wanted to explore with others the key issues as we see them;

- Is there sufficient understanding of acquired brain injury, its causes, effects and consequences for the individual, their families and wider society?
- How do we increase the level of understanding of acquired brain injury amongst the general public, within government and statutory services, across education, health and justice?
- Is there a need for greater statutory/government support for those living with acquired brain injury?
- Can we do more to reduce the incidence or consequences of acquired brain injury through education awareness campaigns or legislation?
- How do we best support those living with an acquired brain injury including their families and carers?
- How are the support needs of those living with acquired brain injury likely to change over the next 5 years?

One way of doing this is to engage with others and for us the proposed panel discussion was one of a number of discussion we have been having and will continue to have with all our stakeholders to assist us understand the landscape and offer appropriate and effective service over the next 5-10 years.

The panel speakers included the Minister for Health Mr. Robin Swann, Mr Chris Bryant M.P, Chair of the All Parliamentary Group on Acquired Brain Injury, Mr Colm Gildernew MLA Chair NI Health Committee, Dr. Eunan McCrudden Clinical Psychologist and Ms Bridget Smyth Head of Children Services Brian Injury Matters (NI). The panel was chaired by Joe McVey CEO Brain Injury Matters (NI)

Arising from the panel discussions, the question and answer sessions and the on line chat a number of key themes emerged which can be summarised as follows:

Awareness Raising: the need to raise awareness of the prevalence, causes and impact across the statutory sectors and with the general public.

Research: the need for accurate data and research to inform policy.

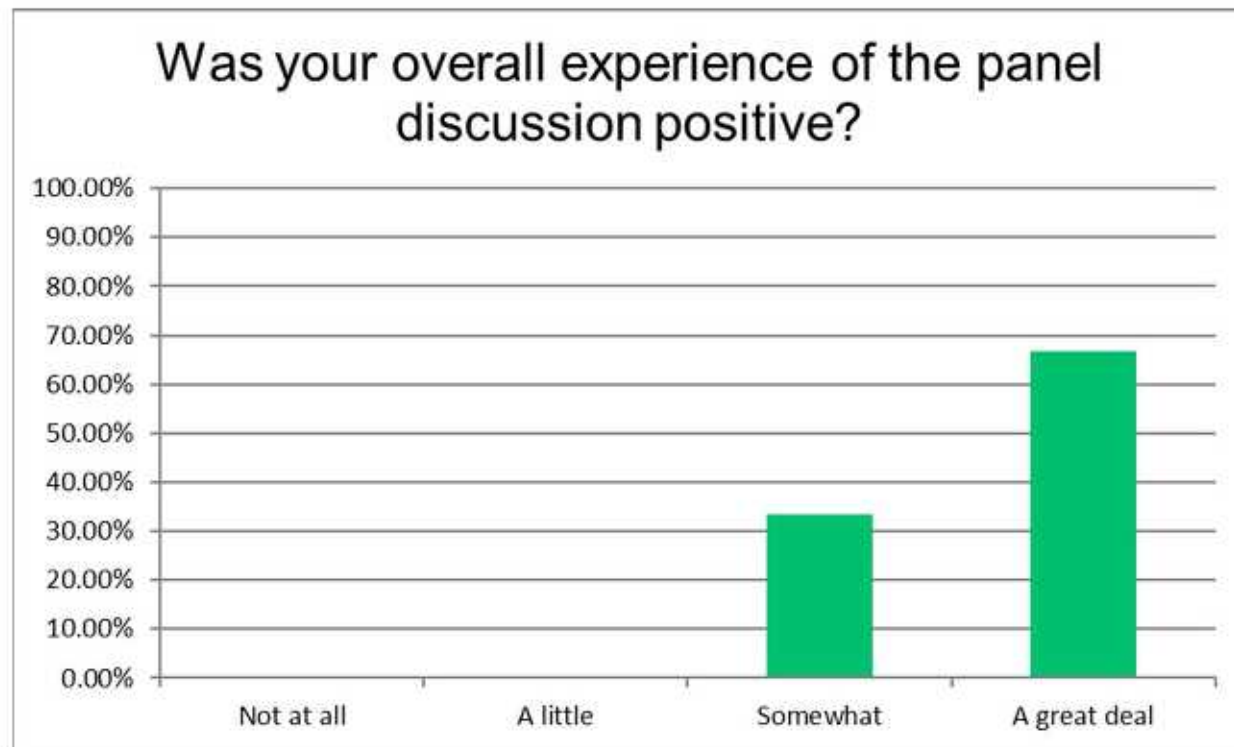
Family support: the need to acknowledge the role of families and carers and offer investment in their support and well-being.

Parity: the need to invest equally in Childrens and Adult services and to see services available equally across all Trust areas.

Transitions: the need to view the patient journey through childhood, youth and adult development and offer services in a seamless fashion with greater collaboration between statutory and voluntary providers.

These themes are explored in more detail in the summary report below and in the record questions and comments provided on page 15 - 17.

Q1: Was your overall experience of the panel discussion positive?



Q2: What part of the panel discussion did you find the most useful/beneficial?

The opportunity to hear about work in different areas to support people with ABI

The perspectives of the panel speakers, very informative

The themes that came through - lack of staffing and funding, reduced awareness across all services

Open and honest discussion from different point of view

I enjoyed the discussions on more joined up care

Hearing from different people with different backgrounds

Recognition of fact that ABI is long term both for individuals and their carers

I found the various speakers contributions very valuable

The analysis of how services are currently operating, the differences between children and adult services and some discussion around the need for a life long service that can be accessed over time as required

The sense that there is a common objective between different disciplines and authorities - to improve, expand and resource person centred services and support to those people living with ABI and their families/ carers

Good opportunity to share experiences across sectors but did feel positive work overshadowed somewhat

Q2: What part of the panel discussion did you find the most useful/beneficial?

Input from Colm Gildernew

Hearing the experience of the panel and the positive and negative aspects of their work in the field of ABI

Insights from the chair of the health committee

Learning about Dr. McCrudden's involvement with social service teams

The level of agreement in the development of services going forward that would provide a holistic, inclusive plan for the individual with ABI

The variety of speakers and topics of conversation.

All aspects

Q3: What would you change about the panel discussion?

A bit more time to discuss changes afoot

Keep Robin Swann a little longer to hear about the experiences of those working in Brain Injury services in NI

More time to address questions

Increase diversity of panel and give shorter time slots with key points and potential solutions, It came across quite negative

Found disconcerting that didn't know who or how many were present. Feel that any discussion like this should be focussed on all those affected by ABI - too much concentration on children and prison inmates. These are important but should be dealt with in sub forums as necessary.

Nothing I felt all contributions were very good

I would have been nice to actually hear from the people in the 'audience' rather than the chat box thing

Perhaps given the context, a Q & A between the Panel chair and an individual with lived experience (either ABI survivor/ carer or both) - to get a sense of the experience of services and support received, and where the gaps of unmet need are - from the perspective of someone with lived experience/ residual support needs.

More diversity, representation from primary care, education, employment, PHA and clinician

Another speaker would have helped. Too much focus on children and young people

Q3: What would you change about the panel discussion?

Nothing, it was managed very well

I think they did as well as they could with the virtual forum

Some time to respond to questions raised in the chat - maybe as they arose and not left to the end

I would have liked to have heard more comments/ questions from the audience

Opened up and more interactive if possible. Maybe answering more questions on the day

My zoom froze a number of times but that was probably to do with my wifi connection

Q4: How do you feel ABI services could be developed in the future?

Continued multi-disciplinary working and communication. Keen for more information to be rolled out to schools

Great Service

We need community neuro rehab teams - not just brain injury teams to ensure that all people with brain injuries and neurological impairments are able to be seen when needed - early, intensive rehabilitation as well as condition management. The teams need to be fully resourced and provide input on a needs basis rather than on a diagnosis basis. We are currently struggling to refer people to community services where they have the skills to work with people with neurological impairments of all kinds. Let's not divide teams up by diagnosis - let's ensure that people are seen by the teams who have the skills to manage the needs of the patients

Agree with summary points made by panel

Ensuring there is greater awareness across all parts of the system

They need to collaborate with other services and take a more neurodiverse approach. We need to stop over pathologist good things and provide practical support and solutions for families

Need data and appropriate analysis to start planning for future services. Also, need analysis of what the reqts are eg respite facilities appalling, comms practically non-existent, unless in crisis which is of course too late

Given the geographical disparity that was raised have possible clinics in a variety of areas

I think more discussion could be had about the quality and longevity of support available to people with ABI. In particular, I think that there needs to be better collaboration between the services involved with children to make sure that there is good communication, that the appropriate support is in place and there is no duplication of resources

Q4: How do you feel ABI services could be developed in the future?

The concept put forward by Colm Gildernew MLA, of an appointed individual (almost like an ABI caseworker) to be a single point of contact - linking in with the various agencies and professionals as required by each individual case, seems like a good way to develop services, to ensure a joined up approach that doesn't require the individual/ family to 'start again' with every new service/ professional they encounter, and also maximises the opportunities for individuals and families to access all supports available. This system would also help to shift focus on the needs of the individual, rather than being diagnosis –led

Longer term follow up and support not defined and perhaps this could be area for clearer guidance. Funded post discharge rehabilitation; consider additional funding with trauma network review. Family & patient support for adjustment/ grief / anger etc. Guidance evidence based document for CYP/ adult re-entering school/ employment

Ideally, the various sectors need to work in a more cohesive way to provide a more streamlined service for patients when they leave acute services

Support for children and families with ABI across all sectors. There have been various health strategies looking at the needs of adults - a focused look at the needs of children would be welcome if appropriate resources could be found

Supporting families to learn and use strategies that work for the individual so there is consistent reinforcing of these maximising the opportunity for success

More investment required. We need a regional approach, currently each Trust works differently and has different criteria and pathways for referring into CBIT

More cross working and money funded to support an underfunded area of health and support

Q4: How do you feel ABI services could be developed in the future?

I am someone who slipped through the system and it has made my journey much more difficult and traumatic than it needed to be. My ABI was missed at hospital following a RTA (I was a cyclist hit head on by a car). I was assessed as 15 on the GCS so no investigations were made or follow ups. I had no CT scan and wasn't given a concussion checklist on discharge on the same day. All I was told was that I would feel worse before I felt better. I assume they didn't think the accident was serious, as I didn't think I had lost consciousness and thought the speed was slow. It was subsequently estimated to be 25mph, so maybe they shouldn't rely on the patient for that information as everything was in slow motion for me. Over time I developed significant post concussive symptoms, but I wasn't in the system, so didn't know how to get help as my GP didn't know either. Eventually I spoke to Headway as I wondered if I might have a brain injury and was told that some of the things I described were typical of a brain injury and that a brain injury unit could help me, but I needed an official diagnosis. This was 5 months after my accident. My GP was happy to confirm a brain injury as we had ruled out vestibular causes for my dizziness symptoms, however she didn't even know there was a brain injury unit she could refer me into. I was able to tell her that it was at Grove Wellbeing Centre, and she eventually found an email address for CBIRT. However it turns out that this was not the correct email address, as after 8 weeks with no appointment letter received I called CBIRT to find out where I was on the waiting list. It seems that the CBIRT team could see my GP's email, but that it was to the wrong email account and therefore I wasn't in the system at all. I then had to contact my GP again and request that she send the referral to a different CBIRT address. This was late Jan 2020. I received an appointment letter 6 weeks later for a date in the beginning of April 2020, but of course lockdown happened, so it was cancelled. If my GP had been aware of CBIRT and knew the process, this wouldn't have happened and I would have been in and under CBIRT care before lockdown. I eventually had initial contact with a neurophysio in June 2020, who triaged me to prioritise which patients who had had a delayed start due to lockdown and was deemed highest priority. I only started seeing the neuropsychologist in August last year, nearly 14 months after my accident. I'll never know if my recovery journey would have looked different if my concussion symptoms had been picked up earlier, but I am now on a very long journey to rehabilitation and don't know how much of my old life I will get back. I would hate someone else to have such a challenging journey and hope that you can raise awareness within GP practices and even at ED that any head impact should have follow up care, if that had happened, my developing symptoms could have been picked up and I could have got appropriate care. I'd like it to be an experience the system learns from.

Q5: How can we raise awareness of acquired brain injury within the general public and statutory services?

Training for school staff, community groups. publicity drives, fundraising

More public statements, advertisement, more government input

By resourcing the teams appropriately we can ensure that all of those with brain injuries get access to help - this will help raise awareness as acute and community services, including GPs etc will be able to access services for people including those with mild brain injuries. If we embed appropriate services within the system and fund them appropriately (by government) then that will help raise awareness

Use celeb stories think of awareness at moment with MND

I'm sure some sort of training or information could help and an understanding that brain injuries come in a range of severities. I didn't think I could have a brain injury until I literally had nothing else left to consider and it wasn't even on my GP's radar. Once I had seen ENT for a BPPV vestibular examination, she didn't know what else to do. If people realise that brain injuries don't have to come from catastrophic accidents, but could happen with a seeming innocuous knock to head of a kitchen cupboard door or something, they might be more aware. Also that the symptoms aren't all there at the beginning, but develop. Most people also don't know that brain injuries aren't evident when they see someone. I find that very hard to deal with

Join forces. Do short videos. Offer practical support to employers - tips for supporting people in the work place

More advances and appropriate planning for ABI week (May). This is something we can hang awareness on (by its very title!) - but need to start planning NOW. And need to communicate and INVOLVE 'ALL' affected by ABI

Raise awareness through schools and continue to have strong links with Educational Psychology

Q5: How can we raise awareness of acquired brain injury within the general public and statutory services?

It was interesting how the message about concussion really took off after the personal story of the the young rugby player from Carrick. Young people themselves started talking about the issue and have become a lot more knowledgeable in the interim. I think that social media is a powerful tool for dissemination of information in the general public. I think schools are an obvious location for educating staff, pupils and parents. A rolling programme is important. Similarly for Statutory Services-training needs to be regular, current and accessible. the option for online training has made access more flexible and perhaps more inclusive

Target wide-ranging audiences: Ask e.g. BBC to feature content on Steven Nolan Live on a Wednesday night. A 10-15 minute piece to highlight key information and raise awareness of the long-term impact/often - hidden nature/chronic difficulties & challenges / support needs of individuals with ABI and families, would reach more people and impart more information than a longer-term leaflet/ poster campaign. A piece on the Nolan radio show during May during the annual campaign would also be a great reinforcement in peoples' minds. In terms of Statutory Services - perhaps a training video could be developed with representation from individuals/ families/ carers/ acute medical services/GPs/community ABI teams/social work/ justice service/ education/ employers/voluntary sector services - which would serve to raise awareness of the journey of an individual and highlight the impact/ needs of individuals and families - but also act to foster a better understanding of what other key professionals/ services are out there with a role to play and increase co-working/ joined up support within and across sectors. Key contact information could be included at the end of the training video. A video could be easily disseminated and it is also more 'permanent' than a leaflet - as professionals can refer back to it when appropriate

Silent disability/ cognition/communication /reception difficulties/ behavioural/ etc could be social media/ TV series soap story ..hearing impairment featuring on silent witness/ EastEnders/ Strictly

I work within the education sector and we have a number of initiatives for raising awareness including training for teachers. I think more joint up initiatives with professionals in the health sector would be useful especially for children with ABI returning to their school community

Events like this, cross sector workshops with senior leaders, talks in schools - mental health workshops are fairly common in schools and workplaces now - perhaps this model could be applied

Q5: How can we raise awareness of acquired brain injury within the general public and statutory services?

In statutory services, Brain Injury Awareness training should be mandatory at induction

Through events like this being aired to a wider audience

Funding specifically set aside for promotion this and more people like Robert Swann other MLAs from all parties taking an active interest and helping promote the need for the services

Panel Discussion key questions posed

What research has been done re ABI? How many affected? How many carers affected by ABI?
How aware are people re what 'acquired' brain injury is?
Comms very poor. Especially if haven't been thru RABIU.
No advice re ABI week activities etc. What can be done to improve?
Is there a plan for reducing waiting times for community brain injury teams regionally? Equally is there a plan to streamline referral and acceptance criteria?
As carers, and folk with an ABI age and their condition alters, what should be planned ahead for, in relation to continuing to have good quality lives?
There has always been a disparity between adult and paediatric services, but across brain injury this seems extreme, with no specialist paediatric regional community brain injury services existing in the same way as adult services with most patients having to go to Belfast for support or rely on outreach clinics. Are there plans to address the gap between adult and paediatric brain injury services, or do you have thoughts on how these gaps could be addressed in a smart way, or, do you think the current model works?
There are challenges in the delivery of care and support. Social resources for within family support are increasingly limited due to changes in population demographics and the growth of single adult households over time. People continue to have needs around their ongoing sequelae, many of which are not amenable to rehabilitation. What is the commitment to services for support, accommodation, and transition from paediatrics? Is there support for re-provision of Neuropsychiatry – which is no longer available and is paramount in challenging behaviour, Mental Health interaction with BI and the interface with addictions?
How can we work together to ensure support is shared equally across the whole country- outflowing from the 2 main regional centres in Belfast
How can we help the health committee understand the needs of people with acquired brain injuries and the current unmet needs in service provision and inequalities across the region?
Across the UK there has been an increased focus on neurology services, with the Neurological Conditions Delivery Plan for Wales, the Neurological Care and Support in Scotland Framework 2020 – 2025 and in Northern Ireland, the Review of Neurology services, but they lean heavily on adult services with very limited focus or scope to address paediatric gaps in services. Across the UK and specifically Northern Ireland, do you think enough is being done to assess, review and address paediatric support needs, especially in the current review of neurology services in Northern Ireland?
To each member of the panel: If we think of the patient pathway through Acute services, In-patient rehabilitation and then Community Rehabilitation, also the journey from childhood, through being a teenager and then an adult having joined up communications would be helpful to reduce the stress on families trying to access services - within statutory and independent sectors too
What would the 'perfect' health, social and community services (statutory and voluntary) provide for those living with Brain Injury, their families, friends, colleagues and friends as they engage in employment, leisure, artistic and sporting activities throughout life?
Do the panel think social workers are sufficiently trained to deal with ABI issues? With statutory chimney ABI inclined to be pushed under Physical & Sensory Disability cos nowhere else to go.
Social isolation with resultant mental health pressures is biggest single issue survivors and Carers face. Resources invested in this area which is largely addressed by the voluntary sector have not kept pace with both need and demand.

Panel Discussion Comments offered on Chat function

As we raise the awareness of concussion MTBI where best is the service provision for this? Coming from CBIS is it through CBIS teams.

Should there be a specialist service for BI in justice system for diagnosis, treatment

Hopefully #EncompassNI will help with data collection and numbers post launch. Digital information will hopefully be more accessible.

Very insightful comments from every panel member - there are real opportunities for a true collective leadership approach to looking at what is needed particularly for children and families and how it can be properly resourced, delivered and supported. The needs of home based carers mentioned by Colm are really significant both emotionally and practically.

I agree with entirely about the lack of data, particularly NI specific data. It is difficult to develop targeted policy in a vacuum. There was an ABI conference 'Costs and Consequences' on 11 March 2016 introduced by Mr Justice Stephens in which Eunan was involved. There were 6 recommendations of the expert panel, the second of which was 'Magnitude' i.e. data collection

Throughout Covid we have managed to gather huge amounts of data. The ability is there if the will is there.

Cross departmental work would be fantastic- housing/roads/safety/health/education- sometimes the biggest challenge for children is the housing and education needs post injury

Great points raised about the importance of awareness raising and great to hear Dr. McCrudden talking about working with social workers to increase and hopefully improve understanding of ABI.

Think important to note that often ABI is hidden and not visible to the general public, which causes lots of difficulties for carers

Don't just need data but need people there to affectively analyse the data to plan effectively for the future benefit of all those affected.

Not only children have challenging behaviours as a result of ABI - this is one of the most difficult aspects of caring and coping.

Lack of access to psychological supports not confined to ABI- particularly in children - paediatric psychology services have not had sufficient investment in local trust areas - CBIT for adults are available in all trusts for adults and provide much of the issues around psychological/ behavioural support - albeit challenges of capacity also

Transition into appropriate adult services is really challenging especially for young people living with the consequences of a severe ABI

In Prison people often have multiple diagnoses. There is considerable overlap at the complex end and HSC and voluntary services need to work together to offer support and services to people not their condition.

Bridget, its inspiring to hear you talk so passionately about the challenges faced by families with children with ABI. What I've observed to be a challenge is when needs related to abi only emerge later down the line, when the child has been discharged from acute services. Particularly around educational difficulties. It can then be difficult to re-access what is available.

Panel Discussion Comments offered on Chat function

Services need to provide both early, intensive rehabilitation as well as condition management and long term support. Teams need to be sufficiently staffed to provide this and services need to be equitable across the trusts.

Most are concerned with the issue that causes ABI like stroke or epilepsy and once this is stabilised (!) very little further support...

Need to think about how we get this issue heard - covid 19 investment around rehab needs (needed and gratefully received) but no investment for rehab of children in spite of discussion over the years. Misperception of "plasticity of children's brain" possibly still an influence

Early identification of brain injury within all aspects of the criminal justice system is key. From the moment of arrest, through to potential prosecution and sentencing, brain injury has to be taken into account in order to ensure the survivor's needs are understood and supported. Some good work already going on in this area via Headway's Justice Project, including in NI; as ever, more progress needed across all aspects of the CJS.

Covid investment, whilst very welcome, has overtaken so many other services which have been left behind.

Unfortunately too often Carers needs fall under "unmet need"

May need to think about developing wider models of rehab both for adults and children - often similar issues across orthopaedic/ spinal and brain injury and wider neurological presentations - Long term condition models helpful - with specialist knowledge in built into provision

A small difference that would have a big impact is integrated discharge coordination on discharge from acute care services or from hospital when a child is going back into the community and back into education. This should include input from key non-statutory services. On discharge, every child should have a comprehensive discharge letter or where appropriate, rehabilitation prescription or hospital fit Note that covers all aspects of the injury/illness and support needs within input from the network around the child (including family). These should automatically be shared with schools and education professionals with links into community support networks for schools, including the Children's Acquired Brain Injury Consultant Service, Brain Injury Matters and the Child Brain Injury Trust or other key services.

We need to get reliable measures of complexity- Eunan makes an important point- complexity and co-morbidity in childhood neurodisability eg post ABI is becoming more and more apparent

Agree with Eunan that need to take some learning from acute services in terms of their messaging and better impact on highlighting need - community and longer term needs less well articulated.

An early intervention acute neurological specialist rehab team that encompasses all MDT that can go in for 6 weeks on discharge similar to the early supported discharge in stroke teams would be useful and is definitely required.

We need to be able to provide appropriate, timely support for people on discharge from hospital but also ensure that specialist community neuro teams are able to provide condition management support, this is prior to community brain injury team becoming involved

The services should be needs based and not diagnosis based - this would ensure that all those who have needs that require specialist neuro support are able to access it and people aren't missing out on specialist input.

ESD stroke models could be used to reflect on needs