

# The **Family First** Service

A New Family Focused Intervention Service for  
Children with Acquired Brain Injury in Northern Ireland

**Summary Document of Evaluation Report 2020**



## Section 1 - Introduction

### The Family First Service

The Family First service is a unique project in Northern Ireland that has developed and evolved significantly over the last five years. Family First delivers evidence-based, family focused interventions to children with Acquired Brain Injury (ABI) and their families through home-based support, family workshops, tele-therapy, online services, and advocacy and consultation with statutory services.

The project was developed by Brain Injury Matters (NI) in partnership with Psychological Services within the Belfast Health and Social Care Trust in response to the absence of regional or specialist community brain injury teams for children with an ABI<sup>1</sup>. A proposal was submitted to the National Lottery Community Fund resulting in a five year funding programme of £500,000. This investment supported a team of practitioners to develop and deliver a programme of evidence based interventions for children with acquired brain injury (and their families) across Northern Ireland in conjunction with clinicians within Psychological Services at the Royal Belfast Hospital for Sick Children (RBHSC).

A five year independent evaluation of the project was completed in June 2020 by Dr Chris McCusker<sup>2</sup>. The service evaluation was based upon an outcomes monitoring framework, focusing upon Accessibility, Acceptability and Effectiveness using both quantitative and qualitative measures, based on recognised tools and clinical approaches<sup>3</sup>.

The following document below provides a synopsis of the project's achievements and highlights the considerable difference made to the lives of over 200 people impacted by ABI, the contribution to service provision and capacity building in education and health services.

<sup>1</sup> Regional Acquired Brain Injury implementation Group (RABIG) Acquired Brain Injury Pathway for Children and Young People

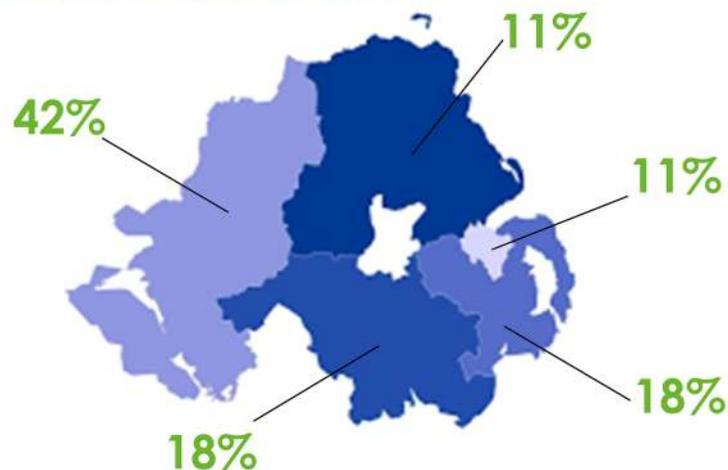
<sup>2</sup> Consultant Clinical Psychologist/ Neuropsychologist and Senior Lecturer in Clinical Psychology in University College Cork

<sup>3</sup> The Full report is available to [view here](#)

## Section 2 - Key Learning and Achievements

### Demographics

Outreach across Northern Ireland was important to the project and indeed the **greatest proportion of referrals came from the Western Health and Social Care Trust**, which has often been disadvantaged when accessing Belfast based services.



TRUST AREA	% OF REFERRALS
BELFAST	11%
NORTHERN	11%
SOUTHERN	18%
WESTERN	42%
SOUTH EASTERN	18%

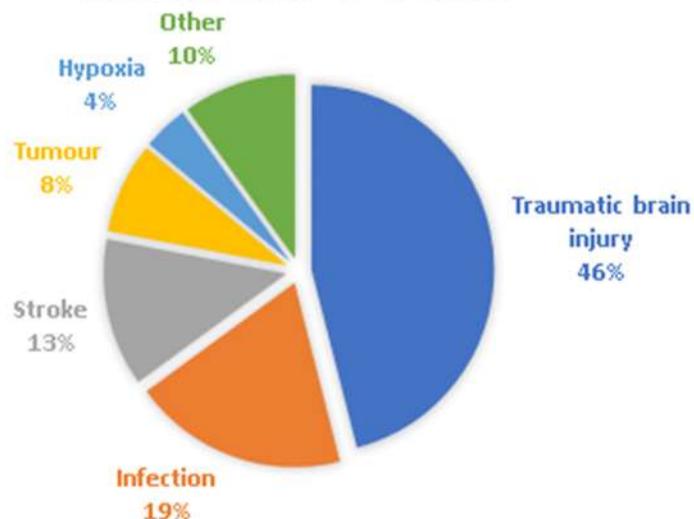


Almost all referred families had **siblings (83%)** and, as we know that an ABI can impact the whole family unit including siblings, this supports the family-focused model adopted by Family First.

There was a significant proportion of **lone parent families (42%)** and a significant proportion of families from **areas of higher socioeconomic deprivation (32%)** as measured by Northern Ireland Statistics and Research Agency (NISRA) deprivation indices.

## Clinical Data

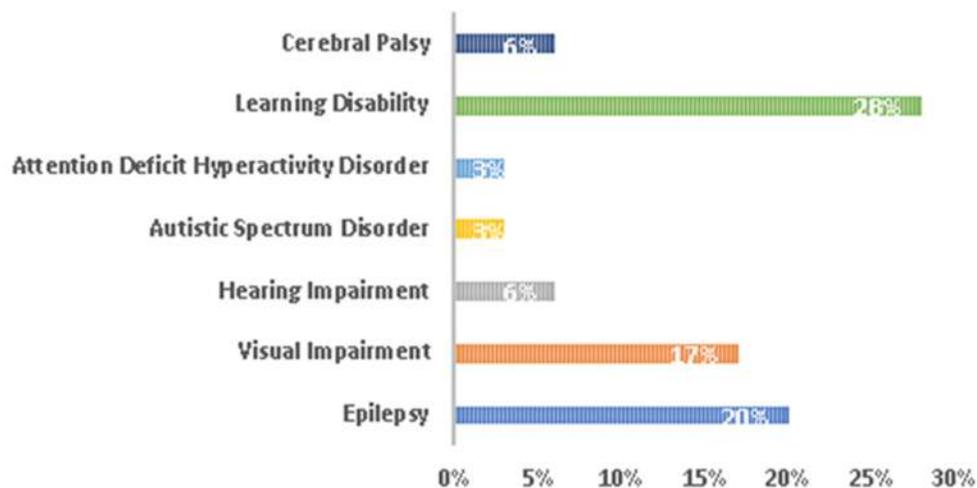
### MECHANISM OF INJURY



In terms of the clinical presentation of the children referred to the service, about half of the children sustained traumatic brain injuries but other mechanisms (stroke, tumour, hypoxia etc.) were evident.

**This variety of mechanism of injury demanded additional knowledge and training among project staff.**

### CO-MORBID DIAGNOSES



Most children fell in the "moderate" range of post injury issues (83%) based on King's Outcome Scale of Childhood Head Injury (KOSCHI) grading. **These are the children who, because they do not have "severe" disability, can fall below threshold for specialist neurology and other disability services.** However, a significant proportion also reported co-morbid diagnoses such as epilepsy, ADHD, ASD and learning disability.



## Positive Impact on Children & Families

The report strongly evidenced the significant positive impact of the **Family First** Service to children and families. Formal outcomes on standardized tools have indicated:

- **Improvements in child competencies** (social and school).
- **Reductions in behavioural difficulties** and improvements in psychological adjustment and quality of life – for both the child and the family.
- Parent and child reports referenced **increased understanding**, improvements in family wellbeing and communication and **more informed parenting** skills.
- Parents also reported increased **attainment of therapeutic goals**.
- Evidence for **maintenance of gains** across time.

Being a family-focused service, it was important to also hear the voice of the sibling of the child affected by ABI:

- Siblings spoke about how Family First helped them to **understanding the brain injury's impact** of damage on the child with an ABI.
- Children spoke about **specific coping strategies** they had been taught to help them cope better and also highlighted a **feeling of happiness in their families** with greater understanding of ABI and coping skills.

“My child gained so much. The team gave her strategies to help her to reduce her stress levels which really helped her at school” (Parent)

“Brain injury matters in all honesty has been a real lifeline for us, I would be completely lost without the help” (Parent)

“I better understand [sibling] and the reasons for her behaviour” (Sibling)

“I liked the remote control page because it helped me to think more about my thoughts and how to help my feelings” (Child)

Formal qualitative analysis of family feedback indicated:

98%

of families **would recommend**  
the Family First programme to  
**friends/family**

71%

of families reported an  
**increase in sibling wellbeing**

92%

of families reported **positive**  
**impact** on the family

95%

of families reported an  
**increase in parenting**  
**confidence**

95%

of families reported an  
**increase in parental**  
**understanding**



## Impact on Staff Development

The report was very explicit on its commendation of the project team, governance and evolution of the Family First Service. Skills and expertise within the team, the partnership with staff from RBHSC, supervision and training arrangements “*suggest a safe service which has been capable of responding to the increasing complexity of family presentations*”. There has been an evolution in staff skills and an evolution in service delivery methods highlighted most recently by the move towards remote service delivery though the online portal in the wake of COVID-19.

The report findings illustrated a significant range of presenting difficulties, both physical (70%) and psychological (between 73% -94%) in the children that were referred into the Family First Service. This highlighted the range of knowledge and skills required in the team to meet such needs or to be able to liaise with relevant statutory services to attain relevant interventions.



“A safe service which has been capable of **responding to the increasing complexity** of family presentations.”

## Impact on Wider Service Landscape

The service landscape in Northern Ireland for children with ABI has not changed since the Family First Service began in 2015. Unlike for adults, there is no regional or specialist community brain injury teams for children with an ABI<sup>4</sup>. After discharge from the acute hospital (Royal Belfast Hospital for Sick Children), these children's healthcare and rehabilitation needs are met through the acute hospital and /or Core community services (e.g. physiotherapy, clinical psychology, speech and language, CAMHS).

This report clearly outlines the positive "**Impact on Service Landscape**" that Family First has had. The theme of "**Filling a Gap**" was very evident in referrer feedback, which was also apparent in parental experiences.

Moreover, referrer feedback contained a theme "**Enhances Capacity of Statutory Services**". This indicates that not only did this service fill a gap in services but that the capacity of these professionals to understand and work with children with ABI was enhanced through liaison and consultation with the Family First Service.

Feedback from Health and Educational professionals also noted the positive impact of Family First on therapeutic outcomes for their patients and clients.

“ Prior to the project's existence there was no specific place to **access support for families** who had children with ABI ”

“ The service has had a **very positive impact** on the patients and their families ”

“ BIM is a **bridge between our service** and the things that need to change at home. It **compliments rather than duplicates** what we do ”



## Section 3 - Future Directions

Following the project successes, Family First attained a further 2 years of funding from the National Lottery Community Fund to **continue and develop the project and extend its reach** to children and young people aged 0-18.

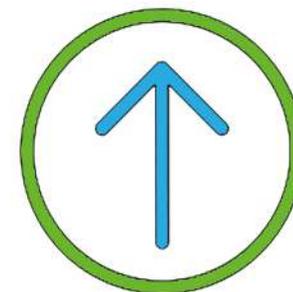
Given the positive feedback the **Family First Online Portal** has received, this will be developed further. To date, there have been workshops delivered online and a community of parents affected by childhood ABI has been established on this platform.

Family First is collaborating with a local web technology service to enhance the features of this resource, whilst ensuring it remains functional and user-friendly.

It is also felt that the Family First Online Portal could be used to **increase accessibility to the service, as well as staff capacity**. The staff team is currently looking at ways to incorporate this online intervention into the core family-focused model which will reduce time devoted to travel across Northern Ireland, and allow a larger number of families to gain access to the service at any one time.

The **collaborative relationship** with Psychological Services within BHSCT will continue, and new clinical consultation through the Children's Acquired Brain Injury Service (CABC's) will support delivery of the project.

Given the impact of the Family First service on the statutory service landscape, through increasing referrals, capacity building and service liaison, **sustainability** in terms of longer term funding will be explored through statutory commissioning.



## Section 4 - Conclusions

### The Family First Service

The family-focused model adopted by Family First demonstrates that supporting parents and families is key to supporting the individual with an acquired brain injury. This project clearly highlights the importance of early intervention, personalised and tailored support and the need to empower parents who are affected by childhood ABI. Where parents hold an appropriate understanding of their children's condition, development and rehabilitation goals they can effectively co-rehabilitate, educate and advocate on behalf of their child. In this context parents can play a pivotal role in facilitating a continuity of care, identifying learning needs in professionals and ensuring communication between children's services, and a shared understanding of their child's needs post-injury. In order for this to be actualised, parents benefit from continued support, and this was clearly evidenced in the evaluation of the Family First service.

The evidence provided highlights how service provision within Family First is working alongside and collaboratively with other services and families, i.e. a whole systems approach, co-producing and co-designing a service to meet the needs of families. The project recognises that the upskilling of staff is an effective use of limited resources to ensure that services are both evidence-based and evidence-informed.

The report strongly evidences how the Family First Project has not only improved the lives of children and young people, but has changed the wider landscape of service delivery and is delivering in line with current policy context. Family First are supporting families to use the health service better, empowering them to access services and to be able to articulate more what they need out of statutory services. We are addressing a need for which there are no services designed, and supporting the whole family unit following childhood ABI.

Overall, it is evident that Family First is creating the conditions for individuals, families and indeed communities to take control of their own lives, achieve their full health and wellbeing potential and live beyond acquired brain injury. In real terms without this service over 200 people would not have achieved the positive outcomes evidenced in this report. To read the report in full, [click here](#).



## Case Study 1 - *Living With ABI* by Courtney, mother to child (5) with ABI

My son who is now 5 received an ABI following a serious road traffic accident in April 2019.

The Family First service (BIM) has been my main source of help and information since my son's accident. Staff (pre-Covid) came to our house to talk with me at length about all different aspects of life after ABI - medical, emotional, practical. They also commenced some play-based sessions with my son and myself and some joint sessions with his 3 year old brother which really helped guide me on how to approach getting my son to open up through play and also introduce types of play (e.g. sensory) that pre-accident wouldn't have been on my radar.

We have been using the service since mid-September 2019. We were referred to the service by Specialist Clinical Psychologist, as we were struggling to cope with the significant changes in my son's personality since his accident.

BIM has had a very large and very positive impact on our life. The input of the Family First initiative has largely shaped our management of life and how to approach our new challenges since my son's accident.

I have benefitted most from probably just having someone to talk to that understands the complexity of living with and parenting a child with a brain injury. Someone who has good in-depth knowledge and hands on experience of the issues, ideas of techniques to try, and also from the practical side of staff chasing up referrals and trying to coordinate some sort of cohesive plan of action for my sons ongoing treatment.

I feel that having the weight of an organisation behind you often makes these tasks easier and I felt that I didn't really have the confidence in my own knowledge of brain injury treatments etc. to do this myself.

*"I would just like to express my thanks that the service exists to help families like mine"*

During Covid I have signed up to the Portal. I have been engaging in weekly phone calls with staff. I have also been receiving ideas from staff about different play/learning ideas to help my son during his home-schooling.

I am happy with how Brain Injury Matters has responded during the crisis. I feel that they are absolutely doing the best they can to continue to engage with our family and to help out in any way they can.

I would just like to express my thanks that the service exists to help families like mine. There appears to be precious little to help children living with brain injury and I really feel that without the service our family would be totally floundering trying to cope with our new normal.



## Case Study 2 - *Living With ABI* by Sarah, mother to child (6) with ABI

Our family engage with the Family First Service provided through Brain Injury Matters. Our engagement is tailored to meet our family's individual needs and is provided on a one to one basis in our home where we can focus specifically on our child's needs (as a result of an ABI) and the impacts this has on our family unit.

Our direct engagement with the service began in January 2020 following a self-referral through the Brain Injury Matters website. Our child attends a range of appointments to meet his physical needs, both locally and regionally with his physical progress regularly monitored and treatments adjusted accordingly. That being said, an injury to the brain has wide reaching consequences and a great deal of this impact is on the psychological, social and emotional as well as the physical. Access to these types of services are more limited in our area and are sometimes accompanied by specific 'entry' criteria which we have not met in the past. We were alerted to Brain Injury Matters by a local paediatrician and I followed up with a self-referral in order to explore what services were available that may be of benefit to us.

Engagement with Brain Injury Matters has been a really empowering experience for our family. Our experiences have been listened to and we have been given the time to discuss our concerns whilst also receiving the tools and advice to help progress forward through a range of solution-oriented approaches. Our child is maturing and developing skills to manage his emotions and behaviour and we are learning strategies to ensure we can assist him with this.

The most beneficial aspect is that the service we receive is tailor made. Acquired brain injuries are not one size fits all and therefore the solutions cannot be either. The one to one support from the Family First Psychologist has been outstanding. The support we receive is also outcome oriented and we regularly review and refer back to those goals to track progress made.

***"We have seen  
some absolutely  
wonderful progress"***



Our engagement has continued despite Covid 19. We are now utilising support virtually through planned regular telephone calls and the use of the Brain Injury Matters Portal where I can engage with other families, as well as the Team from Brain Injury Matters. The Portal has been a fantastic resource as we have received various documents and strategies for activity ideas during lockdown as well as a social platform to share ideas with other parents and families.

The team have not broken their stride during this whole epidemic. Communication from Brain Injury Matters has been ongoing, timely and informative as to how they planned to deliver their services during the crisis and they did so with the consent and support of the family. Engagement while not face to face has been productive and helpful and I have also received various materials through the post to help our family along the way.

Brain Injury Matters offer a really family centric service that is both positive and progressive. In the few short months since our contact began, we have seen some absolutely wonderful progress against the targets we set during our first meeting. This is such a rewarding feeling to know we are moving forward together.

## Acknowledgements

We would like to sincerely thank the National Lottery Community Fund for providing the financial resources to enable us to provide evidence based interventions to families and children with acquired brain injury over the last 5 years. The National Lottery Community Fund has agreed an extension of that financial support for a further two years based on the findings in the interim evaluation report, which clearly demonstrated positive changes for families.

We would also like to thank our partner, the BHSCT, and in particular the Department of Psychological Services led by Dr Sarah Meekin and Dr Eunan McCrudden. We thank Dr Eunan McCrudden for the sharing of his clinical knowledge of ABI which has been invaluable and instrumental. We would like to thank the members of the steering group, the parent representatives, Elizabeth Downey and Mari McDonnell and previous Family First staff. We take this opportunity to also thank our esteemed colleague Dr Marie Goss whose expertise has challenged and enabled creativity.

We thank Dr Chris McCusker for his support and guidance in terms of the Evaluation Framework and authorisations of this report.

To the current staff team Meg Irwin and Catherine Quinn, directed and led by Bridget Smyth, for their hard work, motivation, skill and expertise that has ensured families have been supported to live beyond ABI.

To Icon Creative for their support, in the development of the Family First portal.

Finally, a special thanks is extended to our families who have engaged in the programme, shared their stories, and helped to shape and inform the Family First Project.

### ***The Board and Management of Brain Injury Matters***