The Family First Project

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

Five Year Evaluation Report

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CONTENTS

Preface and Acknowledgements

The *Family First* project began back in 2015 prompted by increasing evidence that families – their resilience or their fragilities – seemed to be crucial to the adjustment and recovery of their child with an acquired brain injury. When *Brain Injury Matters* formed a collaborative relationship with the *Department of Psychological Services of the Belfast Health and Social Care Trust,* we were interested in the fact that their clinical and research work suggested that family functioning was often a greater predictor of outcomes for a child with any chronic illness or disability than the severity of the injury or illness per se.

Brain Injury Matters set about developing a programme of evidence based intervention for children and their families with acquired brain injury entitled the *Family First* Service. This unique service has developed and evolved over the last 5 years adapting and adjusting to the changing landscape and providing tailored support to families.

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, Elisabeth 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.

Bridget Smyth Head of Children and Youth Services Brain Injury Matters
Joe McVey CEO Brain Injury Matters

Executive Summary

1. Initially funded for 5 years by the *National Lottery Community Fund*, the *Family First* project has endeavored to improve outcomes for children with acquired brain injury (ABI) by bolstering the resilience and coping of families. Unique in Northern Ireland, this was undertaken through a home visiting programme, family workshops, tele-therapy, advocacy and consultation with other statutory services. Specific therapies are outlined in the report, delivered by the team in consultation with statutory child psychology services at *Royal Belfast Hospital for Sick Children*. An outcomes monitoring framework was in-built and an interim evaluation in 2018 suggested the project was on track to meet its aims and objectives.

2. At final evaluation, the project has reached 80 families and 60% above original targets. An increasing proportion of referrals has come across the 5 years from statutory health and educational services (64%), although self-referrals have remained in evidence. The project has reached children with complex health and educational needs and families at greatest risk. The home visiting service has been the mainstay of the programme and was instrumental in facilitating access according to both family and referrer feedback.

3. Formal outcomes on standardized tools suggested 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 well-being and communication and more informed parenting skills. Parents reported

increased attainment of therapeutic goals and there was evidence for maintenance of gains across time.

4. These formal outcomes were supported and complemented by the narratives of parents and children themselves. Themes from their stories related to family empowerment, family connectivity and that this service filled an important gap in current statutory service provision. Triangulating this evidence was the feedback of referrers to the service who spoke about their experience of such positive outcomes for their clients, the accessibility of the service and that consultation and liaison with the service had enhanced their own capacity to help these families.

5. Staff of the service have reported new and innovative ways of working (e.g. a new online portal) and effective adaptations to COVID-19. However, they have highlighted an increasing complexity of cases coming from statutory referrals and their working in ways which were perhaps not envisaged at the outset of the project.

6. Clear strengths of the project are outlined. These relate to impressive positive outcomes, the reach of the project, the service gaps filled and the capacity building evident and attention to rigorous outcomes monitoring. Challenges and recommendations are also outlined for the service to consider in collaboration with commissioners and stakeholders.

1. Context and Methodology

1.1. The importance of families in childhood brain injury

Brain injury is the leading cause of disability in childhood. We also know that this results in social-emotional, cognitive and physical problems for the child – which can grow across time as the injured brain fails to develop properly[1,2]. As they develop, these problems can lead to educational (and later occupational) disadvantage, disability, mental health difficulties and social exclusion[1-3].

However, these outcomes are not inevitable. Moreover, we know that the severity of the brain injury is not always the greatest predictor of outcome. Rather, the resilience, coping resources and parenting style of the family are important determinants of outcome for the injured child[4-6]. This is something which we can do something about and this was the underlying premise for the *Family First Project*.

1.2. The Family First Project – Strategic Aims

The research evidence, both in studies conducted at *The Royal Belfast Hospital for Sick Children*, and internationally, suggests that family focused interventions, which relate to psychoeducation, problem solving skills training, family communication, meaning making and resilience training, benefits not only family adjustment but ultimately outcomes for the child with chronic illnesses and disabilities including brain injury[5,7].

Thus, the specific aims and objectives of this project were:

- To bolster family resilience and problem solving.

- To facilitate adjustment to the losses and new challenges precipitated by the acquired brain injury (ABI).
- To promote family cohesion, communication and effective parenting under the changed circumstances and dynamics evident following brain injury.
- To increase understanding of brain injury across all family members – parents, siblings and the child with the brain injury themselves.
- To consequently reduce the impact of cognitive, emotional and behavioural difficulties in the child with the ABI and to reduce distress and adjustment difficulties in parents and siblings.

The *Family First* programme was targeted at the whole family – parents, the child with the brain injury and siblings. As discussed in the interim report (December 2018)[8] it aimed to promote "expert families", who have the knowledge and skills to meet as many of the challenges of ABI as possible themselves, and to prevent escalation of such challenges into chronic longer-term problems.

1.3. The Family First Project in a Northern Ireland Context

The service landscape in Northern Ireland for children with ABI has not changed since inception of this programme. Unlike for adults, there is no regional rehabilitation service for children with ABI, nor are there specialist community brain injury services. 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 generic community services (e.g. physiotherapy, clinical psychology, speech and language, CAMHS). The *Children's Acquired Brain Injury Consultation Service*

(Children's ABC) is a small statutory funded service to provide consultation and advice to these generic services – rather than offer direct therapeutic provision per se. The *Children's Brain Injury Trust* is another charity service which receives statutory support to provide support and advice to families and carers / schools.

A recurrent theme, from both referring professionals and families themselves, in the interim evaluation report was that the *Family First* project "fills a gap" and indeed this was an argument in the original application to *Big Lottery*. The, now *National Lottery Community Fund,* supported the project with funding and the *Brain Injury Matters* charity in East Belfast developed and delivered the programme with collaboration and consultation from child Clinical Psychology at the *Royal Belfast Hospital for Sick Children*. The aims related to family-focused interventions were as outlined above and remain unique in Northern Ireland in terms of services for these families and their children.

The project began in 2015 with staffing which includes a project coordinator, with specific therapeutic expertise herself, and two team members, again with specific therapeutic knowledge and expertise in working with children and families. These have been supported by consultation from Clinical Psychologists from within the charity and from the *Royal Belfast Hospital for Sick Children*, together with the director of the charity itself (see Appendix 2).

For quality assurance purposes, the team engage in peer supervision and consultation from the Consultant Clinical Psychologists, noted above, and have been supported to engage in continued professional development activities relevant to their roles (see Appendix 2). Wider expertise and strategic monitoring has been provided by a steering group of relevant stakeholders and experts from the region.

The service has operated out of the *Brain Injury Matters* base in the community in East Belfast, but has been delivered in community services across Northern Ireland and indeed in the homes of the families themselves.

As noted in the interim report, this new project was successful in establishing itself in the service landscape for children with ABI and by 2018 referrals were almost twice the projected levels at the outset of the project. Referrals are accepted from families themselves as well as the range of educational, health and social service professionals working with these children. The criteria for referral includes (a) the child having sustained their brain injury between 0 – 12 years (b) an acquired -v- congenital brain injury and (c) a willingness on the part of families to engage with the family focused interventions offered by the service.

As noted above, core interventions offered by *Family First* have related to building family resilience, coping strategies and psychosocial adjustment. The specific interventions have evolved across time as the team learned what worked and what did not work logistically for families. A home visiting programme has been the predominant format for service delivery. This was appreciated by families in the interim report and helped facilitate access for hard to reach families. In addition, the project has offered direct interventions through family workshops (for parents, the child with an ABI and their siblings), an online "portal" for families and indirect interventions through consultations to schools and other health services. The nature of therapeutic interventions are described in the 2018 interim report but included psychoeducation, narrative and problem solving therapies, parenting skills for children with ABI and specific interventions related to specific problems when required (e.g. mood management, thinking skills retraining).

1.4. Review of Previous Evaluation

As noted above, an interim evaluation of the programme was conducted by the same author towards the end of 2018 and 3 years after project inception[8]. At that time key findings suggested the project was reaching more families than anticipated, from across Northern Ireland, and that both families and professionals experienced the project as "filling a gap" in statutory service provision. High levels of programme acceptability were found in families and thematic analysis suggested positive outcomes related to empowerment, coping skills and family resilience. Professionals sampled suggested the project had increased their own capacity for responding to children with ABI and their families. Formal outcome measures of effectiveness showed promising outcomes on standardized measures. However, the outcomes portfolio had taken some time to become fully implemented and this data set was low at that time. Nevertheless, families told the service about increased understanding of brain injury and improved skills in parenting, understanding and communicating with their child. Improvements in overall family functioning were reported.

The interim evaluation concluded with some recommendations for the second part of the life of the project. These related to developing a sustainability strategy, increasing family participation in the workshops, more fully implementing the outcomes portfolio, strengthening and maintaining the partnership with the *Royal Belfast Hospital for Sick Children*, engaging service users in the steering committee and disseminating their findings from this innovative and unique project.

1.5. Current Methodology

The current evaluation replicated, but extended, the methodology used in the interim evaluation. The evaluation was based on three outcome pillars:

- *Accessibility* – has the project reached the target population, and in sufficient numbers? What are the needs and profile of those who access the project to inform interventions?
- *Acceptability* – have the project interventions been acceptable and been experienced as helpful to families both in terms of content and format?
- *Effectiveness* – have the project interventions been helpful or instrumental to achieving the therapeutic aims and objectives as outlined above?

Table 1 below outlines how data relevant to each of these pillars was collected. Data came from thematic analyses of parent and child feedback, referrer feedback and the feedback of the project staff themselves. Both project bespoke tools and standardized instruments were used to capture data related to effectiveness.

Table 1 Outcomes Framework for the Family First Project

Outcomes	Comments / Notes
Accessibility	
• Demographics of presenting families. • Referral patterns and collaboration with other services. • Brain injury profiles (severity, mechanism of action etc.). • Clinical presentations (including baseline profiles on many of the outcome measures noted below). • Service contacts and services accessed. • Feedback from the families, referrers and project staff on accessibility.	• Collected through intake assessment interviews, questionnaire completed at that time and thematic analysis of relevant accessibility feedback offered on the *Patient experience of Care* (PEC) questionnaire noted below.
Acceptability	
• A bespoke *Patient Experience of Care* (PEC) questionnaire was constructed which was adapted from that used to evaluate psychological services in the Belfast Health and Social Care Trust. • *Friends and Family Test*.[9] – this simple measure has been used nationally to evaluate all sorts of clinical services and simply asks whether clients would recommend the service to friends or family who were experiencing similar difficulties. • Referrers and collaborating professionals from statutory services were surveyed annually (by telephone survey) for their feedback and experience of the service (by a research assistant not involved in service delivery).	• The current evaluation only analysed that qualitative and quantitative data which was collected systematically through the PECs. • A focus group evaluation of staff experiences related to the project was also conducted.
Effectiveness	
• The PECs questionnaire elicited qualitative feedback on the impact of attending the project on all members of the family. In addition quantitative items surveyed their experience of the service on understanding, parenting skills, relationship with the child, the child's levels of understanding, behavioural and school adjustment as well as the	• Response rates were good for the PECS as outlined in section 3 below. • Response rates were much improved at this evaluation in terms of returns of the formal, standardized, outcomes measures. • The standardized scales measures a number of key outcomes – psychological adjustment in parents,

understanding and adjustment of the whole family.
- In addition a number of standardized clinical measures were conducted at baseline and service completion (or at 6 months if longer term involvement. These included:
    - *Child Behavior Checklist*[10] – competency and problem behavior scales – completed by parents and teachers as well as young people if age-appropriate.
    - *Beck Youth Inventory*[11] – young person's view on their self-concept, anxiety, depression, anger and disruptive behavior.
    - *Pediatric Quality of Life Scale*[12] – and specifically the social functioning and family functioning subscales.

family quality of life, child adjustment and child quality of life.

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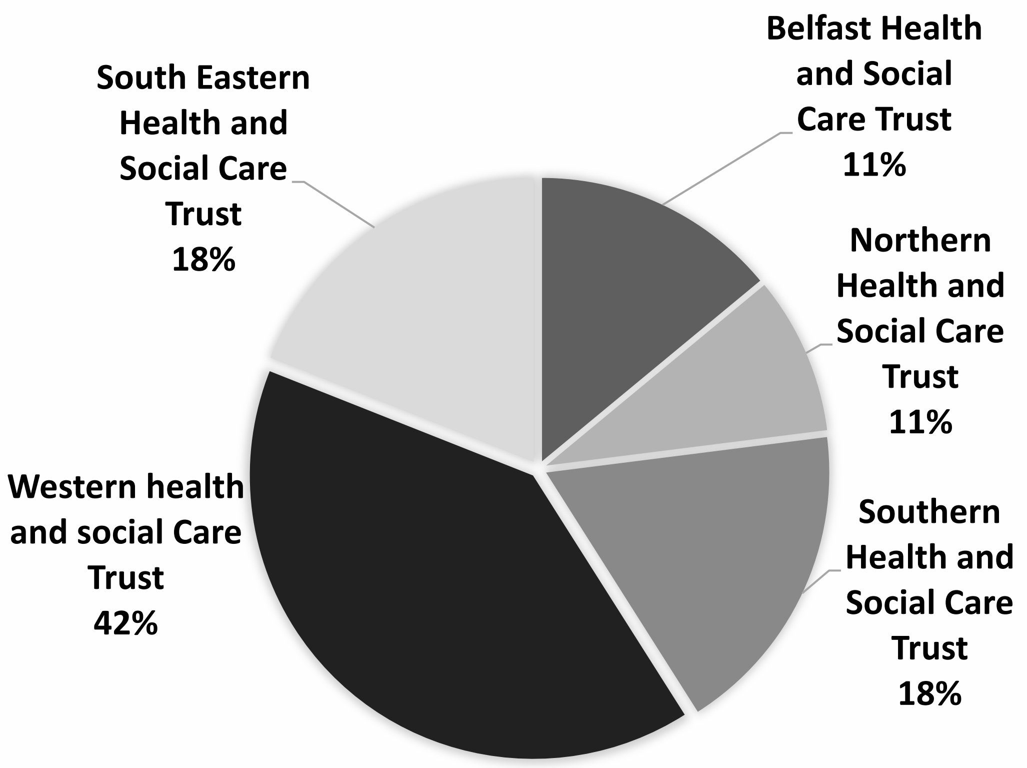
2. Families accessing the service

2.1. Referral Patterns

A total of 80 families were referred to the *Family First* project which is 60% more than the 50 originally projected. It was a primary intention to reach families directly and 36% of these referrals were self-referrals. Staff noted that as awareness of the project increased in Northern Ireland the number of referrals from other statutory and voluntary services proportionately increased to 64% of total referrals. These came from a great diversity of sources (e.g. Clinical Psychology, Occupational Therapy, mental health services, community pediatrics and social work). Outreach across Northern Ireland was important to the project and indeed the greatest proportion of referral came from the *Western Health and Social Care Trust*, which has often been disadvantaged when accessing Belfast based services. The distribution of referrals across all Trust is outlined in Figure 1.

FIGURE 1: REFERRAL SOURCES BY TRUST



2.2. Child and Family Presentations

Table 2 highlights that the project generally accessed those children who had sustained their brain injury between 0 – 12 years as originally targeted. The time since injury and referral was 3.8 years which is shorter than at 3 year interim assessment (4.7 years). This is likely to reflect the incremental awareness of the project resource in the region. However, it also continues to highlight that the difficulties experienced by such children and families may not ameliorate with time and it may be worth thinking about how to further reduce this gap. Almost all presenting families had siblings (83%) and we know that an ABI in a child in the family can impact on siblings too, supporting the focus of *Family First* on the total family. Table 2 highlights high rates of parental unemployment, a significant proportion of lone parent families (42%) and a greater proportion of families from areas of greater socioeconomic deprivation as measured *Northern Ireland Statistics and Research Agency* (NISRA) deprivation indices (32% in the most deprived areas of Northern Ireland).

Table 2: Presentations to the Service (N = 80)*

Demographic	% / Means
Children	
Age at Injury (years)	3.8 (±3.7)
	Range 0 – 13 years
Age at referral (years)	8.1 (±3.5)
	Range 1 – 15 years
Time since injury (years)	3.8 (±3.8)
Gender (male / female)	56% / 44%
Families	
Family Composition	
Lone Parent	42%
Two parents	58%
Parental Employment	
Unemployed	48%
Full / Part Time Employed	42%
Number of Siblings	
None	17%
One	38%
Two	28%
Three +	17%
Deprivation Index	
1st quartile	32%
2nd quartile	35%
3rd quartile	16%
4th quartile	17%

*Percentages for all categories are based on where known – varied from 61 – 80 cases

Table 3 summarises the clinical presentation of the children referred to the service. About half of the children sustained traumatic brain injuries but other mechanisms of damage (stroke, tumour, hypoxia etc.) were evident which has implications for staff training. Most children fell in the “moderate” range of neurodisability based on KOSCHI gradings. These are the children who, because they do not have “severe” disability, can fall below threshold for specialist neurology and other disability services. However, the data also suggest significant involvement with community paediatrics, allied health and psychology service and child mental health services. A significant proportion also reported co-morbid diagnoses such as epilepsy, ADHD, ASD and learning disability.

Findings also suggest a significant range of presenting difficulties, both physical (70%) and psychological. Emotional, social and neuropsychological difficulties were ubiquitous – 73% - 94% of children. Again this highlights 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.

These are children who have largely remained in mainstream schooling (72%) with 16% in special needs education. It was not known how many in special education schools transferred there because of the brain injury. However, despite most remaining in mainstream schooling it was striking that a formal statement of special education needs had been attained, or was in progress, for 59%. This highlights the need for interventions with parents to support the specific learning difficulties of ABI.

Table 3: Clinical presentations (N = 80)*

Clinical Presentations	%
Mechanism of Injury	
Traumatic brain injury	46%
Infection	19%
Stroke	13%
Tumour	8%
Hypoxia	4%
Other	10%
Severity (KOSCHI)	
Severe Disability	15%
Moderate Disability	83%
Mild Disability	2%
Co-morbid Diagnoses	
Epilepsy	20%
Visual Impairment	17%
Hearing Impairment	6%
Autistic Spectrum Disorder	3%
Attention Deficit Hyperactivity Disorder	3%
Learning Disability	28%
Cerebral Palsy	6%
Presenting Problems	
Physical	70%
Neuropsychological	94%
Emotional	73%
Speech and language	48%
Behavioural / Social	82%
School / Education	
Not school age	9%
Mainstream	72%
Special needs	16%
Not attending	3%
Statementing occurred or in progress	59%
Informal extra assistance	25%
Other generic professionals involved	
Community Paediatrics	70%
Physiotherapy	38%
Occupational Therapy	60%
Speech and Language Therapy	48%
Clinical Psychology	45%
CAMHS	24%
Social Services	38%
Educational Psychology	69%
Voluntary Services	43%

* Percentages for all categories are based on where known – varied from 55 – 80 cases

2.3. Services Accessed

Table 4 below summarises the extent and nature of service engagement. The majority of referrals had at least one consultation session (75%), with 59% engaging in a therapeutic programme of work. Data suggests that this was

- Mostly through one-to-one family contacts (on average 11 direct contacts per family, averaging 2 hours per contact);
- Approximately 10% of parents, children with ABI and siblings attended a family workshop;
- That project team members had an average of 3 consultations per family, with other agencies with, or on behalf of, participating families.
- Families are also able to access information and services through an online portal.

Table 4: Services accessed

Services / Status	% / Mean Service Contacts
Outcome of Initial Assessment	
Not appropriate / did not engage	20%
Onward referral with support	5%
One session consultation only	16%
Service engagement (now closed)	43%
Service engagement (ongoing)	16%
Service Contacts	
Direct one to one family contacts	11 (±11)
	Range 0 – 43
Consultations with other agencies	3.2 (±4.8)
	Range 0 – 23
% attended parent workshops	11%
% attended child workshops	10%
% attended sibling workshops	8%

Staff reports suggested that from initial referral, wait times for contacting families varied from 4 weeks to 3 months maximum. Typically, longer wait times were due to the project sourcing clinical / educational assessments from referrers relevant to their subsequent work with the families. All children and their families referred have been seen and assessed for suitability of work.

2.4. Family and referrer experience of service accessibility

As outlined in section 3, some of the qualitative feedback received from *Patient Experience of Care* (PEC) questionnaires, and the annual survey of referrer experiences, highlighted that the home visiting procedures, information and communications from the service, enhanced accessibility to the service. Some specific examples included:

> *"It has been great having Family First because appointments have usually been made at a time that suited our family and they have never been cancelled. It was great having that consistency"* (Parent)

> *"Excellent personal service. Home visits at agreed times"* (Parent)

> *"I liked that [staff member] came to visit me in my house and I did not need to go to Belfast"* (Child with ABI)

> *"I think the home visits they do are very important"* (Referrer)

> *"The referral form is accessible and easy to complete and the leaflets are informative"…The service is easy to access. I think it is great".* (Referrer)

3. Acceptability

3.1. Parent experiences

A *Patient Experience of Care* (PEC) feedback form (see Table 1 above and Appendix 1) was the key tool used to elicit feedback on the acceptability (satisfaction) of the programme to families. Forty-four returns were received which represents an 81% return rate from those families which had been seen for one or more sessions. This is a high response rate which minimizes any concerns about sample representativeness.

One item on this questionnaire (*Friends and Family Test*)[9] asked parents if they would recommend this service to friends or family experiencing similar difficulties. This is a test used by NHS England, across all types of services, and gives a snapshot indicator of how acceptable patients find various services. Data are published on the NHS website and were sourced for this report for comparison purposes. Published data for January – February 2020 suggested that the percentage of patient respondents who said that they would recommend various community NHS services varied from 85% - 95%. In the current sample of parent respondents, almost all (98%) suggested they would recommend the *Family First* programme to friends or family. This benchmarking suggests high levels of acceptability are evident.

Other data were also impressive here. All respondents agreed or strongly agreed with items asking about whether they were treated with "*respect and courtesy*", whether they were "*satisfied with home visits*", whether their consent was obtained for all interventions and whether "*appointments were made to suit*" them.

In addition to these brief indicators of acceptability parents were asked to provide written feedback about their experiences with *Family First* – either at discharge or 6 months into their work with the programme. This data was subjected to thematic analysis. This involves clustering units of meaning together and organizing these under thematic labels which capture content. This exercise had been completed at the 3 year, interim evaluation stage (see interim report, December 2018)[8]. The thematic frame which had been developed then was the starting point for the current thematic analysis, as it was important to retain the experience of those previous users of the service. The new data was woven into this framework, where it was consistent. However, the new information also resulted in some thematic reworking and the final thematic frame is outlined below in Table 5.

Table 5: Parents Experience – Thematic Analysis

Superordinate	Subordinate	Example Quotations
Empowerment	Knowledge	• *“It helped us to understand why he can’t do stuff”.* • *“The family first team gave me a better understanding of the effects of brain injury. Everything I needed was covered”* • *“Absolutely perfect service, very helpful for understanding my child’s condition”*
	Coping strategies	• *“My child gained so much. The team gave her strategies to help her to reduce her stress levels which really helped her at school”.* • *“We got support with our daughter's behaviour needs”.* • *“They helped us to take on board doing things differently. They helped us to brain storm ideas”.* • *“They helped my son with his anger issues, his anger has reduced”.* • *“He has settled well in his secondary school- they helped him prepare for that”.* • *“My daughter has difficulties concentrating and can find it hard to get through her homework. They gave us strategies for her homework”.* • *“They did activities with my daughter; they worked with her when she was going on school trips to reduce her nerves”.* • *"[Staff member] has given [child] coping mechanisms which will benefit him throughout his life”* • *“Very beneficial in a whole lot of ways for giving us ideas and strategies to use when (child) is upset”* • *“They’ve even helped us create a daily planner to help with (child’s) daily activities and morning routine which has been very useful”* • *“I have learned a lot from Family First, things that I had never thought about before or that no one else had ever brought to my attention”*

Family connectivity	Not alone	- *“It was good to talk to other parents and hear what they had gone through. They had similar problems to us”.* - *“Connecting with the other parents”.* - *“Helping us as a family feel not alone.”* - *“My daughter really enjoyed it as well, she met other children with ABI which was good for her”.* - *“It was good for my son’s siblings as they could know that they weren’t the only ones”.*
	Family meaning making	- *“Interaction with (child) and me separately. Family First allowed me to understand my barriers”* - *“They taught me how to co-operate with (child)”* - *“Family First helped us tell [child] about his injury”* - *“Things are much better now at home when I speak to the kids, we understand each other a lot more and a lot better now”* - *“Our daughter was able to open up through the 1-1 work and was then able to talk to us as a family”.* - *“Useful for my other children to attend as they learned about ABI as well”.* - *“She felt able to talk about being bullied since her ABI and found out others had similar experiences to her”.* - *“They suggested that we stand back and think of things from our daughter's perspective. This was eye-opening as it changed how we dealt with things in our family. It was very positive”.*

An accessible and important service	Accessibility	• *“Excellent personal and bespoke service. Home visits at agreed times”* • *“FF provides a safe environment for [child] and us to discuss our worries and fears”*
		• *“It has been great having Family First because appointments have usually been made at a time that suited our family and they have never been cancelled. It was great having that consistency”* • *“Brain injury matters in all honesty has been a real lifeline for us, I would be completely lost without the help”*
	Filling a gap	• *“More time to ask questions to the FF team and I asked the FF team things I wouldn’t ask a doctor or would feel silly asking someone else”* • *“Apart from brain injury matters we get very little help”* • *“We had no information from the hospital. It was good to have a support network as it was hard to get the medical team for any support”.*
Difficulties and Suggestions	Accessibility	• *“The school was frustrated that I kept taking my child out of class, the workshops are always on early, it would be better if it was after school hours so I don’t have to take them out of class”* • *“That many different charities and organisations got involved that by the time you came to us it was less needed – it was late and we got that kind of support through other avenues”* • *“It was too far for travelling. My son doesn’t travel well. Somewhere closer to our home would have been better”.*
	Wanting more	• *One thing maybe would be to have it run a little longer, after a year I’m a bit concerned about what we’re going to do*

Four superordinate themes were evident from the parent feedback. "*Empowerment*" was a major theme in parent narratives. This was comprised of two subordinate themes related to "*Knowledge*" and "*Coping Strategies*". Parents reported increased understanding of their child's brain injury and the impact of this on their difficulties. Perhaps more importantly, they described how they came to learn a whole range of coping strategies related to managing their child's stress, behavior and social difficulties, reintegration back into school and their cognitive and learning difficulties.

Narratives related to the second major theme "*Family Connectivity*" continued to be evident. The "*Not Alone*" subordinate theme captures the reduction in feelings of social isolation and being "different" that came through participation in the family workshops. However, given the underlying premise of the programme that family resilience promotes better outcomes for the child with ABI, the "*Family Meaning Making*" subordinate theme is particularly encouraging to see. Narratives suggest parents perceived increased family communication, understanding of, and empathy with, each other and there are some beautiful examples of this process enabling the child to express how they felt more in the table above. This is very encouraging.

The third superordinate theme "*An Accessible and Important Service*" captured parents' experience of the service more generally. The "*Accessibility*" subordinate theme provides further confirmation of the importance of the home visiting programming in facilitating access to the interventions of the programme. "*Filling A Gap*" continued to emerged as a subordinate theme and narratives here spoke about families not having had access to any such other service in Northern Ireland. This is a theme which was echoed in the referrer feedback as outlined below.

Finally, "*Difficulties and Suggestions*" emerged as a theme at this evaluation. Travel (for the family workshop) and having to take the child out of school highlighted the practical difficulties accessing interventions which take place during weekday working hours. Related to this superordinate theme there were some comments relating to "*Wanting Mo*re" of the service interventions beyond discharge.

3.2. Child experiences

At the interim evaluation there was little data returned which related to directly hearing about the experience of the children themselves. A child-friendly version of the PECs tool was formulated and greater returns were achieved for those child. Understandably, the level of detail in the child narratives was briefer. However, it was still possible to undertake a thematic analysis and findings (from both the child with ABI and their siblings) are outlined in Table 6 below.

It was striking that similar themes emerged to those evident in parent narratives. Thus, children spoke about understanding the brain and the impact of damage on their sibling; they also spoke about specific coping strategies they had been taught to use to help them cope better. These narratives were consistent with a "*Knowledge and Coping*" theme as outlined in Table 6. Also consistent with adult narratives was a "*Family Connectivity*" theme. Here they noted that they had appreciated meeting other children with ABI and their families and quotations

Table 6: Child and Sibling Experiences – Thematic Analysis

Superordinate	Subordinate	Example Quotations
Knowledge and coping		- *"I liked the model of the brain because it helped me to know more about my own brain"* - *"[Staff] made me my own unicorn daily routine and that it helped me to get dressed in the morning"* - *"I liked the remote control page because it helped me to think more about my thoughts and how to help my feelings"* - *"Helps us to understand how to take care of (sibling) better"*
Family connectivity	Not alone	- *"Meeting other people with the same injury (was good)"* - *"Meeting other people with the same injury and hearing their story"*
	Family meaning making	- *"My family are happy"* - *"I found out how to understand (sibling) more"* - *"I better understand [sibling] and the reasons for her behavior"* - *"I am closer to [sibling]"*
Accessibility		- *"It was helpful"* - *"Really enjoyed play activities when [Staff members] visited my home"* - *"I liked that [staff member] came to visit me in my house and I did not need to go to Belfast"*

also highlighted a feeling of happier families with greater understanding. Finally, an "*Accessibility*" theme highlighted that the children also appreciated being seen in the home environment.

3.3. Referrers experience

Eleven professionals (out of 28 invited), who had referred to the *Family First* project since the interim report, were interviewed by telephone with respect to their experience of the service. Interviews were conducted by an intern research assistant not involved in service delivery. These included psychologists, pediatricians, teachers and allied health professionals. Comments were transcribed and subjected to thematic analysis as with the parent and child feedback.

Table 7 below summarises the thematic analysis conducted on their feedback.

Table 7: Professionals Experience of Service

Superordinate	Subordinate	Example Quotations
Accessibility	Effective family engagement	• *"I think the home visits they do are very important"* • *"They got back to me promptly and made contact quickly with the family".* • *"The service was very accessible to the family".*
	Good communication	• *"They phoned me with details of what support was going to be offered to the family".* • *"There was good communication between the service and ourselves".* • *"They sent me out a letter to provide feedback about the involvement they had with the young person- this was good for follow-up knowledge".* • *"Good feedback is always provided. There is the opportunity to link in and to discuss the children that I am referring in which is very helpful. It is nice to hear back about patients and get intermittent updates on their progress".* • *"I was given updated information as things went along".* • *"The information available was impressive and very informative"*
Good outcomes		• *"The service has had a very positive impact on the patients and their families".* • *"The work on behaviour management for families is also really good".* • *"The service provided great support for a client of mine. It was exactly what they needed".* • *"They pitched any work at the child's level".* • *"I can say that the family and child found it very beneficial and I think it's a great intervention"* • *"It has been very useful and feedback from families has been positive"* • *"It has definitely had an impact and a very positive one"* • *"The mother of the child was very vulnerable and I believe the help and support she got from family first was definitely needed and it was on her level"*

Impact on service landscape	Enhances capacity of statutory services	• *“Positively- they arranged a date to meet and talked me through family first and other projects, they gave me a lot of insight”* • *“They were great – they came out to the school last year and did staff training”* • *“They understood the difficulties that I had and they were keen to work alongside me. We were on the same page in that we weren’t duplicating the work we were doing”* • *“We know more about brain injuries – it was absolutely new to me”* • *“Very positive to see an organisation who is so well networked and present at so many events I go to”*
	Filling a gap	• *“Prior to the project’s existence there was no specific place to access support for families who had children with ABI”.* • *“Although the Children’s ABCs service provided support to professionals there was no-where to access that provided direct work with families. The service is important due to the gap in services available for children with ABI”.* • *“They’re plugging a gap in terms of service provision”* • *“BIM is a bridge between our service and the things that need to change at home. It compliments rather than duplicates what we do”* • *“It is great to have a specific service to ABI as people are at a loss as to where to get support”*
Suggestions for improvement	Liaison and communication	• *“When reviewing the case it would be good to be invited along to reviews, or staff could provide information about these reviews”* • *“It would be good to link in with yourselves if we have any cases maybe once a term or once a year”.* • *“Give us more feedback”* • *“Linking in with neurology could be useful- a lot of kids end up going up there and then coming to us. Targeting surgeons could be a good idea”*

Training	• *“More links with the trust – I would suggest designated times for interface meetings as and when a case comes up, and in regular intervals from then on”* • *“Maybe some training on ABI within schools for staff members, just to hopefully raise awareness and educate others, I think if more people within schools that interacted with the child knew more about ABI it would make a real difference”* • *“I suppose maybe more support for schools”*

As noted above, and consistent with parent and child feedback, a strong theme related to the "*Accessibility*" of the service was evident in referrer reports. Comments here pertained to effective processes and family engagement and communications which facilitated understanding of service objectives and collaborative working.

It is always useful to "triangulate" research data – confirm outcomes from several perspectives – and the theme of "*Good Outcomes*" highlights that these health and educational professionals were also noting positive therapeutic outcomes for their patients and clients.

As in the interim report, there was a theme related to "*Impact on Service Landscape*". Again the "*Filling a Gap*" subordinate theme was evident, with feedback which was also apparent in parental experiences. Moreover, referrer feedback contained a theme "*Enhances Capacity of Statutory Services*". Quotations suggested that the capacity of these professionals to understand and work with children with ABI was enhanced through liaison and consultation with the *Family First* programme.

Finally in "*Suggestions for Improvement*" it is clear that these referring professionals would like even more of this liaison, consultation and feedback.

4. Effectiveness

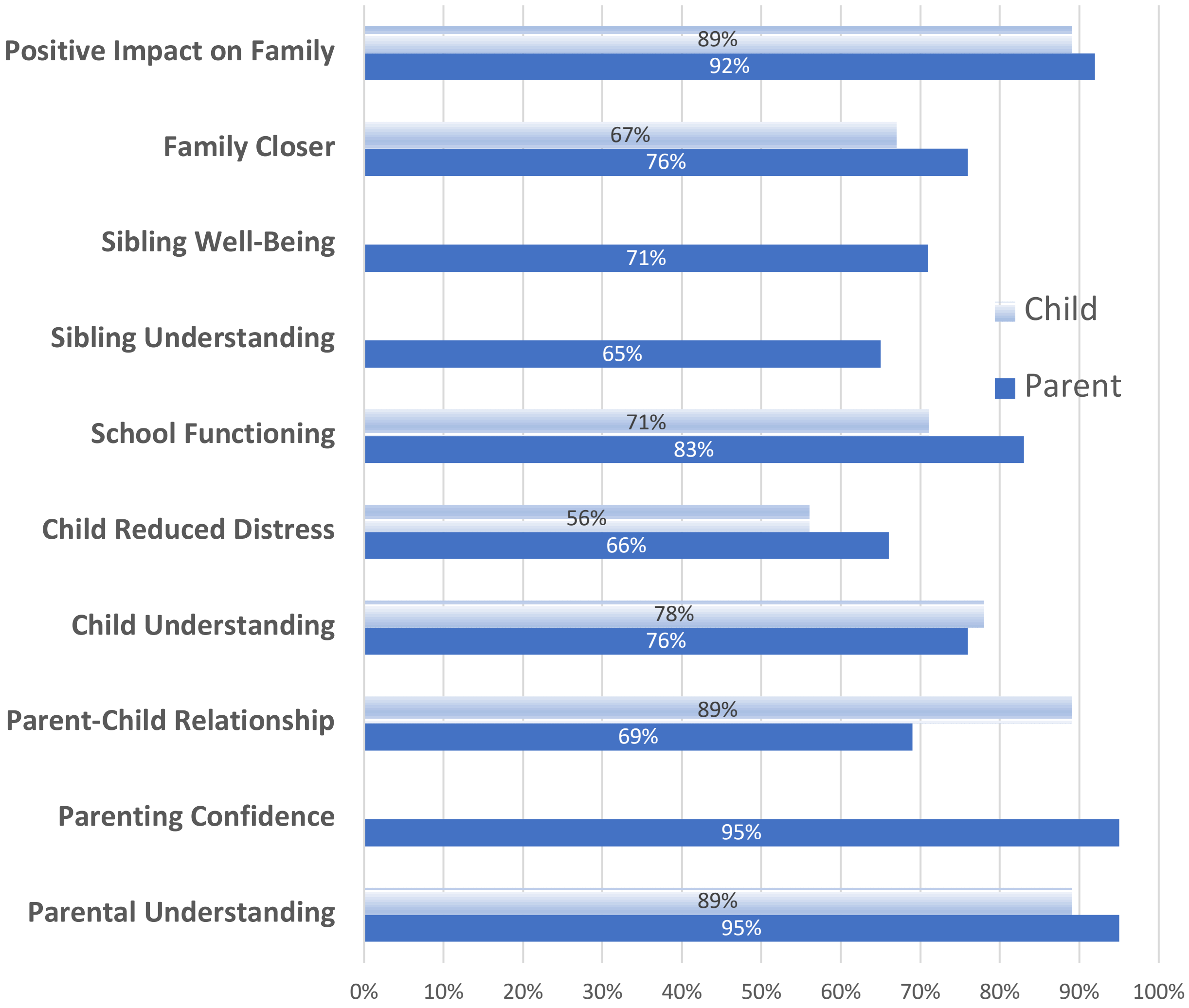
4.1. Family reported outcomes

Parents were asked to rate, on Likert scales in the PEC (see Appendix 1), the degree to which they agreed with various statements following their participation in the programme. These statements directly mapped onto project aims and objectives and related to:

- Improvements in their understanding of their child's brain injury and the understanding shown by the child themselves;
- Confidence in parenting skills;
- Improvements in their relationship with the child;
- Reductions in child distress and improvements in the child's capacity to manage school;
- Improvements in the emotional well-being of siblings;
- Improvements in family cohesion and overall positive impact on the family.

Parents could disagree with each statement or rate agreement as only "*a little*". Figure 2 below summarises the percentage of parents who endorsed each statement either "*somewhat*" or "*a great deal*". Data are reported at the end of project participation, or 6 months into participation, for n = 39 parents. In addition, a small number of children (n = 9) were able to complete a child-friendly version of the same exercise and the percentages who endorsed each comparable item are also summarised in Figure 2.

Figure 2: Percentage of Parents / Children Reporting Each Positive Outcome



This summary data are consistent with the thematic analysis noted above. As at the interim report stage, the greatest positive effects are seen by parents as relating to their understanding of their child’s condition, confidence in their own parenting and an overall positive impact on the family as a whole (92% - 95%). Approximately three-quarters of parents also noted positive outcomes in terms of the child’s understanding of ABI, sibling well-being, school functioning and the family generally becoming closer. Although the percentages endorsing other items were reduced

(65% - 69%), the majority were also noting improvements in child distress, sibling understanding and in the parent-child relationship. Overall, percentages reporting gains were a little higher than was evident in the interim report.

Similarly, although the smaller sample size makes their data less robust, it is encouraging to see that a majority of children (56% - 89%) also endorse positive outcomes on each item. The relative pattern of gains is comparable with the greatest numbers noting improved parental understanding and an overall positive impact on the family. Like the parent data, the fewest noted gains related to their own distress levels.

Siblings were also invited to report on their perceptions of their family's participation in *Family First*. Returns here were too small (n = 5) to present percentages. However, most of these sibling (3 – 5) endorsed comparable positive gains as noted above for the children with ABI.

For this final report, follow-up data from parents was requested in order to see whether the gains reported above were maintained across time. Thus, parents were asked to complete the same questionnaire 6 – 12 months later. Even amalgamating the 6 and 12 month data, returns here were very small (n = 10). However, for that sub-sample of parents who did make returns the majority continued to endorse the same positive outcomes as noted above, with percentages varying from 60% - 100%. Percentage of parents providing positive endorsements generally increased.

This may reflect gains becoming more apparent across time, but numbers were too small here for statistical analyses.

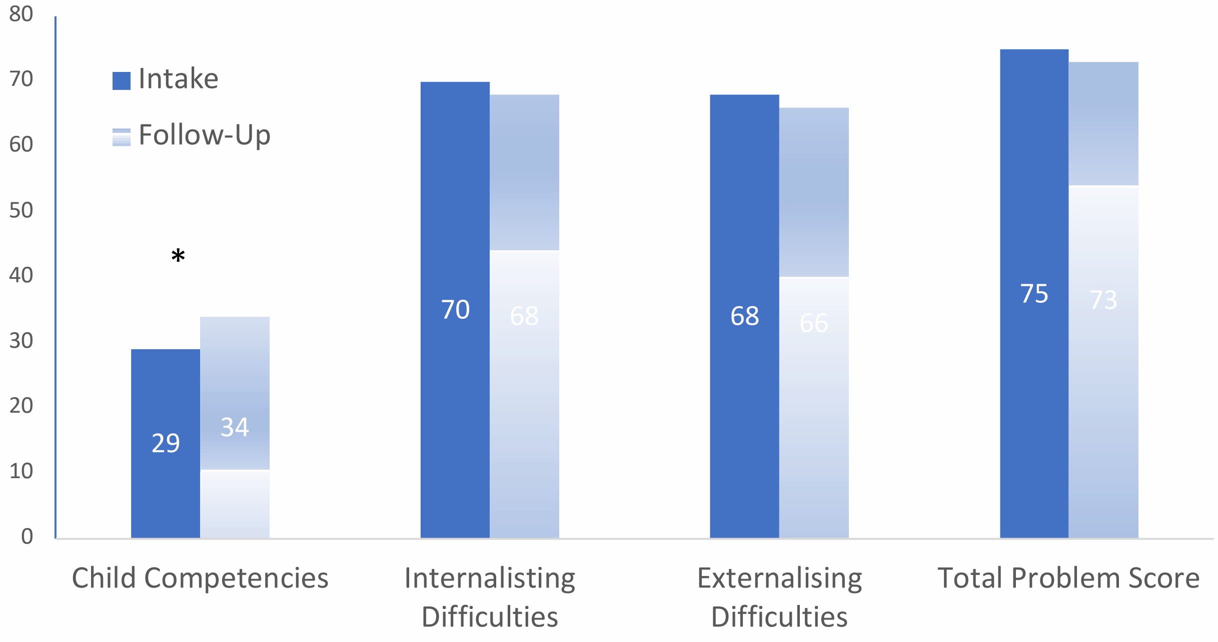
4.2. Outcomes on clinical scales

Whilst the parent and child reported outcomes – via the thematic analyses and the endorsement of gains measure – are important, the most scientifically robust outcome measures use standarised scales and these were built into this project evaluation (see Table 1). These compare features and levels of the child's behavior, competencies, social functioning, self-perception, quality of life etc. to peer referenced population norms and allow us to determine whether the child (and family's) functioning across these domains is in the "normal" or clinically significant range (i.e. at a level which may indicate clinical need). Importantly, they also allow us to monitor change across time. At the interim evaluation there had been poor completion of these scales and it was a recommendation to explore strategies to increase completion rates. This was generally achieved for the discharge / six month follow-up period with missing data in pre- and post-intervention data pairs being sufficiently small to allow replacement with the series mean. This meant there were sufficient numbers to complete statistical analyses. Across scales this approximated 20 – 40 pairs of data points, which was a significant improvement on the interim report data and allows greater confidence in the data.

4.2.1. Child Adjustment – Parental completed scales

Figure 3 below summarises intake assessment profiles on the *Child Behaviour Checklist*[10]. This provides measures of levels of behavior problems and there are standardized scores for *Internalising problems* (e.g. anxiety, depression and other mood disturbances), *Externalizing problems* (e.g. social functioning difficulties, behavioural disinhibition etc.) and a *Total problems* score (a summary of all problems). There is also a *Competencies* subscale which is essentially a measure of the child's academic and social competencies. This scale's standardised scores mean that 50 is the "average" and anything above 65 (on the problems scales) or below 35 (on the competence scales) is clinically significant. Changes in scores across time (generally after discharge or after 6 months) compared to baseline scores (at intake assessment) are noted.

Figure 3: Child behaviour problems and competencies before and after FF paritcipation



Findings suggest that these children are generally in the clinically significant range with respect to elevated behavioural difficulties and compromised social and academic competencies. However, findings also suggest a reduction in difficulties across time and an increase in child competencies with the latter reaching statistical significance.

4.2.2. Child Adjustment – Child completed scales

Figure 4 below summarises the data from the *Beck Youth Inventory*[11]. This scale is based on the reports of the child / young person themselves. It contains 5 subscales which reflect the young person's perception of their self-concept and features of anxiety, depression, anger and disruptive behavior. Again, 50 is the normal / average score with scores below 35 on self-concept and above 65 on the other scales indicative of clinically significant distress.

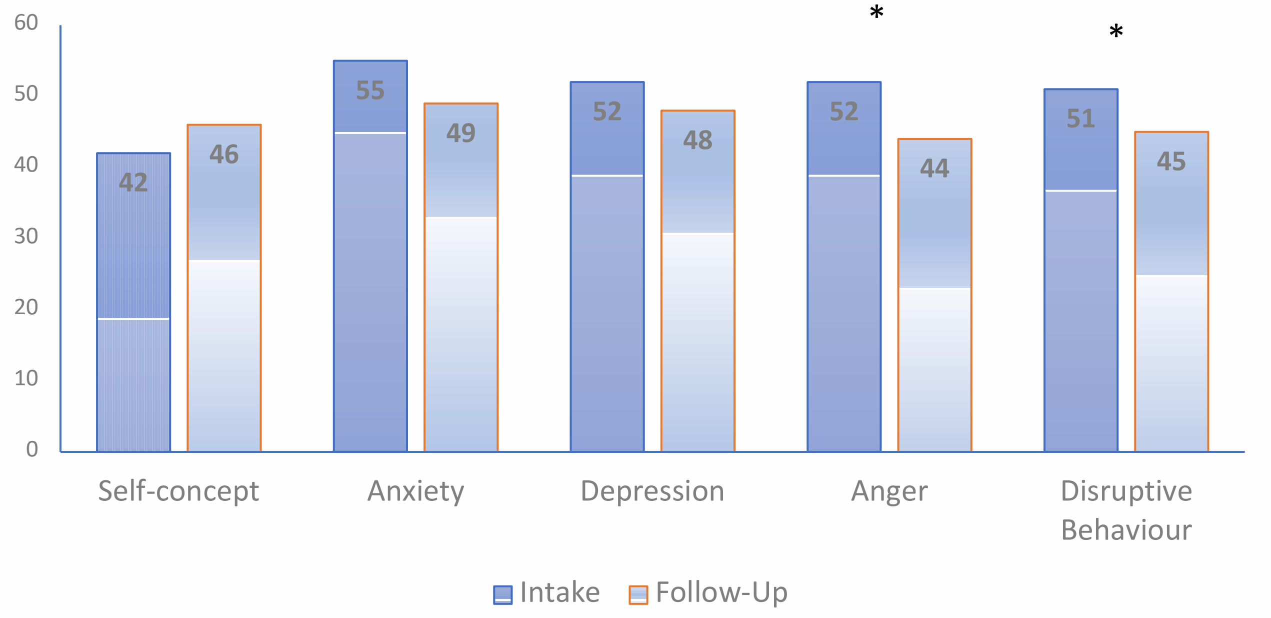


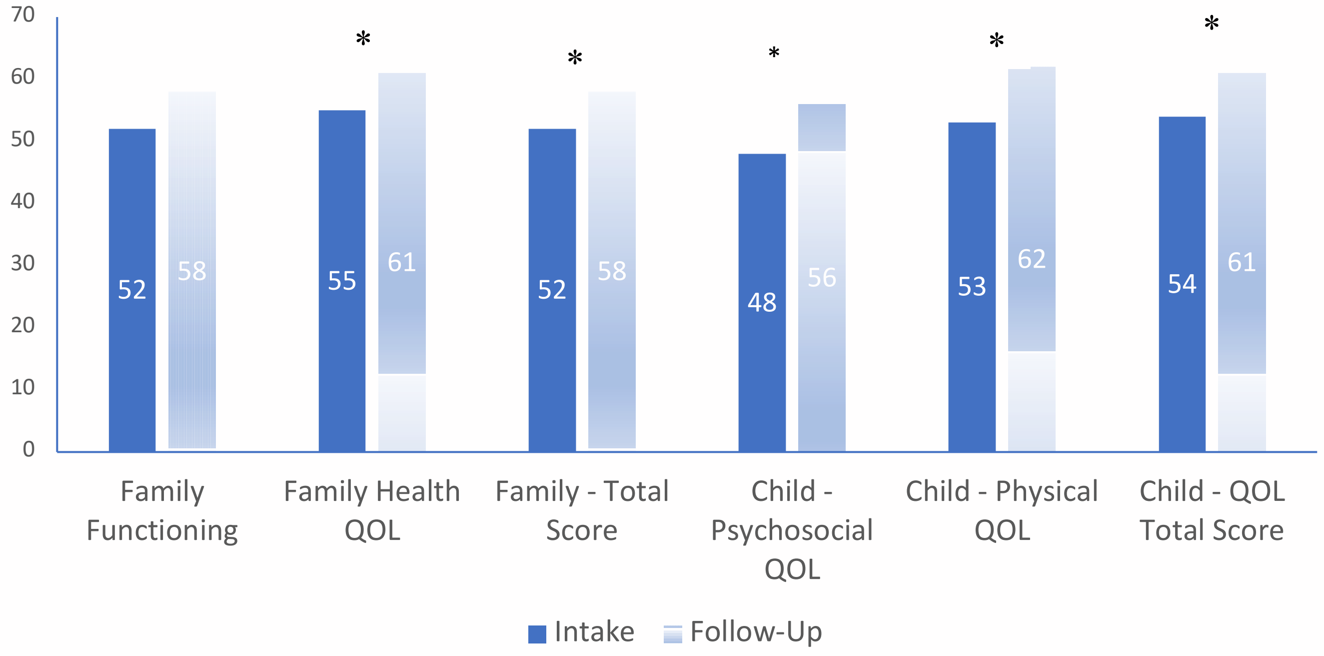
Figure 4: Changes in child self-reports of adjustemnt pre- and post-intervention

As in the interim report, it is of interest that these young people generally do not perceive themselves as having psychological difficulties. All scores were within the normal range at intake assessment, whereas parental perceptions, as noted above were distinctly different. This may be because parents are over-estimating their child's difficulties. However, research in this area would suggest that brain injury affects insight and this may mean that scores are unrealistically low here. In addition, children generally may be more reluctant to acknowledge their difficulties than their parents. Nevertheless, the change in scores from intake to follow-up are consistent with that seen on the parental reports. Self-concept scores increase and scores on the measures of psychological distress decrease. These decreases were statistically significant for anger and disruptive behaviour.

4.2.3. Quality of life

A standardized measure of child and family quality of life was utilised - *Pediatric Quality of Life inventory*[12]. This profiled quality of life (a) for the child – on *psychosocial* and *physical* domains plus a total score and (b) for the family – on *family functioning* and overall *health related quality of life* domains, plus a total score. These scales have not the same norms related to caseness or "abnormality" and so only the change scores are reported in Figure 5 below.

Figure 5: Changes in parental reported quality of life for child and family

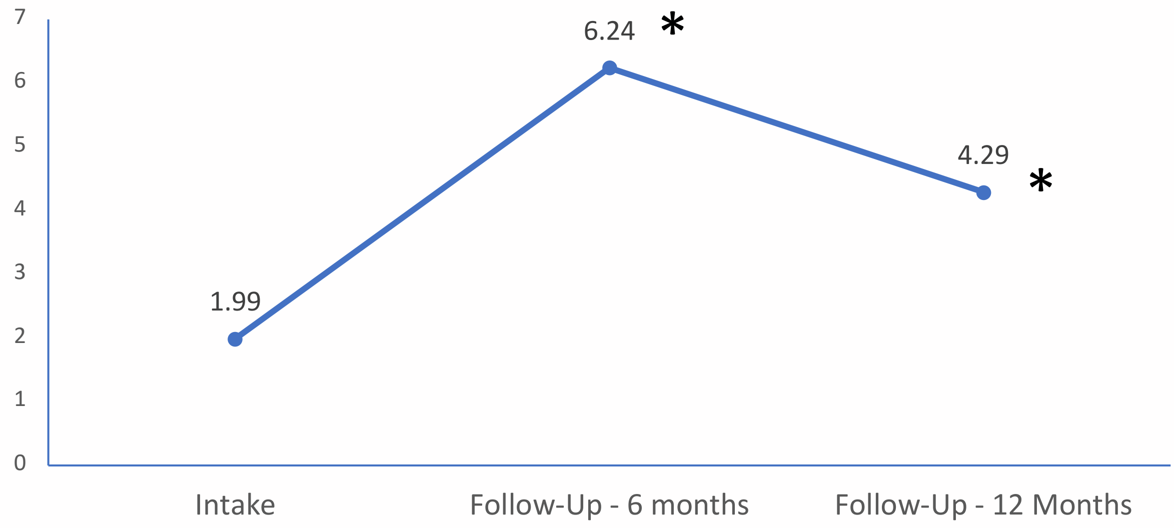


Findings suggest gains on all measures of quality of life for both the child and the family. In almost all cases these increases reached statistical significance.

4.3. Goal attainment

Finally, at intake assessment specific therapeutic goals were agreed with parents. These goals were aligned with the World Health Organisation's *International Classification of Functioning, Disability and Health* in that parents and project staff discussed current functioning across various domains and agreed which domains were the most pertinent to work on as "goals" through their participation in the *Family First* project. Across those families who engaged in extended therapeutic work with the service, 95 goals were formulated. These were too multiple to fully outline but generally related to psychosocial functioning, cognitive functioning, independence and communication. At intake assessment parents rated (on a 10 point scale) how close they felt their child was to attaining the specific goals formulated. They then rated goal attainment on the same scale at discharge, or at 6 months into project participation, with sufficient numbers returned to also examine 12 month follow-ups. Mean scores for all goals targeted are summarized in Figure 6.

Figure 6: Goal attainment ratings from intake to 6 and 12 month follow-up



Proximity to goal attainment shows a statistically significant increase across time. Although there are reductions from 6 – 12 month follow-up perceptions of increased goal attainment remain. It is also important to note that the 12 month data reflect new goals following satisfactory attainment of previous goals. It is gratifying to see that carry over benefits into such new goals are retained.

5. Staff feedback and responding to COVID-19

5.1. Staff feedback

Project staff are summarized in Appendix 2, together with their roles and contract hours. Supervision and continued professional development training undertaken is also outlined.

In January 2020 an online focus group was conducted with staff of the project. As the project's biggest resource, and given the insights they hold about what has been working, and what has been challenging in the project, this was an important aspect of the final evaluation. Discussion probes were exploratory in nature and simply asked them about their experience of working on the project and what they perceived as strengths and limitations. The focus group was transcribed and subjected to thematic analysis in the same way as occurred for parent, child and referrer feedback. Findings are summarised in Table 8 below.

Table 8: Family First Staff Experience – Thematic Analysis

Superordinate	Subordinate	Sample Quotations
Evolution	A progressive service	- *"I've seen the progression of the project, progression of staff skills and expertise… even in terms of the delivery of the project and how its changed over those last two years"* - *"Other thing in terms of engaging families from the last report we now have two families on the steering group"*
	Building capacity in others	- *"There's an indirect impact that we are having to some of the other professionals that we are involved with (educating through co-working)"* - *"We've noticed In the last year to year and a half that we've been more involved in schools and more involved with other professionals as well"* - *"I suppose more and more we've had parents ask us specifically if we could contact the school or if we could contact teachers"*
	Home visiting the most fruitful format	- *"I suppose the reality its home based work that seems to be the most fruitful"* - *"We tried a bit of variety on the workshops…one did work very well. We had sibling group, parent group and the child with the ABI"* - *"Whilst families are saying they want to get together and they would like to get together, when we try to make that available to them they don't actually take it up"*
Growing Complexity	Greater range of presentations and needs	- *"Such a variety now in the types of difficulties that families are telling us about but also in terms of the range of impacts"* - *"We were possibly getting more self-referrals earlier on where now I see more of an increase in referrals from professionals and I think with that comes more complexity"* - *"The number of ACES (Adverse childhood experiences) that are there in the background for these families"* - *"In one way the service has been a victim of its own success"*

	Beyond what was envisaged	• *“I think what the team is doing now is probably above and beyond what was ever envisaged”* • *“I think early on we were much more of a support service but I feel we’re much more of a therapeutic intervention service now”* • *“It’s definitely becoming more and more a part of our role (clinical formulation) and I suppose that’s debated; should it or should it not be”*
Minding the gaps	A therapy service?	• *“Partly reflective of lack of comparable services to do the same kind of thing outside of here”* • *“Some of the statutory agencies…are seeing family first as a clinical service. So for example, wanting clinical or therapeutic interventions that you might think are mainly best delivered by the qualified clinicians in the statutory services”*
	Joining up the dots	• *“Sometimes the team has to try to be a coordinator or a social worker or kind of I want to say a complex needs team for some of the families that are coming through”* • *“There’s an awful lot of time spent coordinating something that, to be fair, the team don’t feel it’s their job to coordinate”*
	Plugging an information vacuum	• *“In the absence of a contemporary assessment of what the child’s ability is, it’s very difficult for us to provide specific advice to that family except to say you need a cognitive assessment or a neuropsychological assessment”* • *“And equally, in terms of the crossover with school, sometimes that can be a little bit difficult too where you maybe have teachers saying there’s memory difficulties or concentration difficulties but there’s no actual clinical assessments to back that up”*
Quality Enhancement	Training and supervision	• *“Supervision and CPD are great”* • *“One of the biggest strengths as we’ve already identified is having those case consultation meetings and we are a very reflective service”* • *“I think what we’ve found is that the training that we’ve accessed so far hasn’t maybe met that complexity that we’re facing”*

An interdisciplinary team	• *“Coming from three different disciplines there’s a lot of variety in the staff team but we all work very well and complement each other very well”* • *“Like I said we are an interdisciplinary team and we use the skills of each member of the staff to face that complexity were dealing with”*
The importance of the statutory partnership and psychological expertise	• *“There is something important about having clinical staff who have come and who have experience and knowledge and a background in kind of the clinical management of children with an acquired brain injury, being able to contribute discussions on a day to day basis that are happening. Not because they have all the answers, but for a way of making meaning and sharing understanding”* • *“It’s the statutory framework that we don’t necessarily have up to date knowledge of and an understanding of who to contact and which other services would be involved and which assessments would be useful. So I think that’s where [Psychology staff member’s] support has been valuable”* • *“As part of the partnership there is education and training around that as well so to look at that in terms of what that will mean in terms of the trust”* • *“It’s going to be with children’s ABC’s which is separately funded if you like by the department”*

The themes which emerged from this focus group are interesting and important. The key conclusions are as follows:

- There is consistency with the narratives of families and referrers with respect to capacity building in other professionals and services, the centrality of the home visiting programme and that this programme has filled many gaps in other service provision.
- However, the "*Minding the Gaps*" theme highlights that in order to work effectively with families the team sometimes find themselves coordinating service collaborations for the family. This evolution in functioning would appear important to reflect upon.
- A recurrent theme in the focus group was the growing complexity of presentations and that the work of the team has evolved into therapeutic work beyond what was originally envisaged. Whilst skills and competencies within the project team, and the supervision arrangements for all that are in place, may support this (see "*Quality Enhancement*" theme and Appendix 2), this is again important to reflect upon in moving into a future iteration of this project.
- Finally, the partnership with Clinical Psychology statutory services, and access to other psychological supervision within the charity, emerged as highly important to quality and safe practice. This has perhaps been fundamental to the team having able to respond to more complex presentations and needs as outlined above.

5.2. Responding to COVID-19

Like other services the delivery of *Family First* interventions has been severely impacted by COVID-19. Recently attained information from the project suggests that the team have continued to provide support by telephone, online and through a recently reanimated *Family First Portal*.

The portal allows the team to share information and resources and organize virtual sessions using video conferencing. Families are also able to share their experiences with each other via the portal. Video uploads to demonstrate skills, strategies and activities that parents can employ with their children are being created.

Information suggests 27 families are registered on the portal with 18 more regular users. This forced new way of working has been very positively received by families based on recent feedback elicited by the service. It has led the service to consider moving towards “blended” contact in the future by weaving online interventions into the home visiting programme.

6. Conclusions and Recommendations

6.1. What has the project been about?

Family First has reached the end of its original 5 year project funding from the *National Lottery Community Fund*. It has delivered therapeutic interventions to the families of children with ABI to bolster resilience and coping, and thus indirectly also promote better outcomes for the children themselves (1.1; 1.2). Family focused interventions have included psychoeducation about how brain injury affects the child, narrative family therapy, parenting and problem-solving skills training, advocacy and collaboration with statutory health and education services (1.2; 1.3). Interventions have been delivered through a home visiting programme, through consultations with other service providers and through specific workshops for groups of children with ABI, their parents and siblings (1.3; 2.3). More recently, an on-line portal has been developed – initially to extend reach but more recently to adapt to the post-COVID landscape for service delivery.

6.2. Who has benefited?

A total of 80 families have accessed the project, from right across Northern Ireland; self-referred or increasingly referred by other statutory agencies (2.1). This exceeds the original target by 60%. Data suggest that families and children with the greatest physical and psychosocial needs (and often hard to access families) engaged with the project (2.2). Indeed findings from the staff focus group suggested that managing an increasing complexity of need has been a trend across the life of the project (5.1). Accessing these families is a strength of this project and data from both families and referrers would suggest that the home visiting outreach programme and the projects good engagement strategies have been instrumental here (3.1; 3.3).

A recurrent theme in the feedback of parents, children and referrers has been that the *Family First* project has filled a gap in the service landscape of Northern Ireland for children with ABI (3.1; 3.2; 3.3). No other such service exists and the gratitude of both families and statutory service providers was palpable in their feedback. That the length of time between the injury and referral to the service has reduced by a year from the interim evaluation report, suggests that the service has become better known as a service across the region. A feature of this current evaluation, which was not so evident at the interim evaluation, is that this gap has also been filled in terms of coordination of other services for these families (5.1). This, together with the increased complexity of need noted above, has resulted in the staff feeling that they have been working in a way that was perhaps not envisaged at the start of this project (5.1). This may, or may not, be a positive outcome, but it warrants reflection.

6.3. Did the project interventions make a difference to the lives of the families?

Evidence for the effectiveness of the interventions in promoting improvements in child and family functioning appears strong. On the standardised clinical scales we are seeing statistically significant improvements in child competencies (social functioning, activities and school functioning), reductions in mood and behavioural disturbance and improvements child and family quality of life (4.2). Those changes which were not statistically significant were, nevertheless, going in the right direction.

Without a control group, it is of course difficult to be certain that it was the *Family First* interventions which made this difference. However, the qualitative data analyses of family feedback would suggest that it was. Thematic analysis of both parent and child feedback suggests that knowledge and skills gained through the programme were empowering of positive change (3.1; 3.2). Importantly, both parents and children spoke about positive changes to family connectivity and cohesion (3.1; 3.2) – the very thing targeted by the programme as fundamental to achieving the outcomes to psychosocial adjustment and quality of life noted above.

In addition to the qualitative data, a significant majority of parents and children endorsed statements on the PEC which suggested increased knowledge and understanding, improvements in parenting skills, reductions in child distress and a generally positive impact on the family as a whole (4.1). Specific goals set by the family at intake assessment also showed statistically significant increases towards attainment (4.3).

These outcomes were recorded at project discharge or after 6 months of project participation (1.5). It is important to consider whether gains are maintained across time and the team started to request that discharged families re-complete the outcomes scales. There was generally too few data on most measures to do meaningful analyses. However, there was sufficient data in terms of goal attainment scores (4.3). Although there was a slight drop, goal attainment scores remained significantly elevated from baseline 12 months after project intake. Moreover, although numbers were much smaller at this extended follow-up (n = 10), the percentage of parents who endorsed the positive outcomes on the PEC noted above (4.1) actually increased across time.

6.4. What have been the evident strengths of this programme?

6.4.1. Perhaps the biggest strength has been the positive impact on the lives of children with ABI and their families as outlined above (3.1; 3.2; 3.3; 4.1; 4.2; 4.3; 6.3).

6.4.2. The reach of this programme has been significant, accessing children and families with significant need and risk, and filling a gap in service provision (2.1; 2.2; 2.4; 6.2).

6.4.3. The project team, governance and evolution of the service is commendable. Skills and expertise within the team, the partnership with *Royal Belfast Hospital for Sick Children*, supervision and training arrangements (5.1; Appendix 2) suggest a safe service which has been capable of responding to the increasing complexity of family presentations (5.1). There has been an evolution in staff skills and an evolution in service delivery methods (5.1), highlighted most recently by the move towards tele-therapy through the online portal in the wake of COVID-19 (5.2).

6.4.4. Although not envisaged at project inception, feedback from referrers (3.3) as well as the team themselves (5.1) suggest the project has not just delivered interventions, but been instrumental in capacity building in other health and educational services.

6.4.5. A final strength of this project has been its attention to outcomes monitoring. Increasing returns of outcome measure had been a recommendation at the interim evaluation and this has been achieved. There is a huge wealth of data, utilizing different methodologies, and involving multiple project stakeholders, which captures the impact of the project on children, families, referrers and the service landscape in Northern Ireland. This has not only been important for the team's own reflective practice, but provides practice based evidence for commissioners and users of the service.

6.5. Challenges and recommendations

6.5.1. The project team responded to the recommendations in the interim report with respect to increasing outcomes, securing parent representation on the steering committee, maintaining the partnership with child psychology services and securing funding to continue the project beyond the 5 year term.

6.5.2. Initial family workshops had received very good feedback at the interim evaluation, but uptake subsequently had been poor. The team described how they have explored various strategies to increase participation in these, but had limited success. Given the new portal has received positive feedback (5.2), and this has become an online medium for families to come together, it may be worth exploring if the content and family processes of the workshops can be adapted for an online experience.

6.5.3. The portal generally appears to have been an innovative and well-received new development (5.2). The team plan to further develop this and are collaborating with a web technology service to develop this further and enhance its user friendliness. This is a welcome development. In addition to be explored as a medium for family workshops, it may open up blended interventions in the longer-term – thus reducing time devoted to travel across Northern Ireland to access families and allowing more time for family contacts. This may also address some of the accessibility challenges raised by the families (3.1).

6.5.4. There have been recent staff changes with the very experienced child Clinical Psychologist leaving his post and role in the project. However, it is gratifying to hear that *Family First* have secured new clinical consultation through the

Children's Acquired Brain Injury Service (CABC's) of the health Trust. It will be important to operationalize plans here to maintain the quality assurance and enhancement that this partnership has offered the project to date.

6.5.5. Following project successes as outlined in the interim report, the project has recently attained a further 2 years of funding from the *National Lottery Community Fund* to continue and develop the project. This is a positive development. Nevertheless, given the impact of this project on the statutory service landscape, through increasing referrals, capacity building and service liaison (2.1; 2.2; 3.3; 6.2; 6.4.4) exploring mainstreaming the service through statutory commissioning should be a priority for the longer term.

6.5.6. Dominant themes in the staff focus group related to an increased complexity of presentations, and filling of "gaps" beyond what was originally envisaged at project inception (5.1; 6.2). This certainly has led to benefits related to capacity building in statutory services and advocacy for families. However, the team and stakeholders may wish to reflect upon whether this is positive and if anything further is needed to support these developments safely, or whether ways of containing these developments should be explored.

6.5.7. Finally, the project team have presented and disseminated experiences and findings from this innovative service as recommended in the interim report. This should be continued – especially now that a greater data set of analyses is available.

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Appendix 1 – Patient Experience of Care Tool
Your Experience of The Family First Project

ACCEPTABILITY

	YES	NO	N/A
1. Were you comfortable with family first staff attending your home?	☐	☐	☐
2. Were you treated with courtesy, respect and care by staff?	☐	☐	☐
3. Was your agreement sought before any intervention proceeded?	☐	☐	☐
4. Were sessions arranged at times that were suitable for you?	☐	☐	☐

5. Workshop Did you attend?

If yes what was useful/helpful……………………

Can you offer any suggestions for improvements………………………..

6. What was you experience of the support from the service?

What was useful/helpful?......................

Can you offer any suggestions for improvements?.........................

7. How likely is it that you would recommend this service to a **friend or family member** who had similar difficulties?

NO	**Don't Know**	**Likely**	**Extremely likely**

OUTCOMES

You may respond to the following statements with respect to yourself and / or your child and family.

Please circle the response which best fits your view.

8. I have a better understanding of my child’s condition

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

9. I feel more able and confident in my parenting skills

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

10. I feel that the level of tension between me and my child has reduced

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

11. My child now understands more about their brain injury and how its affects their life

N/A	**NOT AT ALL**	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

12. My child is showing less signs of distress

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

13. My child’s ability to deal with school has improved

N/A	**NOT AT ALL**	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

14. Overall the other children in our family have more understanding about their brother/sister condition

N/A	**NOT AT ALL**	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

15. Overall the emotional wellbeing of the other children in our family has improved

N/A	**NOT AT ALL**	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

16. Engaging with Family First has brought our family closer together and reduced tensions

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

17. Engagement in Family First has had a positive impact on our family

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

IMPACT

18. Did involvement with Family First help you and your family **understand** the problem(s) better?

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

19. Did overall involvement in Family First help you and your family **cope** with the problems better?

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

20. Did involvement in attending Family First **help improve the situation?**

NOT AT ALL	**A LITTLE**	**SOMEWHAT**	**A GREAT DEAL**

Appendix 2: Project Team and Steering Committee

Ms Bridget Smyth Head of Children and Youth Service – Brian Injury Matters
Ms Catherine Quinn Associate Psychologist – Family First
Ms Meg Irwin Family First Practitioner
Mr Joe McVey CEO Brain Injury Matters
Dr Marie Goss Consultant Clinical Psychologist – Brain Injury Matters
Dr Eunan McCrudden Consultant Clinical Psychologist – BHSCT
Mrs Mari McDonnell, Parent Representative
Mrs Elizabeth Downey, Parent Representative

Previous
Ms Fiona McCabe Past CEO Brain Injury Matters
Ms Katy Pedlow Past project lead Family First
Ms Lisa Burke Associate Psychologist
Ms Megan Douglas Associate Psychologist
Ms Keelin White Family First practitioner
Representation Meningitis Now
Representation Educational Psychology
Dr Sarah Meekin Psychology Services Manager - BHSCT

Supervision/ Support Structure

Type of supervision/support	Persons present	Frequency
Clinical supervision	Family First Team/ Head of Children and Youth Service /Dr McCrudden Consultant clinical psychologist BHSCT	Fortnightly
Clinical Supervision	Dr Marie Goss & Catherine Quinn	Fortnightly
Organisational / clinical supervision	Individual team member/ Head of Children and Youth Service	6 weekly
Co working/ case consultation	Team members/ Head of Children and Youth Service	As and when required
Operations meetings re Family First	Team members/ Head of Children and Youth Service	Monthly
Steering group meetings	Team members/ Head of Children and Youth Service /CEO BIM/Dr McCrudden BHSCT/Parents/Dr Marie Goss consultant Neuropsychologist	Quarterly

Examples Training Undertaken

Date of Training	Name of Training / Internal or External / Facilitator	No.days/hours
2018	International Paediatric Acquired Brain Injury Conference	2 days
	Safeguarding children and young people conference	1 day
	Secondary and Vicarious Trauma Training	1 day
	Children with ABI CABC’s Training	2 days
	Introduction to Solihull Approach	3hrs
	LBGT Training	2 Days
	Mental Health First Aid	2 Days
	Accredited Sensory Integration Training – Sensory Integration Education	1 Day

	Young Hearts & Minds Conference	2 Days
	Attachment & Mental Health Training	4hrs
2019	What works, Early Years summit, Stranmillis University	1 day
	Creative counsellors	3hrs
	SHR Counselling – Attachment disorder	3.5hrs
	SHR Counselling – Munchausen Syndrome: A Factitious Disorder imposed on self	3.5hrs
	Incredible Years parent group leaders trainers' programne 3 days	3 days
	Therapeutic Crisis Intervention	3 days
	Creative counsellors	3hrs
	Creative counsellors	3hrs
	Sensory Strategies to Build Resilience in Early Years	3hrs
2019	ASIST Training	2 Days
	Working with the Body – Northern Ireland Counselling Forum	3hrs
	Think Family Training CiNI	1 day
	Managing Challenging Behaviour CiNI	1 day
	CES Masterclass Self-Care	1 day
	Reaching Out, Recharging and Refuelling CES Conference	1 day
	Record Keeping Training CiNI	1 day
	ACE's and Trauma Informed Training	2 hours
	CES Conference	1 day
	Introduction to Solution Focused therapy NICF	3 hours