



*Family Focus*  
*Interim Evaluation*  
**2018**



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# EXECUTIVE SUMMARY

## Family Focus

Family Focus is a new partnership-based initiative developed to offer intensive and tailored support and activities to increase children's development, encourage strong family bonds, reduce isolation and help children reach their full potential.

The five-year programme supported by Big Lottery NI does so through the provision of play-based habilitation, specialist mobility and independent living skills training and therapies for children with a visual impairment.

Delivered by three leading visual impairment charities and support providers (Guide Dogs NI, as project lead, in association with Angel Eyes NI and Sense NI) Family Focus also provides parental and family support through peer sharing, signposting and targeted Time to Play and Coffee & Chat family events across NI.

## Big Lottery support

The rationale for the programme is based in a strongly evidenced research base, that had never been done before and is aligned closely to the funding aims of the Big Lottery NI **Supporting Families Programme** - to help families in Northern Ireland to improve their children's lives.

## Outcomes

In the first two years of the programme Family Focus has achieved many notable successes, summarised below.

- 47 children and families have accessed support
  - Significantly more have benefited from attendance at the programme launch and family fun days
  - The programme team initially set a target that, in retrospect and with the experience of delivering this new and innovative programme, was impractical and has been amended with the agreement of Big Lottery
- Baseline and follow-up assessments have been completed with 26 children (12 via Guide Dogs and 14 with complex/additional needs via Sense NI) demonstrating positive progression in developmental milestones utilising the proven Developmental Journal for Babies and Children with Visual Impairment (DVJI) and a bespoke tool for Complex Needs Developmental Goals
- There are high levels of resilience among participating families
- Parents surveyed overwhelmingly agreed or strongly agreed that there were improvements in the four key outcomes of;

- Confidence, in supporting my child to develop and achieve
- Siblings and other family members are more included and involved
- Levels of happiness relating to feelings of stress and anxiety
- Awareness of other services available.
- Feedback from parents suggests that the logistics of the Time to Play and Coffee & Chat sessions are well suited.

## Looking Ahead

Having completed two years delivery of an impactful family support programme that has improved the lives of children and families, based on the evidence gathered from parental and stakeholder engagement, the project is now looking ahead with a series of conclusions and recommendations identified to develop the service in the final years.

These are summarised below based on the two areas of **programme activities** relating to operational delivery and **programme monitoring** pertaining to reporting and evidence.

Activities	Operations & Monitoring
<ul style="list-style-type: none"> <li>▪ Increased attendance from wider family circle achieved</li> <li>▪ Programme has been flexible responding to family needs</li> <li>▪ Wide geographical coverage, attracting families from across NI</li> <li>▪ Outreach and follow up assessments required with wider pool of parents</li> <li>▪ Powerful peer support levered. Parents should be empowered to develop local family groups</li> </ul>	<ul style="list-style-type: none"> <li>▪ Flexibility in developing an appropriate resilience measurement tool.</li> <li>▪ More centralised reporting of assessments and progressions could benefit the programme. With an agreed process and support for all habilitation staff to ensure the consistent use of assessments.</li> <li>▪ Ongoing engagement with parents and families required such as an electronic survey.</li> <li>▪ Engagement with a large group of families has gone unreported. As such, a new 'contact form' and 'exit form' is proposed to record contact with families only engaged for a short period, specific purpose or one-off event.</li> </ul>

Table 1: Summary of Learning

***"I was extremely impressed at how welcome we felt and how much more positive I feel about Daisy's vision"***

Mum, Year 1

# 1. FAMILY FOCUS

Family Focus is a new initiative developed to offer intensive and tailored support and activities to increase children's development, encourage strong family bonds, reduce isolation and help children reach their full potential. It proposed to do so through the provision of play-based habilitation, specialist mobility and independent living skills training and therapies for children with a visual impairment and parent to parent peer support.



Figure 1: Fiona Brown (Guide Dogs NI) outlines the programme

## 1.1 Programme Delivery

The Family Focus programme of play and family support is being delivered by a group of partner organisations with complementary strengths, experience and family contacts.

Programme delivery arrangements are explained and illustrated below.

On referral or contact by the project team parents complete a starter form

**Habilitation** involves one-to-one play and movement based activities for children and young people with vision impairment. Starting from their existing skills, it aims to develop their personal mobility, navigation and independent living skills. At whatever age the training is started, the overriding goal is to maximise the child or young person's independence.

and a baseline assessment (utilising the Developmental Journal for Babies and Children with Visual Impairment or bespoke tool for Sense NI activities for children with complex needs) is completed to assess readiness for participation.

This included a period of outreach and promotion to engage with parents less likely to access support.

The programme activities are outlined below:



Figure 2: Family Focus Programme

Parents are then invited to attend family support sessions termed 'Time to Play' in locations across the province.

Time to Play sessions provide play-based Habilitation, arts & crafts, movement, independent living skills, parent information and opportunities for peer network and support. Other activities include:

- Coffee & Chat
- Peer support groups of which there are three
- In-home parent support
- 1-1 support (via telephone)
- Family fun days
- Inclusion of siblings

Services have been delivered in partnership with specialist providers including; Mini Explorers, Shine Baby Yoga, Sensory Kids and Music Therapy.

The programme team also sought to influence by engaging with professionals to raise awareness and identify future opportunities to develop the Family Focus programme.

### 1.1.1 Locations

Time to Play sessions take place throughout NI:

- Ballynafeigh (Belfast)
- Ballynahinch
- Banbridge
- Broughshane
- Dungannon
- L'Derry (services have been delivered in Waterside & Eglinton but are no longer active)
  - These sessions will begin again in September on the completion of a current 6-week Music Therapy programme
- Jordanstown

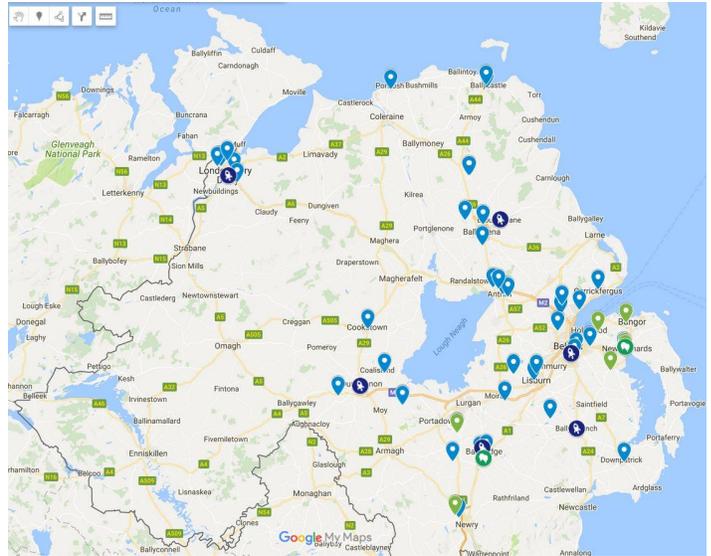


Figure 3: Time to Play group locations

The map opposite indicates the Time to Play locations (blue rocket icon), Coffee & Chat locations (green event icon) and the locations of Time to Play and Coffee & Chat participants.

The significant contribution of facilities from RNIB, Homestart Ballynahinch, the Jordanstown School and Sensory Kids NI has been critical in allowing the services access to quality premises in locations accessible for families.

## 1.2 Promotion & Outreach

In order to engage with the target group of families the programme team undertook an extensive range of outreach and promotional activities.

This allowed for a number of points of referral to be identified that have been effective in encouraging families to take part. Referral sources include:

- Voluntary & Community Sector
  - E.g. RNIB
- Eye Health (ophthalmology)
  - Eye clinic at Altnagelvin
  - Royal Victoria Hospital

- Health & Social Care
  - Sensory teams
  - Children's Disability Team
  - SureStart centres
  - Medical Health centres
- Education
  - Schools
  - Visiting Teacher Scheme

In addition to the Time to Play groups and one-to-one support Angel Eyes NI play a key role in engaging new families with the project. Sense NI has also been engaged with families whose children have additional/complex needs and home visits form an integral part of the family support given.

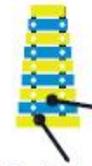


#### Do You Have a Child aged 0-4 years with Sight Loss? Family Focus is here for you.

Family Focus is a lottery funded project led by Guide Dogs' Children and Young People's Services in partnership with Angel Eyes NI and Sense NI.

The project supports:

- Monthly 'Time to Play' groups across NI
- Habilitation assessment by specialists
- Family Support
- A chance to meet other families



The project also aims to increase the understanding of the experience of parenting a child with sight loss. Information from families will help inform future services for children with sight loss.

Figure 4: Family Focus promotion material

The launch of the programme, in August 2017, was a positive event that engaged, not only families that can benefit from the service, but attracted myriad statutory providers and key influencers to provide them with a new understanding about habilitation and the gaps that exist in provision for younger children affected by sight loss.

The engagement and outreach with the extensive networks of the project partners has been critical in raising awareness of the project with service providers. The team engaged with family support hubs and eye health professionals, for example, to inform early diagnosis families of the Family Focus programme.

The Operations Manager produced a communications plan which was signed off by partners and which will help communicate to various audiences what the project is about through social and mainstream media. The Family Fun day was covered by the Belfast Telegraph and UTV, making the 6 o'clock news in August 2017. The video link is provided below (click or scan to view).

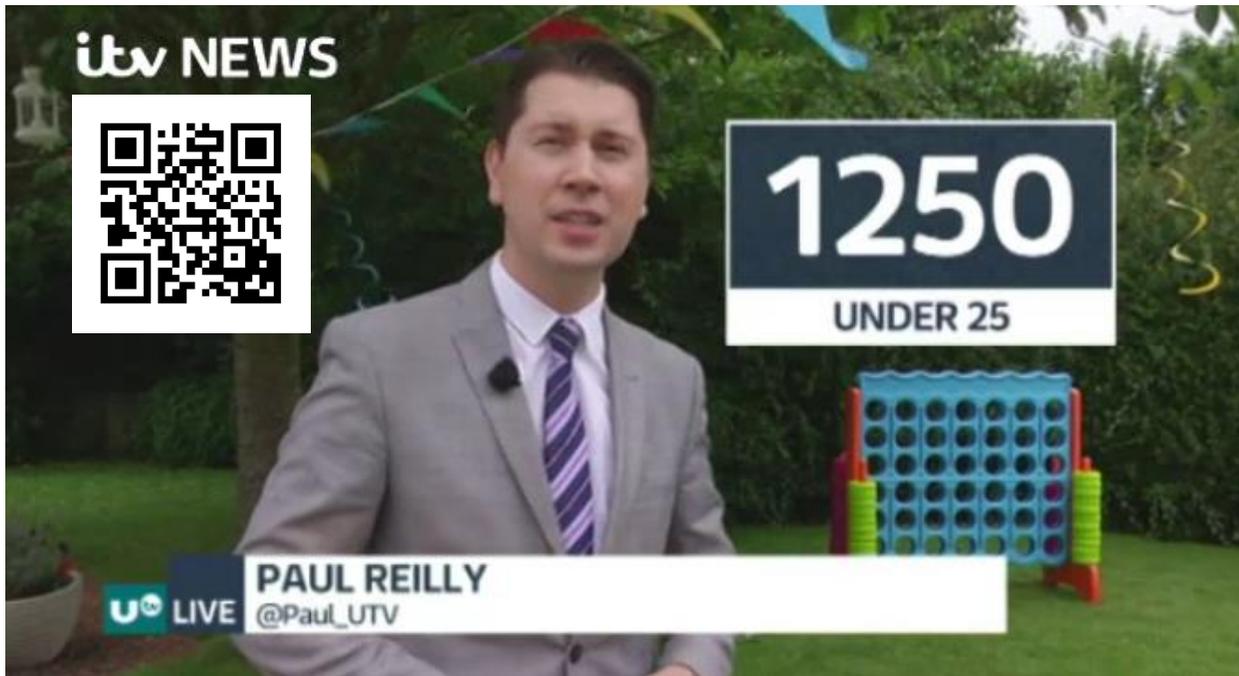


Figure 5: UTV News coverage of Family Focus launch

Marketing activities included:

- Family Focus leaflet
- Online presence through partner's websites and other digital media, primarily Facebook
- Events such as the Family Fun day and resulting PR
- Networking such as Community Evaluation NI's (CENI) 'Meet the MLA' session and the Children and Young People's Strategic Partnership (CYPSP) Southern Area Outcomes Group. Moreover, the relationship with the Centre for Effective Services (CES) proved valuable as they hosted an open day for projects including Family Focus to meet and engage with key influencers.

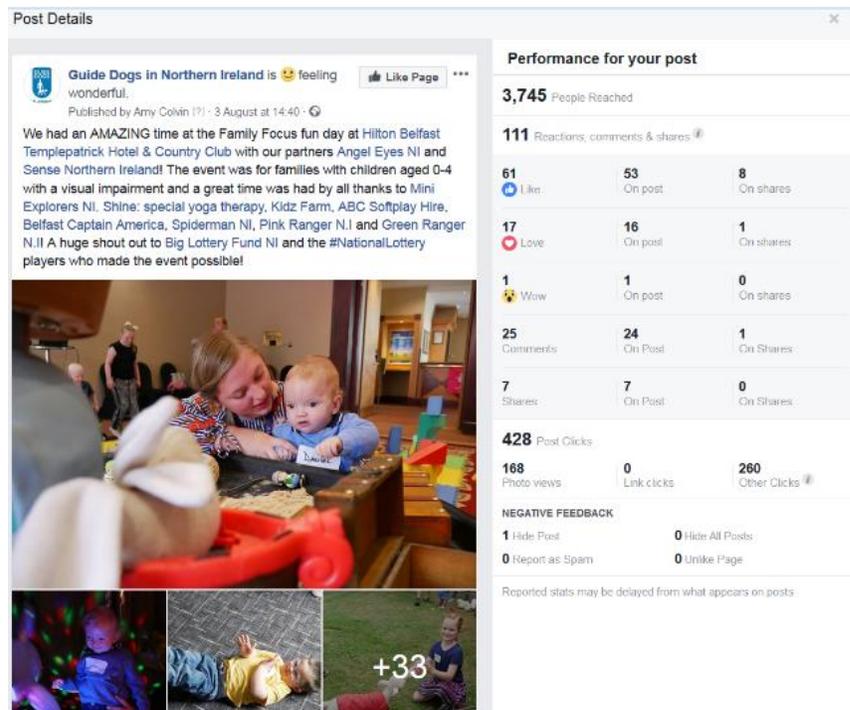


Figure 6: Facebook analytics for Family Fun Day

### 1.3 Operations

The Family Focus programme is led by a Steering Group inclusive of the three partner organisation's senior leadership whilst an Operations Group is made up of the delivery team and led by the Programme Coordinator.

The project team completed a review at the end of year one and identified a series of activities and themes that they were 'proud of' and a number of issues that could be improved upon. A summary is provided below with the full review of the year included in Appendix Three.

What the team was 'proud of'	Areas for improvement
<ul style="list-style-type: none"> <li>▪ Collaboration: the level of collaboration and communication between and with the three partner organisations that allowed for practical solutions to problems, utilising the resources within the partner teams</li> <li>▪ Success: in getting the 'playgroups' started, attracting families and seeing positive changes in the children. This also included the development of an assessment that saves times</li> <li>▪ Inclusion: engaging groups of parents that have developed bonds and seeing siblings and other family members involved</li> </ul>	<ul style="list-style-type: none"> <li>▪ Assessments: could be completed earlier and more effectively</li> <li>▪ Increased attendance: recognising the difficulty in maintaining consistent attendance and being more active in promoting the service</li> <li>▪ Time: how to ensure that parents aren't burdened by paperwork and that they understanding reason behind activities and to set up earlier so more time to develop and reach individual child goals</li> </ul>

Table 2: Year One Review

### 1.4 Innovative Model

The model of delivery developed by the project team represents an innovative partnership approach and one that is based on a new research base that has been developing in the last five years. Detailed in section 4, the improving research base includes a 2014 paper from The University of Liverpool<sup>1</sup> and a scoping study from Guide Dogs NI (formerly Blind Children UK) "Raising a child with sight loss: A scoping study of parent experience in Northern Ireland (2015)<sup>2</sup>"

<sup>1</sup> <http://clock.uclan.ac.uk/15875/>

<sup>2</sup> <https://www.belfasttelegraph.co.uk/news/health/parents-of-visuallyimpaired-children-speak-out-over-lack-of-specialist-care-31296263.html>

## Developmental needs of participating children

The Family Focus team identified from the outset that the habilitation services provided would require a detailed evidence base to demonstrate the impact of the programme whilst also providing the team, and indeed parents and families, with a clear pathway of development for participating children.

To that end the project has implemented a tailored assessment tool developed by and for Guide Dogs NI from the Developmental Journal for Babies and Children with Visual Impairment. This was completed pre-programme by Guide Dogs NI with a dedicated researcher to develop the scaling methodology for each stage of the Journal.

The Developmental Journal (DJVI) is a systematic framework tracking developmental and vision related progress from birth to three years of age (or equivalent developmental age). It aims to:

- help parents and practitioners track and understand the child's achievements, progress and development;
- support goal setting and guidance to promote vision and general development;
- support interdisciplinary and interagency working;
- support information sharing between parents and the practitioners they meet;
- identify areas of difficulty early where more help would be useful.

Offering a six-stage evaluation process the Journal assesses a baby or child's development against a series of themes at different stages of their development. Whilst the assessment themes vary, as the child ages from 1a to stage 5, they can be broadly summarised as follows:

<b>Body Awareness</b>	<ul style="list-style-type: none"> <li>• Being comfortable in different positions</li> <li>□ Position in space-enjoying motion</li> <li>□ Exploring their environment</li> <li>□ Feeling floor surfaces</li> <li>□ Discovering hands</li> </ul>
<b>Sensory Skills</b>	<ul style="list-style-type: none"> <li>□ Learning about touch: Responding to different sensations or textures</li> <li>□ Listening and attending: e.g. parents voice &amp; familiar sounds</li> <li>□ Learning about sound: beginning to learn where sound comes from</li> </ul>
<b>Fine/Gross Motor</b>	<ul style="list-style-type: none"> <li>□ Movement and coordination: head and trunk control</li> <li>Co-ordinating hands and fingers and grasping finger</li> </ul>
<b>Concept Development</b>	<ul style="list-style-type: none"> <li>• Learning about sound: directional hearing.</li> <li>□ Understanding objects presence.</li> <li>□ Understanding actions on objects.</li> </ul>
<b>• Social &amp; Self Help Skills</b>	<ul style="list-style-type: none"> <li>□ Joining in social interactions: enjoying cuddles from parents e.g. snuggling, moving arms and legs when played with.</li> </ul>
<b>• Environmental Awareness</b>	<ul style="list-style-type: none"> <li>□ Recognising features in different rooms e.g. sound of washing machine, smell of toiletries in bathroom, feel of carpet in living room.</li> <li>□ Actively exploring their environment</li> </ul>

Figure 7: DJVI Summary

### Complex Needs Assessment

Due to the complex needs of children supported by Sense NI, the Developmental Journal for Children and Young People with Multiple Needs was the starting point for staff to assess alongside parents' achievable goals for their child based on an initial baseline assessment and noting progress over time. This is individual to each child achieving milestones at their own pace. Observations were recorded both at the monthly Time to Play sessions and on home visits based on the four developmental goals of;

- Personal, Social and Emotional,
- Communication,
- Physical, and
- Thinking

Over time the family support worker in partnership with the parent record the goals under three categories, recording if the goal was Emerging, Developing or Achieved.

Key developmental Goals	Examples <sup>3</sup>
Personal, Social and Emotional	Responds to Touch
Communication	Expresses enjoyment, hunger, tiredness, pain
Physical	Responds when hands are touched
Thinking	Reacts to sounds

Table 3: Sense NI Complex Needs Developmental Goals

This conscious focus of observing activity over a period of time to ensure that milestones are consistent over time is critical. As is the need for fluidity and reliance on the staff member, engaging with parents, to firstly agree then assess a set of developmental milestones.

The flexibility ensures that changes in circumstance, be that a child's condition and diagnosis as well as environmental issues are reflected in the assessments with the validation from parents also ensuring their involvement in recognizing achievements.

Such early intervention and time to make assessments is rarely afforded through a single visit from a health or education professional.

## 1.5 Partnership

The innovative model sought to maximise the range of skills, experience and family engagement from a core team of project partners.



Figure 8: Project Partners

Partner	Role
<b>Guide Dogs NI</b> seeks to change the way that sight loss affects people's lives. Helping everyone with sight loss – and their families – through life-changing services to adults, children and young people with sight loss throughout NI.	<ul style="list-style-type: none"> <li>Lead Partner</li> <li>Provision of habilitation services &amp; programme coordination</li> </ul>
<b>Angel Eyes NI</b> was set up by parents of blind and partially sighted children to provide emotional and practical support for parents in the same position. As a charity they set up to help parents with all the new challenges they will face and hopefully make the future seem a little brighter.	Parent to parent networks and support

<sup>3</sup> Taken from the Developmental Journal for Children and Young People with Multiple Needs

<p><b>Sense NI</b> is a national disability charity that supports people with complex communication needs to be understood, connected and valued. The organisation began, and continues, to support people who are deafblind. Today, they also support a wide range of people with complex communication needs.</p>	<p>Support families with complex and additional needs, advice and support</p>
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Table 4: Partner details

## Partnership Assessment

As an interim report assessing the work of the programme in its first two years it was essential to review the effectiveness of the partnership model that sets Family Focus apart. As such, a measure of partnership effectiveness was identified in this interim report to identify areas of strength and areas for improvement. This was completed utilising the Partnership Effectiveness Continuum (PEC<sup>4</sup>) - a tool designed to help programme providers develop a clearer understanding of the indicators of effective partnerships.

Project partners were interviewed and completed the PEC tool survey to assess:

- Vision
- Institutional Leadership
- Communication & Collaboration
- Joint Ownership & Accountability
- System Alignment, Integration & Sustainability
- Response to Local Context

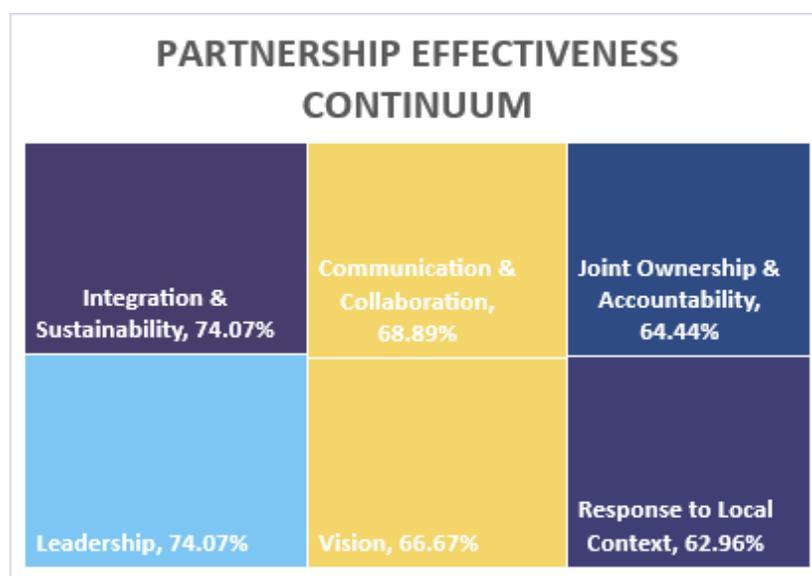


Figure 9: Partnership Effectiveness measures

The results identified a high level of satisfaction with the partnership as a whole with particular strength in 'Leadership' and 'Integration & Stability'. This demonstrates that the values and aims of the project are shared, that there is a good level of advocacy on behalf of the partnership and that resources are committed effectively with clear roles and responsibilities aligned across the partners.

<sup>4</sup> <http://www.wallacefoundation.org/knowledge-center/Documents/Quality-Measures-Partnership-Effectiveness-Continuum.pdf>

The level and quality of interworking between the three organisations has been a success of the programme owing much to the communication channels developed but also of the organisational maturity of the partners.

Whilst all areas were scored highly, those with room for development relate to 'Response to local context' and 'Joint Ownership & Accountability'. This suggests that the programme and the partnership can do more to explore new opportunities to expand the partnership and its role in influencing policy. Moreover, the partnership can improve its use of data, see recommendations in section 5.2.

The steering group met three times per year and in addition held a whole project compliance awareness and review day, with the whole operational and management teams, to ensure the programme was GDPR (General Data Protection Regulations 2018) ready. This created a compliance review list to assist partners to maintain checks on data security and usage which is significant in the context of new GDPR regulations.

## 2. BENEFICIARIES

### 2.1 Stakeholder Analysis

The key beneficiary groups for the Family Focus programme are clearly identified within the proposal and subsequent letter of offer from the Big Lottery Fund, illustrated below.



#### Children, Parents and Families

As the core beneficiaries of the Family Focus programme parents were engaged through 1:1 interviews (\* 8) across three Time to Play sessions, parental surveys (16 completed) and a telephone interview with a Sense NI parent.

In addition, data from 12 children's assessments and 14 from those children with complex/additional needs, using the Developmental Journal, were reviewed with additional data provided by Guide Dogs as the Lead partner and Sense NI.

#### Project Partners

All three project partners were engaged through 1:1 interview and a completed Partnership Effectiveness Continuum survey. Moreover, the evaluator attended a Steering Group and an Operations Group meeting to gather an understanding of the nature of the programme. In addition, an interview was held with Miriam, the Children's Habilitation Specialist, to discuss the role of habilitation.

#### Key Influencers

RNIB NI (Royal National Institute of Blind People) and delivery organisations' of services at Time to Play, Mini-Explorers and Shine Yoga, were interviewed to gather insights into the proposed effects of services and to assess the effectiveness of engagement with the programme.

The delivery organisations interviewed expressed the benefits that they had witnessed for participating children and families as a result of the activities. They include the success of parents seeing their child in a different 'state' or setting,

engaged, active and participating with others. They also recognised the importance of the frequent engagement and opportunity to work with small groups or even working with individual children as larger group activities such as yoga can be less effective.

Moreover, the confidence that the children have developed in their ability to do new things and their body confidence was noted.

The extent to which these identified stakeholders were and are affected by the Family Focus programme is outlined in a detailed Theory of Change developed by the programme team in collaboration with the Centre for Effective Services (CES), outlined below.

## 2.2 Theory of Change

The theory of Change developed with the Centre for Effective Services, illustrated below, has been tested within this interim evaluation with suggestions for data collection and analysis to demonstrate the impact of the programme.

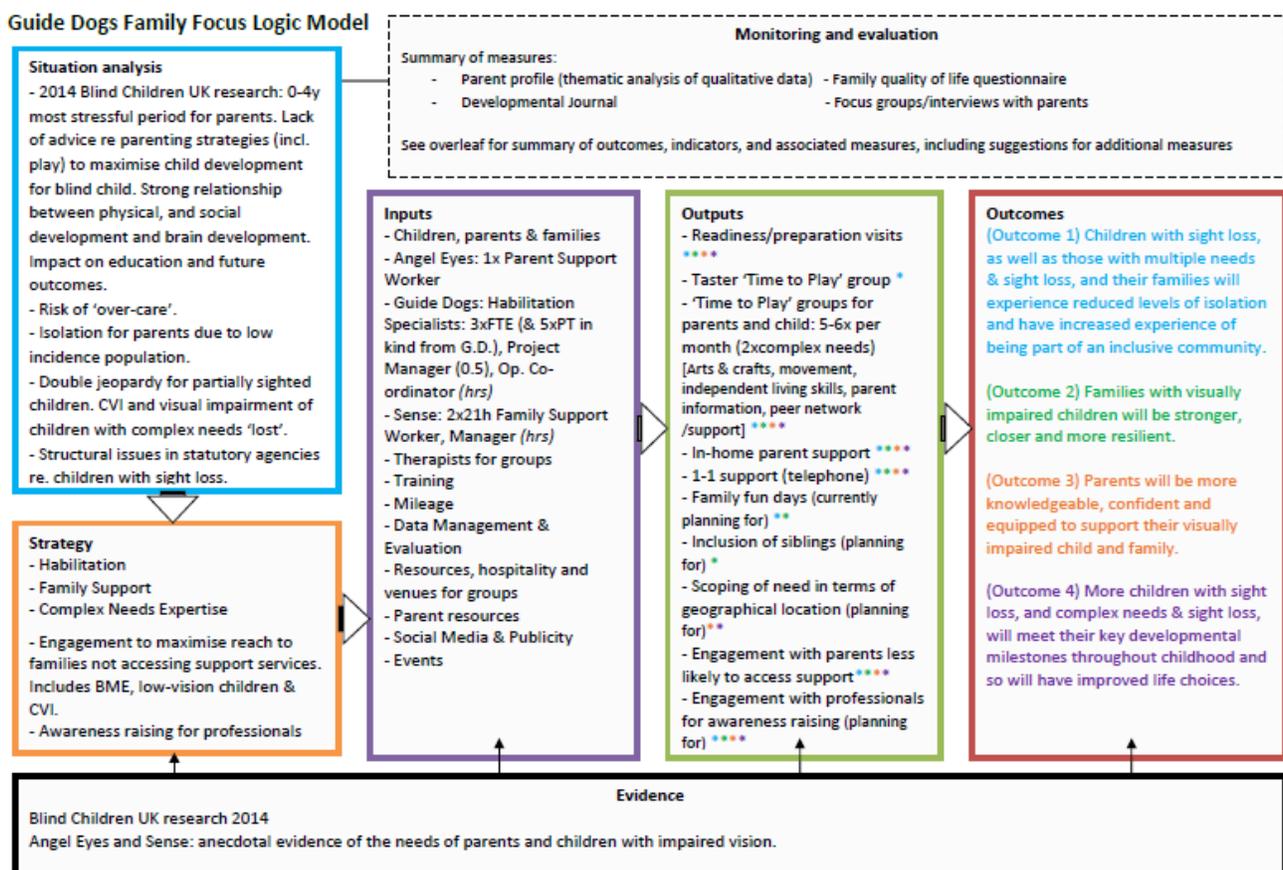


Figure 10: Theory of Change

### 3. ACHIEVEMENTS AND OUTCOMES

At the end of the second year of the programme (March 2018) the following change indicators can be reported<sup>5</sup>:

<i>Outcome</i>				
More children with sight loss and complex needs and sight loss will meet their key development milestones throughout childhood and so will have improved life chances				
<i>Indicators</i>	<i>Target</i>	<i>Year 1</i>	<i>Year 2</i>	<i>Details</i>
Children with VI have access to habilitation-based opportunities	45 children achieved milestones in year 1 increasing by 10 each year	18 children and families accessed	29 children and families accessed through 114 interventions	Data provided from children's assessments identifies that 66% (8/12) have progressed along the developmental milestones including 4 that have moved on to school). The remaining 4 remain active and accessing support
Children have improved social relationships with people around them with no increased no of positive social behaviours				
All children achieve agreed development milestones relative to their disability	85 Children	Baseline assessments completed for 17 with 12 follow up assessments 14 follow up assessments of children with complex needs completed		Almost 95% of children with complex and additional needs have progressed along the developmental milestones (at the Developing or Achieved stages)

<sup>5</sup> As of June 2018, the partnership has reviewed the targets and agreed with the Big Lottery Fund a focus on the percentage of families and children engaged rather than a fixed number of participants and engagements that more adequately reflects the nature of the programme.

<i>Outcome</i>		Parents will be more knowledgeable, confident and equipped to support their VI child and family			
<i>Indicators</i>	<i>Target</i>	<i>Year 1</i>	<i>Year 2</i>	<i>Details</i>	
Parents have increased understanding of and confidence levels associated with their child's milestones.	Minimum of 80% of parents express increase	18 families engaged	29 families engaged	94% of parents agree or strongly agree that they are more confident in supporting their child to develop & achieve (increased family resilience), including using tools at home with other children	
Parents have increased sense of coping.					
Parents have increased skills to support their child's development.	85% parents using habilitation-based skills	94% parents are more confident in supporting their child's development			
<i>Outcome</i>		Families with VI children will be stronger, closer and more resilient			
<i>Indicators</i>	<i>Target</i>	<i>Year 1</i>	<i>Year 2</i>	<i>Details</i>	
Families are confident and able to support their child to develop and achieve increased family resilience.	80% of families	18	High level of satisfaction & confidence, in supporting child to develop and achieve and in how siblings and other family members being more involved	76% agree or strongly agree that siblings are more included.  76% agree or strongly agree that they are happier (feel less stressed or anxious about things and the future.)	
Siblings are more included in family life.	40% of siblings	9 siblings engaged			
Families have increased levels of happiness.	80% of families				

<i>Outcome</i>		Children with sight loss as well as those with multiple needs and sight loss and their families will experience reduced levels of isolation and have increased experience of being part of an inclusive community.			
<i>Indicators</i>	<i>Target</i>	<i>Year 1</i>	<i>Year 2</i>	<i>Details</i>	
Increased numbers of families are aware of and know how to use other services.	Minimum of 80% of families	18 families engaged with the project. No change data processed in year 1.	82% agree or strongly agree that they are more aware of other services available to them and their family	High level of satisfaction of awareness of other services and events available.	
Increased number of families can access events and opportunities outside the project.	60% of families				
Parents are more confident to deal with outside agencies.	80% of families are using other services				

Table 5: Summary of outcomes

There has been a significant level of engagement with families that has been unreported or under reported. Whilst not actively engaged in the programme these families have benefited through attendance at one or a few sessions, large event or 1:1 meeting with project staff that can lead to improved awareness of services and support through signposting and referral and peace of mind (having sought a simple piece of information, reassurance or guidance that could be provided immediately).

### 3.1 Milestones

Of the 12 follow up assessments completed for participating children, without complex needs:

- 1 child had a severe sight impairment
- 1 child had a cerebral visual impairment
- 2 children had additional needs

The assessments illustrate that five children had shown a progression on their developmental milestones whilst three had left for school or nursery. The remaining four remain active, accessing services to support their individual needs.

To date 16 children who attended Sense NI Time to Play groups have completed baseline assessment:

- 7 attended Broughshane Time to Play
- 7 attended Dungannon Time to Play
  - 2 have since joined the Banbridge Time to Play group
- 2 attended former L'derry/Eglinton Time to Play

Of this group, 14 follow up assessments have been completed. On average 69% are at the 'Developing' stage of the four goals, having progressed from the initial 'Emerging' stage, and 25% has 'Achieved' the goals set.

From the completed assessments, six children and families are no longer active with the programme, via Sense NI for a range of reasons including difficulty accessing the services or utilising an alternative service which, due to the complex nature of their conditions is to be somewhat expected. Of this group, one has progressed to full time education and the support that parents receive leading to increasing levels of confidence and understanding of their child's needs that aids the transition and engaging with special needs teams in the education sector.

A key strength of the programme has been the responsiveness of the delivery team to the needs of participants that has led to new developments since its inception such as additional services and flexibility in time and venue arrangements.

Additional services that have been introduced for families include Children's Yoga, Mini-Explorers and Sensory Kids. These providers enriched the range of activities for participating children and particularly those with siblings and with disabilities. Parents also had the chance to take part in Children's Yoga which proved effective in creating a good buzz between families but also in providing parents with exercises to use at home. The provider of yoga, Shine Special Yoga, developed a set of cards that allowed parents to continue exercises at home with their children.



Figure 11: Yoga Prompt Cards developed for Time to Play

### Parental engagement

Through the evaluation process the team developed a simple and consistent parental survey superseding two different versions of feedback forms used in year one. The new survey incorporated outcomes focused evaluative questions that are important in identifying the extent to which Family Focus was delivering upon the identified objectives.

Key to this new survey was the inclusion of an assessment of parental resilience. A proposed 50 question resilience survey proved to be an impediment to completion for parents. As a result, the Brief Resilience Scale<sup>6</sup> was incorporated into the survey. A summary of the results from 16 surveys completed is outlined below:

- High levels of resilience in families
  - Average resilience rating of 3.40 which is on the low end of 'normal' (3.00-4.30 rating is normal)<sup>7</sup>
- High level of satisfaction in the additional questions asked linked to the programme outcomes of:
  - Confidence, in supporting my child to develop and achieve
  - Siblings and other family members are more included and involved
  - Levels of happiness relating to feelings of stress and anxiety
  - Awareness of other services available.

<sup>6</sup> Smith, B.W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P. and Bernard, J. (2008). The Brief Resilience Scale: Assessing the Ability to Bounce Back. *International Journal of Behavioral Medicine*, 15, 194-200

<sup>7</sup> <https://www.psychtoolkit.org/survey-library/resilience-brs.html>

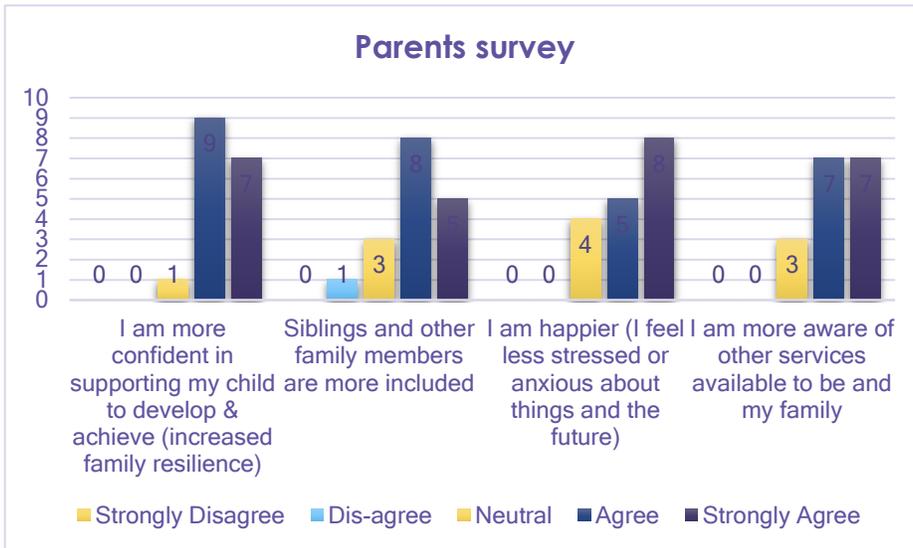


Figure 12: Parental survey - individual questions

Parents surveyed overwhelmingly agreed or strongly agreed that there were improvements in the four key outcomes listed, as illustrated in the tree map chart below:

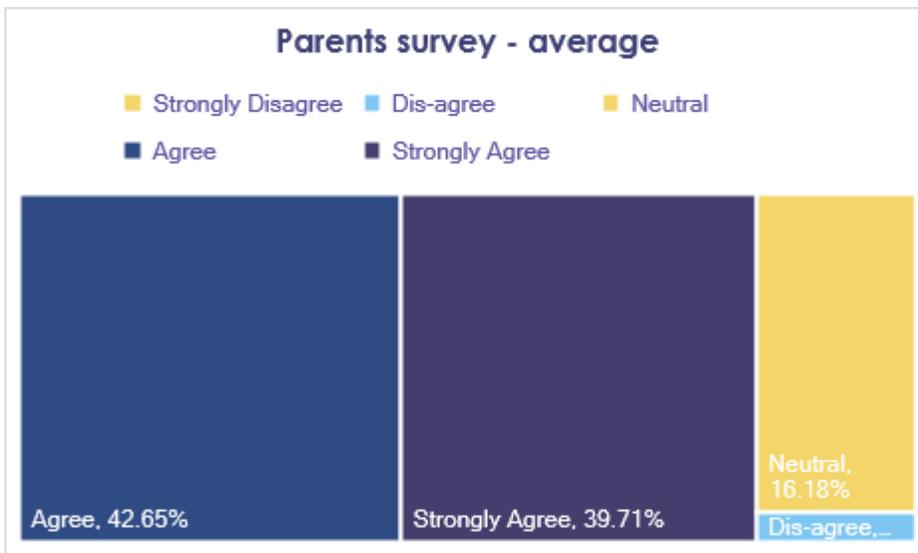


Figure 13: Parental survey - grouped responses

Feedback from parents suggests that the logistics of the Time to Play and Coffee & Chat sessions are suited. Where the day of the week or time did not suit it was attributed to clashed activities such as work or college whilst others suggested that due to school pickups that the time was unsuitable.

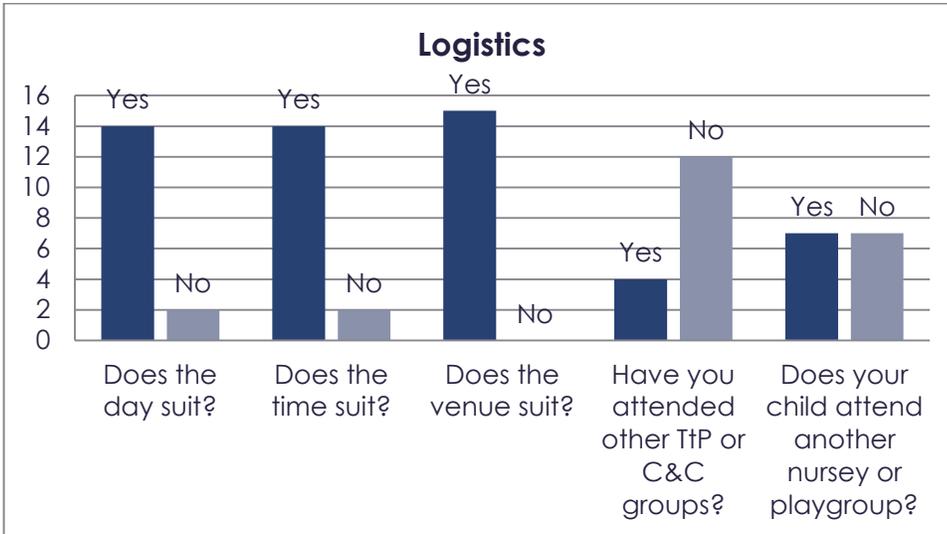


Figure 14: Survey Responses – Logistics

The challenge of multiple hospital and medical appointments and parental responsibilities, of work, education and caring for other siblings, was a significant factor in not attending more sessions for families.

In addition, the diverse range of activities on offer was greatly valued with the most popular activities including sensory play, music and singing and 'messy play' as illustrated below:

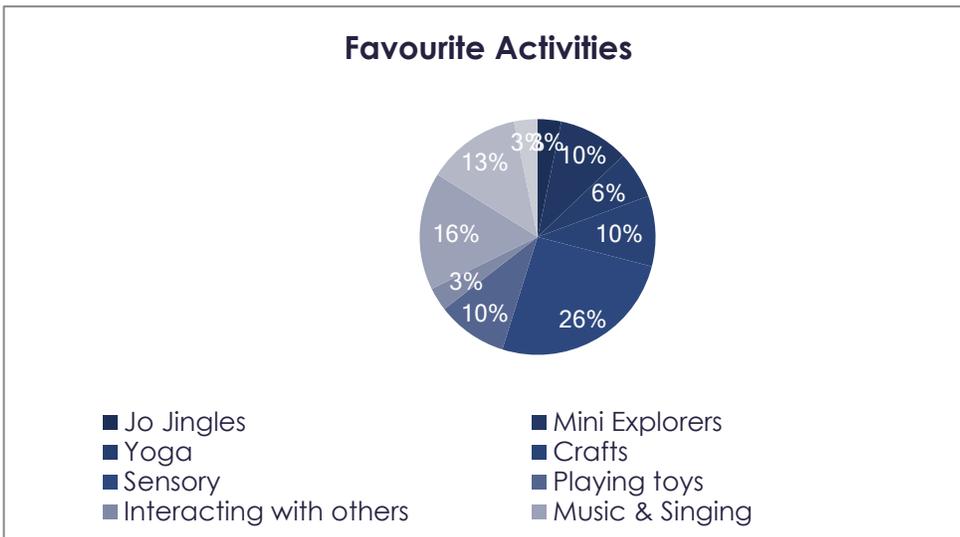


Figure 15: Time to Play activities

The project team seeks to engage as many families as possible within the programme and understanding that not everyone can attend the Time to Play or Coffee & Chat groups have established a virtual forum with Angel Eyes NI facilitating a private Facebook group for parents. The page was established and is maintained by Angel Eyes NI and is not a direct facet of the Family Focus project.

Welcoming 24 families as members (22 mums and 2 dads), the group offers a space for families to share and engage with each other where they can benefit, to some extent, from the peer support and guidance experienced in the offline groups. This is evident from the themes of discussion within the group:

- Time to Play and Coffee & Chat dates
- Events from RNIB
- Accessible toys and equipment
- Parental training programmes from other organisations
- Events and photographs shared by parents

### Case Stories

The evidence from parental surveys and interviews through 1:1 interviews and focus groups are supported by the individual stories of participating families. Two video interviews have been recorded that can be viewed by scanning the QR code in the image or by clicking the image directly.

Caroline and her daughter Aibhilin, have been benefiting from support from the Family Focus project.



Figure 16: Parental interview – Caroline & Aibhilin

“Great for other child to be included. She sometimes feels left out because Micah has different groups / opportunities due to his visual impairment. As a parent it is brilliant that you welcome siblings during the school holidays, otherwise it would be a barrier to us attending.”

**Time to Play Parent**

“Victoria's sister was able to join in with the sensory play & engage with her sister through play.”

**Time to Play Parent**

Sinead, who attends the specialist Time to Play group in Dungannon with her son Shane.

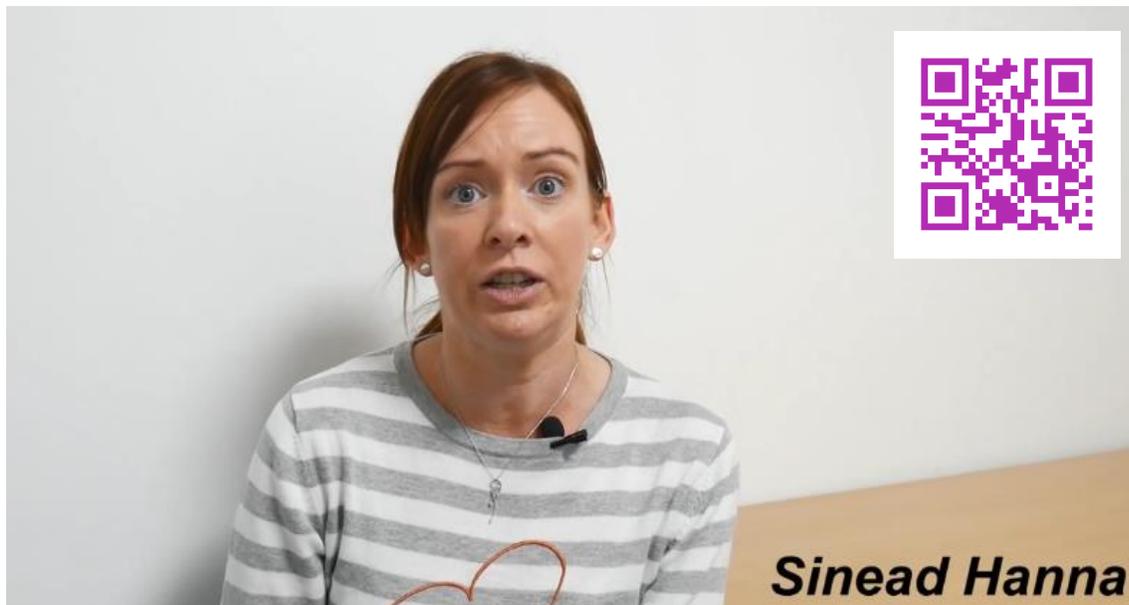


Figure 17: Parental interview – Sinead & Shane

## 4. STRATEGIC CONTEXT

Family Focus has been developed on the basis of a strong evidence base regarding the needs of children, parents and families experiencing sight loss. This section provides an overview of both the research base and the strategic context for the work of the programme.

### 4.1 Research

There is strong evidence of effective Habilitation services on the outcomes of children and young people. A review of the 2014 paper from '**Habilitation services for children and young people with visual impairment in the UK: an exploratory study**'<sup>8</sup> from the University of Liverpool identifies that:

- 0.2% of children and young people affected by vision impairment (Cumberland et al, 2010).
- Estimates for NI are 125 in the 0-4 age range with visual impairment, 75 with complex needs and visual impairment and 50 with additional needs and visual impairment (250 in total for 2016) with approximately 1,200 in total. (Lonergan, Thetford and Robinson, 2014).

Habilitation as a service and concept is a relatively new concept and service offer in UK. As a result, impact research is in the early stages. However, findings from Thetford, Wheeler and Robinson on 16 case studies demonstrated that Habilitation of a qualified and collaborative model as described in the Quality Standards (Millar, 2011) positively affected everything from children with additional needs to parental attitudes and support. These were found to be really important for early years and early intervention in order for children to grow to be confident, happy, included in and achieving in school, achieving academically.

Summary findings from this paper map age/stage against outcomes. These include:

- Increased self-management and care skills for 3 years including dressing, undressing, changing own nappy, self-feeding, using a cup, getting from table to toilet alone and brushing teeth.
- For 5-16-year olds it includes changes such as social skills and confidence, travel and mobility e.g. to school, to shops, social events. Food preparation

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<sup>8</sup> Thetford, C., Wheeler, S., & Robinson, J. <http://clock.uclan.ac.uk/15875/>

(chopping) and using knives and forks as well as making lunch. The outcome of such changes includes benefits for parents and siblings but these are less clear in the research. Psycho-social changes are also highlighted including emotional and social development as a result of being able to move around, travel and eat using a knife and fork, make own lunch, dress self.

While findings evidence some aspects of Habilitation across the 3-16 age range it omits the imperative of habilitation to support parents and children manage and cope with key transitions. These include getting into nursery, pre-school, primary school, year changes and moving into secondary and post-secondary.

The paper identified that, in some cases, young people were reluctant to take Habilitation services because they were sensitive to being different. This wasn't the case in younger children, demonstrating the opportunity and the need for early intervention and starting both children and parents as early as possible.

A scoping study from Guide Dogs NI (formerly Blind Children UK) **“Raising a child with sight loss: A scoping study of parent experience in Northern Ireland (2015)”** sought to bridge the research gap in data and understanding about the parental experience of raising a child with sight loss in NI. The study identified some key findings:

Table 6: Scoping study findings

0-4 Specific Findings	Responses
<ul style="list-style-type: none"> <li>▪ Of all age brackets, the bracket most alert to stress was 0-4.</li> <li>▪ 57% of parents found 0-4 most challenging (n=42)</li> <li>▪ 33% of parents found 5-11 most challenging (n=42)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Age 0-4 as the most stressful stage for parents (57% of n=42)</li> <li>▪ In age 0-4 parenting, 54% did not receive help with habilitation needs such as advice on helping to develop their child's coordination.</li> <li>▪ In age 0-4 parenting, 46% did not get advice and support on ideas for developing interaction with their child.</li> <li>▪ In age 5-11 parenting, 56% did not receive help to develop movement and independence skills.</li> <li>▪ In age 5-11 parenting, 46% worried about their child being able to get out and about safely.</li> </ul>

Within the report habilitation needs linked to future outcomes were recognised as areas of high concern, with parents identifying issues about 'getting out and about'

and 'social opportunities beyond school'. However, it was also clear that the language of habilitation is relatively new and unfamiliar to many parents at all stages.

The recommendations from the research formed the foundation for the new Family Focus programme:

- Adopt the Habilitation Quality Standards as a matter of urgency, incorporating its principles and guidelines into priority for future service planning, provision of assessment, codes of practice and inspection. This includes:
  - Providing parents with clear information regarding their rights to specialist support and relevant pathways through health and education
  - Ensuring that each child receives an assessment, as early as possible, by appropriately qualified Habilitation Specialist
  - They form part of the codes of practice, assessment and inspection within education and health
  - Parents can expect their child's habilitation needs to be included in Statements, Education plans and care plans
  
- Incorporate Habilitation assessment and training into any Early Years (age 0 - 4) strategies and frameworks, recognising this as a critical phase of habilitation provision. This should also address complex needs as a priority area for habilitation and further research.

Such research offers a useful stepping-off point for service development and a clear potential for fuller research about habilitation, parents' needs and resilience. Importantly it points to evidence that parents have an intuitive understanding of the habilitation needs of their own children and how this understanding can be connected to their current and future development and aspirational needs.

## 4.2 Strategic Context

Family Focus has been supported by investment in the innovative model by the Big Lottery Fund's Supporting Families programme and fits strategically with a number of key local policy objectives.

### Big Lottery NI

Family Focus has been supported by the **Supporting Families Programme** from Big Lottery, a £25 million investment in projects lasting five years to help families in Northern Ireland to improve their children's lives.

The aim of this programme is to support families in Northern Ireland to improve their children's lives by building strong and nurturing relationships with specifically targeted outcomes of:

- more families will have greater skills, knowledge and understanding to overcome adversity
- more children and their families will come together and learn
- more children and their families will be part of the community that they live in.

Other key strategies that the Family Focus programme complements and supports are detailed below.

### Programme for Government

The Programme for Government (PfG) is the highest level strategic document of the Executive – setting out the priorities that it will pursue in the current Assembly mandate, and the most significant actions it will take to address them.

Within the context of the Family Focus programme there are a number of outcomes that reflect the draft PfG, none more so than Outcome 12 – ‘We give our children and young people the best start in life.’ Aligned to this are a series of indicators and measures that the programme can be said to be affecting:

Indicator	Measure
Improve child development	% of children who are at the appropriate stage of development in their immediate pre-school year
Increase quality of life for people with disabilities	Average life satisfaction score of people with disabilities
Improve mental health	% of population with GHQ12 scores $\geq 4$ [signifying possible mental health problem]

Table 7: Relevant PfG Indicators

### Children & Young People’s Strategy

The Programme for Government (PfG) identifies that a key desired outcome is “giving our children and young people the best start in life” - this Strategy is a key component to achieve this.

The proposed outcomes of the Family Focus programme can be mapped to those of the Strategy directly contributing to how:

- Children and young people are physically and mentally healthy
- Children and young people enjoy play and leisure
- Children and young people learn and achieve

Working in partnership with other agencies and through the work of a newly developed Advisory Group, the programme is also a key driver for the remaining outcomes of the Strategy.

## **Children's Bill NI - Children's Services Co-operation Act (Northern Ireland) 2015**

The Act was introduced to improve co-operation amongst Departments and a wide range of statutory bodies.

For this purpose the "well-being" of children and young people includes:

- a) physical and mental health;
- b) enjoyment of play and leisure;
- c) learning and achievement
- d) living in safety and with stability;
- e) economic and environmental well-being;
- f) making a positive contribution to society;
- g) respect of rights;
- h) promotion of good relations.

### **Children and Young People's Strategy - Play Matters**

Developed within the Children's Services Co-operation Act, the strategy and Play Matters has a clear focus on a child's right to play as set out in the United Nations Convention on the Rights of the Child (UNCRC). Family Focus with its Time to Play activities and delivery of habilitation delivers on the aims of the strategy to encourage active play but also in engaging parents to provide them with skills, knowledge and confidence to meaningfully play with their children.

## 5. LEARNING & RECOMMENDATIONS

The Family Focus programme has now completed two years of a five-year Big Lottery NI funded investment in the development of an impactful family support programme that has improved the lives of children and families, based on the evidence gathered from parental and stakeholder engagement.

This section provides a series of recommendations and opportunities for learning and development for the final years of the programme based on the two areas of **programme activities** relating to operational delivery and **programme monitoring** pertaining to reporting and evidence.

### 5.1 Activities

5.1.1 The programme has experienced the unintended outcome of increasing attendance from dads and grandparents contributed to the achievement of the programme outcome of 'Families with VI children will be stronger, closer and more resilient.'

5.1.2 Flexibility a key strength.

- New music therapy sessions in L'Derry introduced by Sense NI.
- Adaptive provision: Drop in numbers as children transition into pre-school groups. This has meant adapting where services are located. As a result, a new group was set up in Banbridge which has been very successful from a late start. It is now understood that setting up groups depends both on incidence of where children are born as well as the attrition of children growing up and leaving the groups.

5.1.3 Geographical coverage.

- Developing a significant and consistent grouping in the North West (L'Derry/Derry) has been difficult.
- Targeting cultural and difficult to reach groups through networking with organisations providing support to such groups (Angel Eye's will lead on this aspect as a parent to parent network strategy).
- Follow up assessment with a wider group of parents, proposed through an electronic survey and, where appropriate, direct contact, will identify if transport or accessibility issues persist. This may require aligning costs to cover travel in some instances.

5.1.4 Changing legislative framework.

With the on-coming regulatory demands from the General Data Protection Regulations (GDPR) it has become necessary to take a lot of time and resource to review as a partnership how we process personal data, permissions and consents. As a result, the project team held a day to review compliance within the context of a partnership project to look at systems and processes to make sure that the new regulations were implemented. This continues to be a process of review within the Steering group.

#### 5.1.5 Power of peer support.

The value of peer advice and support has been significant with parents recognizing the valuable experiential learning from others. The challenge to the programme is embracing this and ensuring that such contact is maintained.

- The programme can empower parents to develop local family support groups that will continue the Coffee & Chat ethos beyond the life of the project.
- Best practice can be sought from organisations successfully implementing peer led family support groups such as the Children's Heartbeat Trust with twelve groups throughout Northern Ireland.

#### 5.1.6 Strength in partnership.

The innovative partnership model engaging three organisations within the same area of service has been a positive. Through a range of formal and informal communication channels developed, the operational and steering group teams have worked well together ensuring a constant level of service for families that are often already overwhelmed by appointments and support organisations.

## 5.2 Operations & Monitoring

### 5.2.1 Measuring resilience.

- The project team proposed to measure change from both the Specialist assessments and parent's questionnaires. However, irregular attendance of children has made assessment follow-up less consistent than expected.
- The 50-question tool proposed to measure parent resilience was a barrier to parents who felt overwhelmed by the weight of the survey. In response, the evaluator agreed with the project team to utilise the Brief Resilience Scale, as utilised for this interim report.

### 5.2.2 Centralised reporting of assessments and progressions.

- Reporting on programme activities, outputs and outcomes needs to be more consistent. Throughout the evaluation process the evaluator has engaged with the Operations Coordinator to suggest improvements to data collection. It is

proposed that from year three, a more effective and agreed reporting structure will be in place.

- There needs to be an agreed process and support for all habilitation staff to ensure the consistent use of assessments in order to allow the project to demonstrate the effective progression of participating children e.g. that children are 'signed off' at each stage.
- The partnership should agree how best to consistently and categorically assess the developmental milestones of children with additional and complex needs. Led by Sense NI, as support provider for children with additional needs, the programme could benefit from being able to adequately report on the extent to which a child with complex needs has developed using agreed indicators for each goal and considering the use of 'can do cards' as utilised by the Developmental Journal for Children and Young People with Multiple Needs.<sup>9</sup>

5.2.3 Parental assessment and survey to be reviewed by the Steering Group and reissued annually to assess outcomes for parents.

- An electronic survey for all parents would ease the pressure on habilitation staff and the Operations Coordinator and help to gather data from parents that may only engage for a one-off event or short period of time.

5.2.4 Underreporting of activities and outcomes from the group of families that do not regularly attend Time to Play or Coffee & Chat sessions.

- A new 'Contact Form' is proposed to record contact with all parents at events that will outline a basic assessment of needs, key issues and record any signposting or advice given to allow for effective monitoring of such contacts. That can be followed up by the electronic survey to assess impact and feedback.
- An existing 'exit form' used for events such as the family fun day can be amended to ask parents for example, 'what did you learn today that you didn't know before?'

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<sup>9</sup> <https://councilfordisabledchildren.org.uk/help-resources/resources/development-journal-children-multiple-needs>

## APPENDICES

Appendix One: Reported Outcomes

Appendix Two: Theory of Change

Appendix Three: Year One Review

Appendix Four: Map of Family Focus Activities & Service Users

## Appendix One - Reported Outcomes

<b>Outcome</b> More children with sight loss and complex needs and sight loss will meet their key development milestones throughout childhood and so will have improved life chances			
<b>Change Indicator</b>	<b>Target</b>	<b>Year 1</b>	<b>Year 2</b>
Children with VI have access to habilitation-based opportunities: 45 children achieved milestones in year 1 (60% VI, 40% VI with multiple needs)	45 children will have reached their individual milestone in year 1, increasing by 10 children per year after.	18 children and families accessed	29 children and families accessed through 114 interventions
Children have improved social relationships with people around them with no increased no of positive social behaviours	45 children will have increased positive number of social behaviours in year 1, increasing by 10 children per year after.		
All children achieve agreed development milestones relative to their disability	85 children will reach new milestones defined against complexity of need or disability.	Baseline assessments completed for 17 with 12 follow up assessments 14 follow up assessments of children with complex needs completed	
<b>Details:</b>	<p>Data from provided from children's assessments identifies that 66% (8/12) have progressed along the developmental milestones (at the Developing or Achieved stages) Almost 95% of children with complex and additional needs have progressed along the developmental milestones (at the Developing or Achieved stages) milestones including 4 that have moved on to school). The remaining 4 remain active and accessing support</p>		
<b>Outcome</b>	<b>Parents will be more knowledgeable, confident and equipped to</b>		

## support their VI child and family.

Change Indicator	Target	Year 1	Year 2
Parents have increased understanding of and confidence levels associated with their child's milestones.	Minimum of 80% of parents express increased understanding of their child's abilities and reduced anxiety about their child's development.	18 families engaged with the project.	29 families engaged. High levels of resilience in families and confidence in supporting child
Parents have increased sense of coping.	Minimum of 80% of parents in each group increased confidence in coping with the effects of their child's disability.		
Parents have increased skills to support their child's development.	85 parents use Habilitation based skills to support their child's development and express feeling more informed about their child's potential.	94% parents are more confident in supporting their child's development	

**Details:**

94% of parents agree or strongly agree that they are more confident in supporting their child to develop & achieve (increased family resilience), including using tools at home with other children

**Outcome**

**Families with VI children will be stronger, closer and more resilient.**

Change Indicator	Target	Year 1	Year 2
Families are confident and able to support their child to develop and achieve, increased family resilience.	80% of families express feeling more confident to support their child.	18	High level of satisfaction in the additional questions asked linked to the funders outcomes of confidence, in supporting child to develop and achieve and in how siblings and other family members being more involved
Siblings are more included in family life.	40% of siblings expressing increased happiness in family life following programme.	9 siblings engaged	
Families have increased levels of happiness.	80% of families expressing increased happiness following programme support.	n/a	
<p>76% agree or strongly agree that siblings are more included. 76% agree or strongly agree that they are happier (feel less stressed or anxious about things and the future.)</p> <p><b>Details:</b></p>			
<b>Outcome</b>	<b>Children with sight loss as well as those with multiple needs and sight loss and their families will experience reduced levels of</b>		

**isolation and have increased experience of being part of an inclusive community.**

<b>Change Indicator</b>	<b>Target</b>	<b>Year 1</b>	<b>Year 2</b>
Increased numbers of families are aware of and know how to use other services.	Minimum of 80% of families are accessing parent networks through the project.	18 families engaged with the project. No change data processed in year 1.	82% agree or strongly agree that they are more aware of other services available to them and their family
Increased number of families can access events and opportunities outside the project.	60% of families are accessing social events and opportunities provided outside the project.		
Parents are more confident to deal with outside agencies.	80 of families are using other services and can identify the benefit of this network.		
<b>Details:</b>	High level of satisfaction of awareness of other services and events available.		

## Appendix Two – Theory of Change

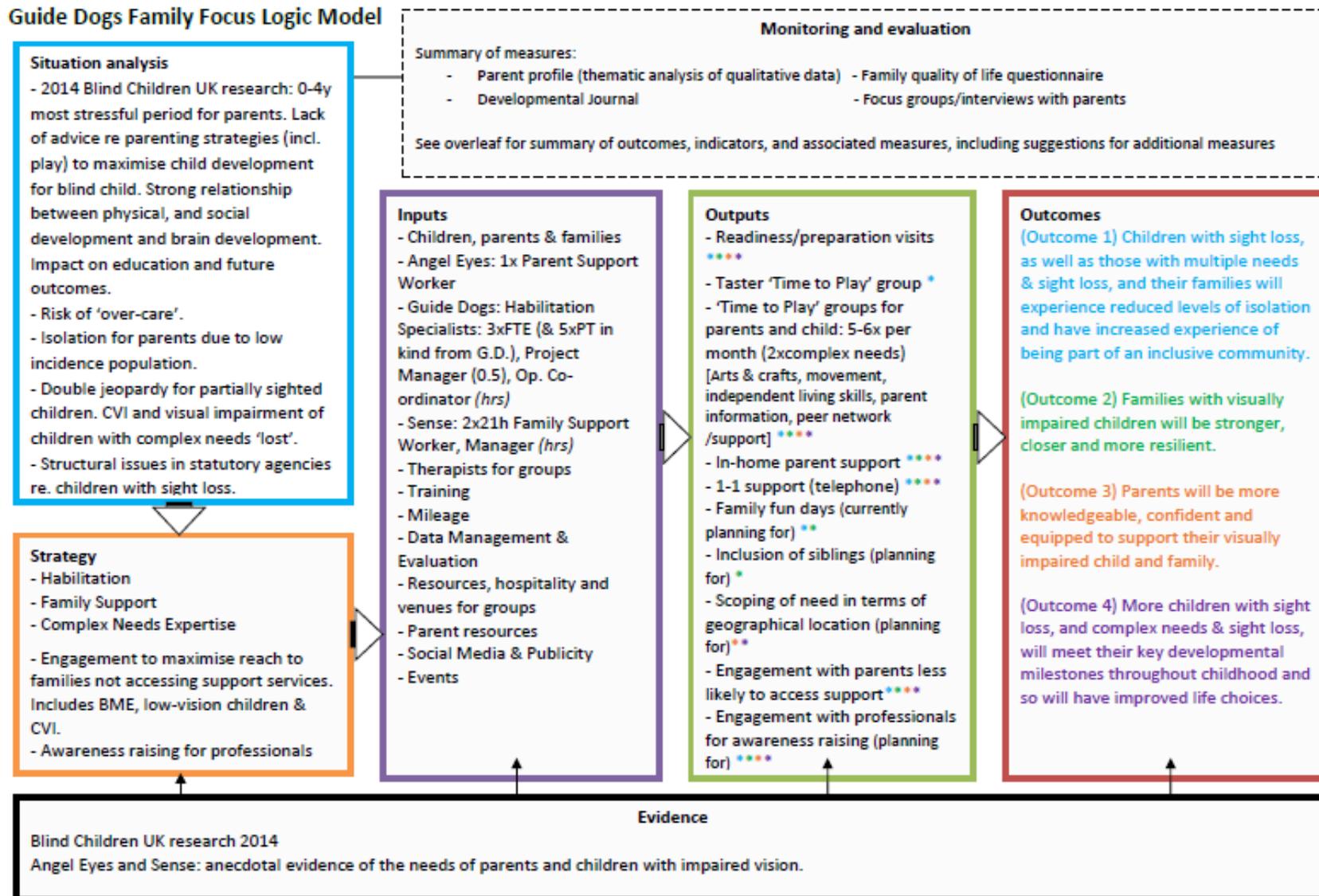


Figure 18: Theory of Change

The suggested indicators and measures developed for the programme were mapped to the required outcomes of the programme funder.

Outcome	Measures
<p>Children with sight loss, as well as those with multiple needs &amp; sight loss, and their families will experience reduced levels of isolation and have increased experience of being part of an inclusive community.</p>	<ul style="list-style-type: none"> <li>▪ Increased numbers of families are aware of and know how to use other services (80% of parents are accessing parent networks)</li> </ul> <p><i>Outcomes and sessional rating scales - click to access (NB must sign up to access range of tools); b) UCLA Loneliness Scale</i></p> <ul style="list-style-type: none"> <li>▪ Increased numbers of families can access social events and opportunities outside the project (60% of parents access social events)</li> <li>▪ Parents are more confident to deal with outside agencies (80% of parents have increased confidence to deal with outside agencies)</li> </ul>
<p>Families with visually impaired children will be stronger, closer and more resilient.</p>	<ul style="list-style-type: none"> <li>▪ Families are confident and able to support their child to develop and achieve (80% of families report increased confidence to cope/resilience) – measured via (1) family quality of life questionnaire (pre and post data) and (2) parent profile</li> <li>▪ Siblings are more included in family life (40% of siblings report increased happiness/life satisfaction) – measured via family quality of life questionnaire (pre and post data) and (2) suggested standardised measure e.g. outcomes and sessional rating scales - click to access</li> <li>▪ Families have increased happiness (80% of families report increased happiness) - measured via family quality of life questionnaire (pre and post data) and (2) parent profile</li> </ul>
<p>Parents will be more knowledgeable, confident and equipped to support their visually impaired child and family.</p>	<ul style="list-style-type: none"> <li>▪ Parents have increased understanding of, and confidence levels associated with their child's milestones (80% of parents report increased confidence) - measured via (1) family quality of life questionnaire (pre and post data) and (2) parent profile</li> <li>▪ Parents have increased sense of coping (80% of parents report improved coping) - measured via (1) family quality of life questionnaire (pre and post data) and (2) parent profile</li> <li>▪ Parents report increased skills to support child (85 in total across the 5 years) - measured via (1) family</li> </ul>

	quality of life questionnaire (pre and post data) and (2) parent profile
More children with sight loss, and complex needs & sight loss, will meet their key developmental milestones throughout childhood and so will have improved life choices.	<ul style="list-style-type: none"> <li>▪ Children with VI have access to habilitation based opportunities and activities using play to stimulate increase in observed movement in their environment (reach, grasp, hold, move, navigate) (60%/40% between VI and VI complex) – measured via developmental journal</li> <li>▪ Children have improved social relationships with people around them with increased number of positive social behaviours (80%/20% between VI and VI complex) - measured via developmental journal</li> <li>▪ Achievement of agreed milestones reached by all children relative to their disability (85 in total across the 5 years) - measured via developmental journal</li> </ul>

## Appendix Three: Year One Review

Broadly, what made the team proud after the first year was:

- *The level of communications between partner teams in different organisations working together and good working relations developed*
- *The ability to develop practical solutions to problems, utilising the resources within the partner teams*
- *Devising an assessment that saves times*
- *Learnt words to nursery rhymes and singing in public*
- *The parents that have engaged*
- *Proud of each individual TTP session, they have all been enjoyable*
- *Proud of relationships built*
- *Positive feedback from parents*
- *Families supported by dedication of staff*
- *The reaction responses of families-positive grateful*
- *Love seeing children progress*
- *Built new relationships with other organisations*
- *Getting 5 playgroups off the ground from scratch-through a partnership which was new*
- *Development of coffee and chat and the Facebook page*
- *Children's confidence*
- *Sibling inclusion*
- *Parents bonds*
- *Ideas for parents*
- *ILS skills developed (pouring and spreading)*
- *Special needs inclusion*
- *Meeting target numbers of groups*
- *Initial positive feedback from parents*
- *Development of complex needs groups in new areas for sense*

These positive responses were tempered by an honest realism that identified areas for improvement:

- *All groups set up earlier so more time to develop and reach individual child goals*
- *Baseline assessments done sooner... but too much other paper work*
- *Time and energy into all the meetings to set up the groups*
- *More time to plan the setting up groups*
- *Assessment could be completed sooner*
- *Perhaps lot of paperwork for families*
- *Parent understanding reason behind activities*
- *Parents having a timetable*
- *Consistent numbers attending*
- *More consistent or regular attendance*
- *Regular attendance to groups has been difficult*
- *Publicity people/professionals knowing we are here*

## Appendix Four: Map



### Key:



Time to Play Locations



Time to Play Family Locations



Coffee & Chat Locations



Coffee & Chat Family Locations