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# Disney EMEA Consortia
# Theory of Change

## Final report

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| **Title:** | Disney EMEA Consortia Theory of Change |
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| **Client:** | The Walt Disney Company Limited |

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# Executive summary

Disney has developed a global enterprise social responsibility strategy with a focus on delivering comfort and inspiration to families with children facing serious illness. As part of this, Disney's Europe, Middle East, and Africa (EMEA) strategy, aims to improve children's emotional resilience through creating 'moments that matter' between children and those closest to them. Emotional resilience is defined variously as the 'ability to bounce back', the 'ability to cope', and to be 'able to deal with life's difficulties'.

Four charity partners – MediCinema, Together for Short Lives, Great Ormond Street Hospital Charity, and Make-A-Wish UK – are working to tackle social isolation and loneliness in childhood. They provide opportunities for children (aged between 2 and 14) with life-threatening or life-limiting conditions to have quality experiences with their families and strengthen the bonds between the children and those closest to them. NEF Consulting was commissioned to work closely with the strategy partners to develop and verify a Theory of Change (ToC) to underpin a shared strategic plan to meet the shared aims of the partners. Interviews were conducted with children, their siblings, and their parents/guardians to verify the ToC as part of this research.

Three headline insights emerged from the research, which informed the strategic ToC.

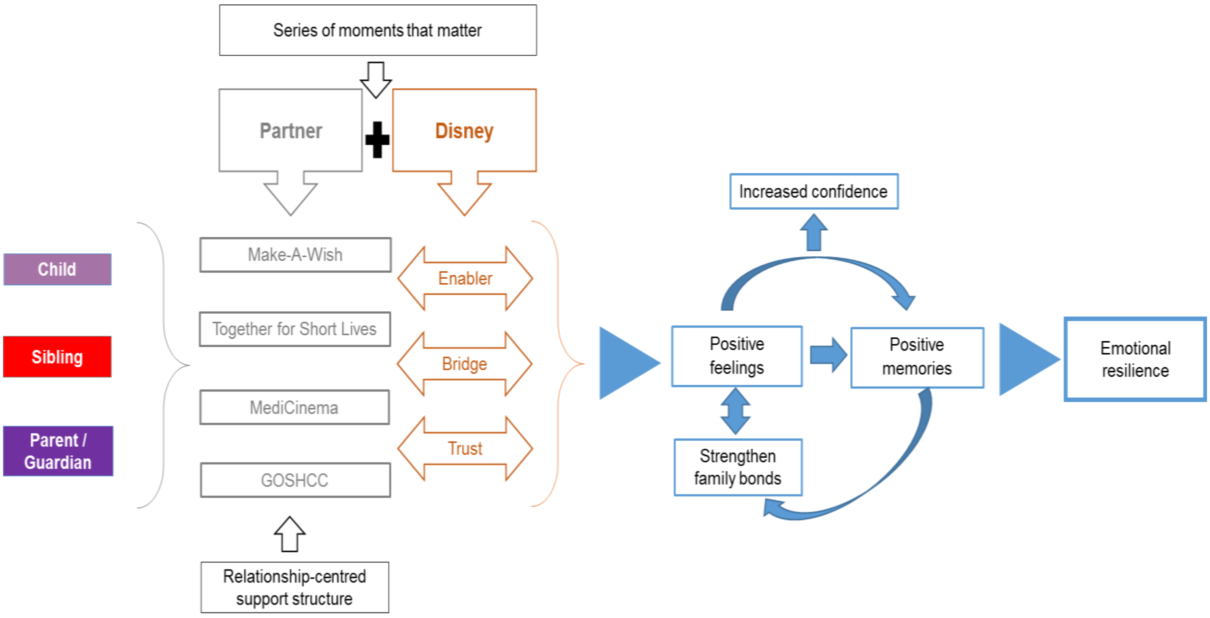
- **There are multiple pathways to emotional resilience** depending on the context the families find themselves in (eg external conditions, including diagnosis and prognosis for their child, available support), as well as their families' internal resources (eg health, self-esteem, optimism).
- **Interventions are successful because of a series of moments that matter** with people who care (where relationships with loved ones, staff, carers, and characters are developed).These support positive feelings which create positive memories that result in a positive impact on children's/people's resilience. Partner services promote a relationship-centred support structure for children and families. Consistency and building trusting relationships helps to bring about positive feelings and a sense of normality and belonging. These then contribute to building emotional resilience.
- **The Disney brand creates a bridge to enable people to build a trusting relationship with the service and the professionals and volunteers providing support.** This then enables people to experience a reduction in their fears and an increase in their sense of belonging and semblance of normality, which supports an increased ability to cope.

The strategic ToC developed from the findings of the research is illustrated in Figure E1 and in the following narrative:

The charity partners **create a relationship-centred support structure** for the child with life-threatening or life-limiting conditions, their siblings, and their parents/guardians to enable them to have **quality experiences with their families**, and **strengthen the bonds** between children and those closest to them, whether this is in a medical or social setting.

There are multiple pathways to emotional resilience and a **series of moments that matter** with people who care, help to build the emotional resilience of the child, their siblings, and their parents. Disney, as a trusted brand, acts as an enabler and a bridge to promoting **positive feelings, increasing confidence, and creating positive memories,** which in turn **strengthen family bonds. Building trusting relationships** between the child and the people who care for them is at the heart of a relationship-centred support structure.

*Figure E1: Strategic Theory of Change*



Detailed theories of change were developed for each of the partners as part of this research. The outcomes detailed in the theories of change have been verified through the interview process, and the research findings for each partner are presented in this report.

# 1. Introduction

## Disney EMEA strategy

Disney has developed a global enterprise social responsibility (ESR) strategy with a focus on delivering comfort and inspiration to families with children facing serious illness. As part of this, Disney’s Europe, Middle East, and Africa (EMEA) strategy aims to improve children’s emotional resilience through creating ‘moments that matter’ between children and those closest to them. The programme, run by four charity partners – MediCinema, Together for Short Lives, Great Ormond Street Hospital Children's Charity (GOSHCC), and Make-A-Wish UK – aims to tackle social isolation and loneliness in childhood (children aged between 2 and 14) by providing opportunities for children with life-threatening or life-limiting conditions to have quality experiences with their families, and strengthen the bonds between the children and those closest to them.

The specific aims of Disney EMEA and the Strategy Group (made up of the four charity partners) are to:

- Increase the emotional resilience of children.
- Increase public awareness of the implications of social isolation and loneliness for these children.
- Increase public awareness of the role emotional resilience can play in addressing social isolation and loneliness in a child’s life leading to better outcomes for the child and their family.
- Increase public awareness of the potential for moments that matter to increase the emotional resilience of a child and those closest to them.

The aims of the programme to support the emotional resilience of the children are delivered through a range of activities provided by the partner organisations. Make-A-Wish UK organises trips for children and their families to Disneyland Paris. MediCinema provides opportunities for children and their families to watch movies at the hospital together. Together for Short Lives organises events and parties for families to enjoy together, as well as for families who have experienced the loss of a child/sibling. The GOSHCC play teams support children to understand and better cope with their treatment in hospital and deal with their fears and worries.

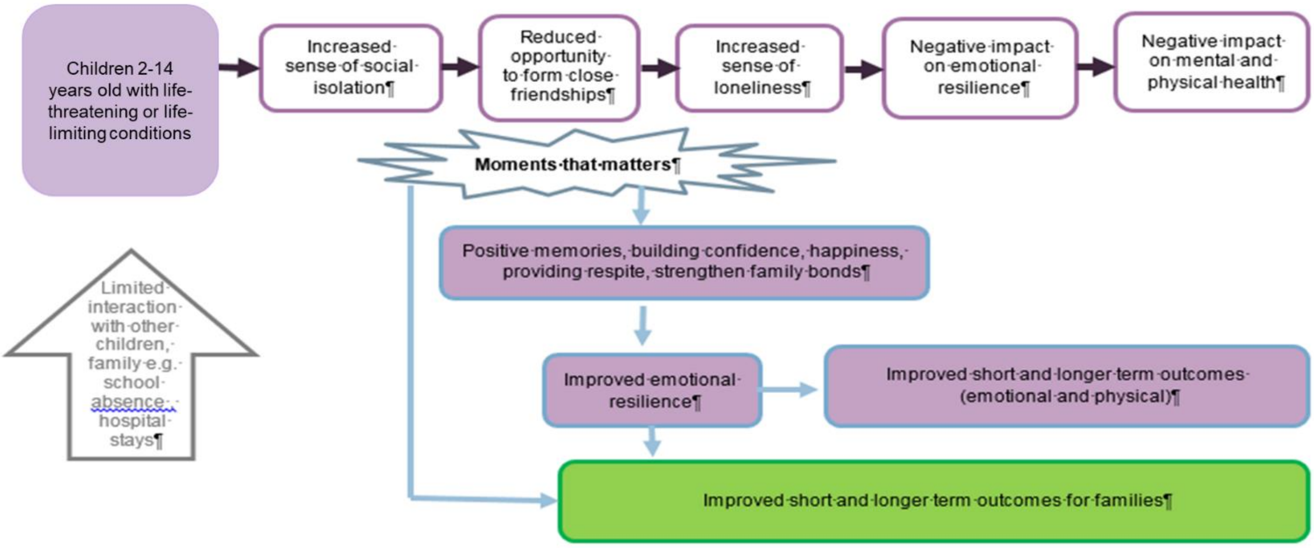
NEF Consulting was commissioned to work closely with the strategy partners to develop a Theory of Change (ToC) to underpin a shared strategic plan to meet the shared aims of the partners. A ToC is a description and illustration of how and why a desired change is expected to happen in a particular context. It depicts a journey of change linking the activities of a programme to short-term, medium-term, and longer-term outcomes, as experienced by stakeholders.

## Initial hypothesis

The initial working hypothesis framing the shared aims of the partnership, is depicted in Figure 1, and can be summarised as follows:

> Children with life-limiting and life-threatening conditions can experience social isolation and loneliness, which can be reduced through moments that matter (positive experiences and quality time spent shared between the child and those closest to them). These moments provide the opportunity to develop positive memories, build confidence, and strengthen family bonds which lead to improved emotional resilience (an increased ability to cope with challenges) and better emotional and physical outcomes for the child in later life.

*Figure 1 Disney EMEA Initial working hypothesis*



The key assumptions underpinning the hypothesis are:

1. Positive moments improve emotional wellbeing, and they have a longer-term impact which continues to positively affect emotional outcomes.
2. Positive outcomes for the family can be promoted through the child's improved emotional wellbeing.
3. Strengthening family bonds improve emotional resilience.

# 2. Research approach

The research methodology was delivered in three phases: research, co-design, and testing.

### Research

A rapid review of key project documents, and interviews with key staff members were undertaken to understand the activities of the partner projects.

### Co-design

Five ToC sessions were held with each of the four strategy partners (Make-A-Wish-UK, Together for Short Lives, MediCinema, and the GOSHCC) and Disney to develop ToCs for their programmes. The partner ToC sessions involved staff directly supporting or engaging with the children.

The identified outcomes were tested against secondary research to ensure that the ToCs were robust. An iterative process was used to refine and revise the ToCs with each partner individually, as well as online review sessions with the partners as a group.

### Verification and testing

The ToCs were used to identify common outcomes across the partner programmes for children, their siblings, and their parents/guardians. Table 2.1 summarises the nine common outcome areas identified and described in different ways across the partner ToCs.

*Table 2.1: Common outcome areas*

| Outcome area |
|---|
| Increased opportunity to form friendships. |
| Increased opportunity to spend quality time with family (parents, guardians, siblings) and strengthen bonds. |
| Increased positive feelings (e.g. happy, excited). |
| Creation of positive memories. |
| Increased choice and control. |
| Increased resilience. |
| Increased confidence and self-esteem. |
| Better relationships with staff/hospices/medical institutions |
| Respite/relief |

The common outcomes were verified through a process of saturation interviews with children experiencing the moment that matters, their siblings, and their parents/guardians. Saturation theory applies the concept of theoretical saturation, which is the phase of qualitative data analysis in which the researcher has continued sampling and analysing data until no new data appear and all concepts in the theory are well-developed. Interview guides were developed for children, siblings, and parents. Each partner reviewed the interview methodology prior to it being finalised. An example interview guide is detailed in Appendix 1.

A maximum of 10 research units made up of parent/guardian, child experiencing the moment that matters, and sibling involved in the moment that matters were planned per partner. The partner invited the families to take part in the research. The following considerations were used to inform the sampling frame:

- A range of children experiencing a moment that matters from the two age groups: 2–8 years and 9–14 years.
- The length of time expired since the moment that matters. We suggested 2–3 months, with some examples of 6–8 months to test how long the outcomes lasted.
- Duration of experience. For MediCinema we suggested identifying children who had been in the cinema more than once.

Twenty-one interviews were conducted to reach saturation (Table 2.2). In cases where the children had cognitive disabilities or were too young, parents were interviewed on their behalf. The results of the verification process was compared to the partner-generated ToC and differences were identified. The partner ToCs, and the results of the secondary research were used to further develop the strategic ToC, and this was discussed with partners.

*Table 2.2: Research unit interviews completed*

| Stakeholder | Interviews completed (number of research units) |
|---|---|
| Make-A-Wish UK | 3 |
| MediCinema | 7 |
| GOSHCC | 7 |
| Together for Short Lives | 4 |

A summary of the research methodology is provided in Table 2.3.

*Table 2.3: Summary methodology*

| Partner | Methodology |
|---|---|
| Make-A-Wish UK | ▪ Develop ToC diagram.<br>▪ Identify common outcomes framework and data collection method.<br>▪ Verify through interviews.<br>▪ Refine ToC diagram by including verified outcomes. |
| MediCinema | |
| GOSHCC | |
| Together for Short Lives | |
| Disney | ▪ Develop ToC diagram. |
| All | ▪ Use the verified ToCs to develop the strategic ToC. |

## Limitations

Over the course of the research, the methodologies were adapted to address practical challenges of capturing data. Some of the children declined to take part in the interviews because they were too shy, or they could not engage for a sustained amount of time or did not understand some of the questions (due to age and cognitive ability). In those circumstances, parents were interviewed on behalf of their children.

There were challenges with identifying families who had attended Disney parties for Together for Short Lives. As a result, the sampling criteria was adapted, and four families who had attended hospice events designed for families were identified. Only two of those families had attended a Disney themed event, and two of the families were bereaved.

In some cases, families found it challenging to recall films or activities specifically associated with Disney. Some parents recalled the film experience in MediCinema more generally, and the support they had received from the GOSHCC play team.

The four charities selected the families to be interviewed and as such, there is a risk of selection bias.

# 3. Strategic Theory of Change

## Headline insights

Three headline insights emerged from the research, which inform the strategic ToC.

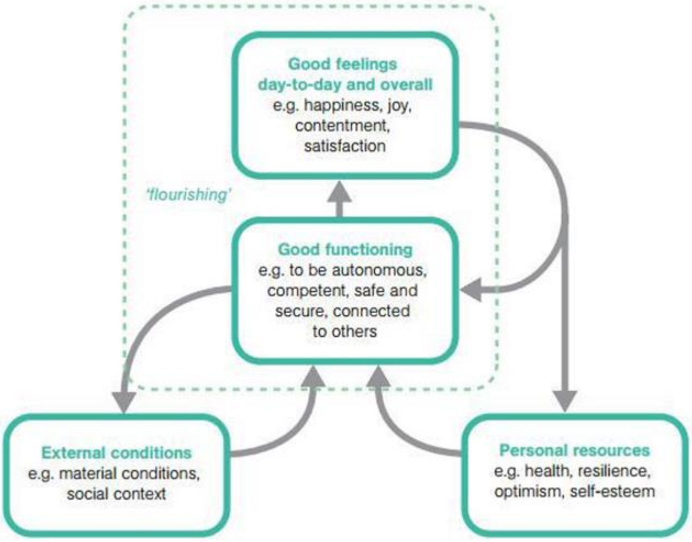
### Multiple pathways to emotional resilience

Emotional resilience is defined variously as the ability to bounce back, the ability to cope, the ability to deal with life's difficulties. In times of difficulty, children are very vulnerable to the effects of traumatic events. **Without resilience, they become vulnerable to long-term physical and mental health problems.**

The findings suggest there are **different pathways to emotional resilience**, depending on the context the families find themselves in (e.g. external conditions, including diagnosis and prognosis for their child, available support), as well as their families' internal resources (e.g. health, self-esteem, optimism). For example, a break and experiencing fun activities with loved ones were reported as supporting coping mechanisms, while for others it was reducing their children's fears in relation to their illnesses.

This is echoed by NEF's research on the dynamic model of wellbeing, developed for the Government Office for Science's 2008 Foresight project, which shows the different features of wellbeing, and the relationships between them.[1] There is a link between the external conditions that an individual operates within, and their personal resources, which in turn influences how well each person is able to function.

*Figure 3.1: The dynamic model of wellbeing*



### Moments that matter

Findings suggest the interventions are successful because of a '**series' of 'moments that matter'** with people who care (where **relationships** with loved ones, staff, carers, characters are developed) support **positive feelings** which create **positive memories** that result in a **positive impact on children's/people's resilience**.

For example, going to the cinema on a number of occasions, developing a routine, regularly meeting with a particular play worker, taking part in multiple events (for Together for Short Lives), and visiting Disneyland Paris is over a number of days.

Creating social bonds and togetherness is critical for children and is proven to help build emotional resilience. Partner services promote a **relationship-centred support structure** for children and families. Consistency and **building trusting relationships** help to bring about **positive feelings** and a **sense of normality** and **belonging**. These then contribute **to build emotional resilience**.

### A bridge to trust

Disney is widely recognised and familiar amongst children and adults as **a trusted brand** that can bring a **sense of normality**. The Disney brand **creates a bridge** to **enable people to build a trusting relationship** with the service, and those professionals and volunteers providing support. This then enables people to experience a **reduction in their fears**, an **increase in their sense of belonging,** and a semblance of normality, which supports an increased ability to cope.

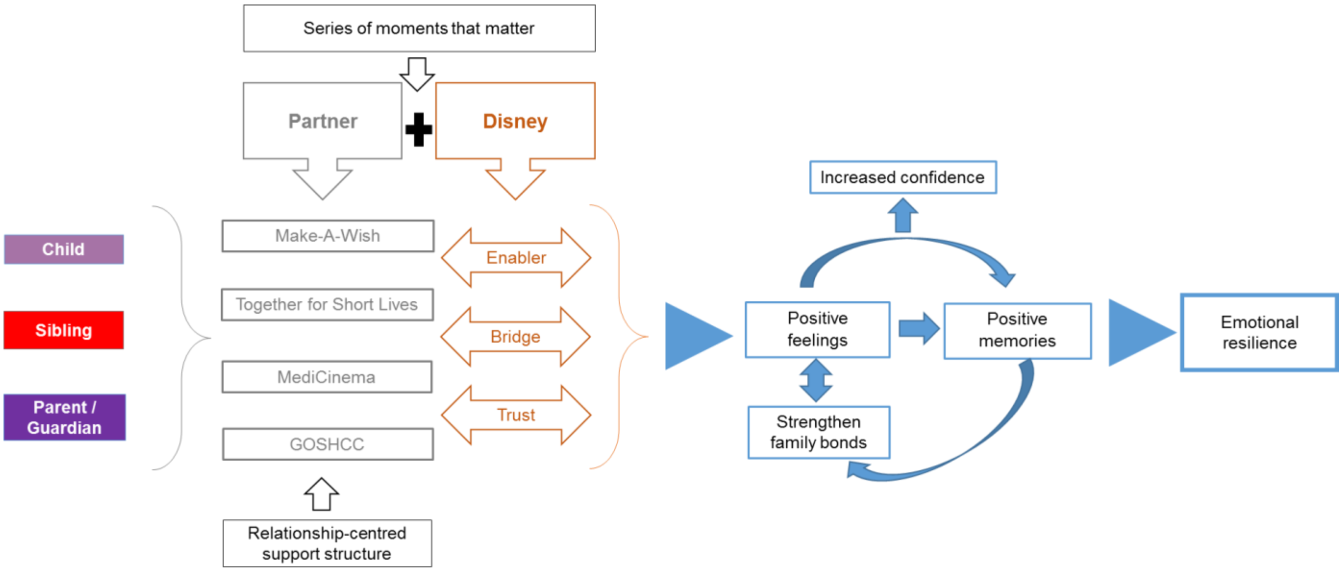
## Strategic Theory of Change

The strategic ToC is illustrated in Figure 3.2.

The charity partners **create a relationship-centred support structure** for the child with life-threatening or life-limiting conditions, their siblings, and their parents/guardians to enable them to have **quality experiences with their families**, and **strengthen the bonds** between children and those closest to them, be it in a medical or social setting.

There are multiple pathways to emotional resilience. A **series of moments that matter** with people who care helps to build the emotional resilience of the child, their siblings, and their parents. Disney, as a trusted brand, acts as an enabler and a bridge to promoting **positive feelings, increasing confidence, and creating positive memories,** which in turn **strengthen family bonds. Building trusting relationships** between the child and the people who care for them is at the heart of a relationship-centred support structure.

*Figure 3.2: Strategic Theory of Change*



To reflect the different service delivery models of the partners, two further generalised ToC models were developed for the relationship-centred support models in a medical/clinical setting, and a social setting (Figures 3.3 and 3.4, respectively) based on the findings of the research.

*Figure 3.3: Social relationships model in a medical / clinical setting*

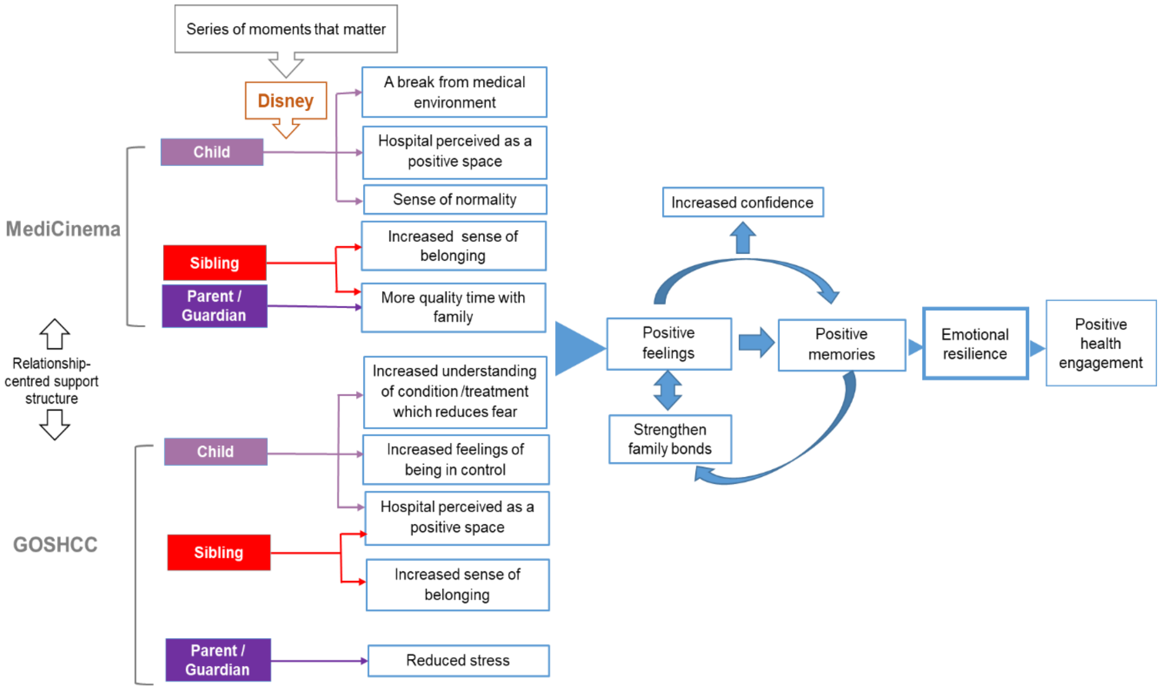


Figure 3.3 illustrates the high-level pathways to support **emotional resilienc**e for MediCinema and GOSHCC in a medical setting, and the material outcomes (most significant and relevant outcomes) for the child, sibling, and parent/guardian identified through the research supported through the moments that matter.

In the MediCinema pathway, the moments that matter, and the Disney-related activities offer a **break from the medical environment,** support **the hospital to be perceived as a positive space**, and **offer a sense of normality** for the child and the opportunity to spend **quality time with family**. In Figure 3.3, reduced social isolation has been framed positively as an increased **sense of belonging** for siblings. These experiences promotes **positive feelings, increase confidence,** and **create positive memories,** which in turn **strengthen family bonds,** which helps to build **emotional resilience** and **promotes positive health engagement.**

In the GOSHCC pathway, the moments that matter and the Disney-related activities help to build trusted relationships and support the child to i**ncrease their understanding of their condition** which reduces fear and **increases their feelings of being in control**. In Figure 3.3, reduced social isolation has been framed positively as an **increased sense of belonging** for siblings. This experience promotes **positive feelings, increases confidence,** and **creates positive memories,** which in turn **strengthen family bonds,** which helps to build **emotional resilience** and **promotes positive health engagement.**

*Figure 3.4: Social relationships model in a community setting*

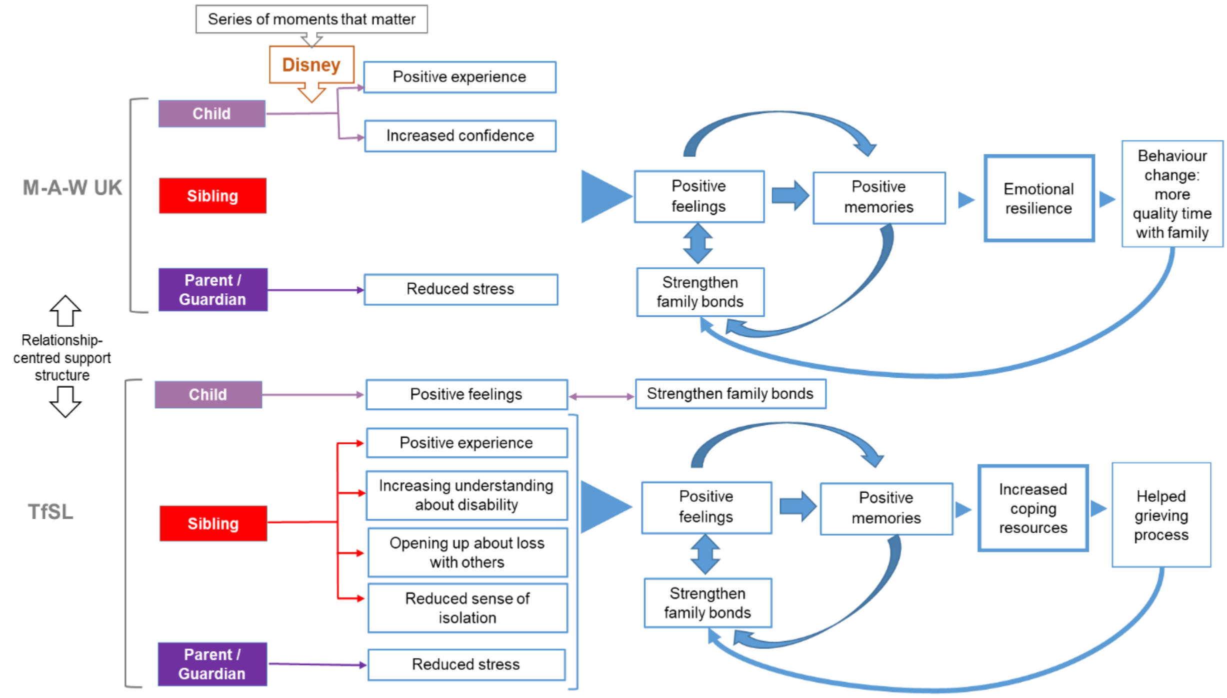


Figure 3.4 illustrates the high-level pathways to support emotional resilience for Make-A-Wish UK and Together for Short Lives in a community setting, and the material outcomes

(most significant and relevant outcomes) for the child, sibling, and parent/guardian identified through the research supported through the 'moments that matter.

In the Make-A-Wish UK pathway, the moments that matter, and the Disney-related activities create a **positive experience**, which **increases the child's confidence**. This experience promotes **positive feelings** and **creates positive memories,** which in turn **strengthen family bonds,** which helps to build **emotional resilience**. Family members spend more **quality time** with each other, which again **strengthens family bonds.**

In the Together for Short Lives pathway, 'moments that matter, and the Disney-related activities create a **positive feeling** for the child which **strengthens family bonds.** Siblings experience a **positive experience,** and they **increase their understanding about disability**. The supportive environment allows them to **open up about loss with others.** This experience promotes **positive feelings** and **creates positive memories,** which in turn **strengthen family bonds.** Siblings and parents are **better able to cope** and are **helped in the grieving process,** which again **strengthens family bonds.**

More detailed ToCs were developed for each of the partners as part of this research. The outcomes detailed in the ToCs have been verified through the interview process, and the research findings for each partner are presented in the following chapters of this report.

# 4. Make-A-Wish UK, Disneyland Paris

Make-A-Wish UK is a charity that grants wishes to children with life-limiting illnesses and their families. While the types of wishes Make-A-Wish UK grants are varied, this research has only verified outcomes relating to one of their activities- trips to Disneyland Paris. Make-A-Wish UK provides the opportunity for families to go abroad and enjoy a trip to Disneyland Paris. Often this might be the first time the family has had a holiday abroad, and visiting Disneyland Paris is usually the children's one true wish.

## Key findings

What follows are the key findings from the interviews conducted as part of this research.

**Visiting Disneyland Paris led to a break from the daily struggles for most families, fun and excitement (positive feelings), increased bonding with their families, an increased sense of belonging and inclusion,** and **feelings of normality**. This was achieved through excitement as soon as the application for the trip was successful, as well as the ability to enjoy a variety of activities (Disney rides, restaurants, fireworks) in Disneyland Paris. The families' needs were fully catered for (including enabling carers to accompany one family) and the Disney lanyard enabled families to get special treatment leading them to feeling valued and included.

**The trip has also contributed to an increase in coping mechanisms/resilience as a result of the positive experiences and quality time spent with loved ones.** Families were better able to cope with their feelings, pushing themselves to experience new things for themselves, as well as for their children. Evidence shows experiencing positive emotions may build effective coping resources that help buffer against negative emotional life.[2] Families also reported experiencing an increase in confidence; some children felt more confident to try new things/experiences as a result of the trip.

**Families reported that the positive memories from the trip enabled them to both recall the memories and re-experience those positive emotions** both on their own, and with others. This enabled them to further interact and engage with others (both family members and those outside the family).

**All families reported a change in behaviour as a result of the trip** – it brought them closer and enabled them to experience positive feelings, as well as reducing their children's fears and increasing their confidence and coping mechanisms. As a result, they were more inclined to prioritise quality family time as part of their lifestyle, travel more, and provide opportunities for their children to try new things.

These key findings echo the findings of research by Aston University,[3] which found that Make-A-Wish UK wishes led families and children to experience joy and excitement, as well as increasing resilience and coping, bringing the family together, and facilitating lifestyle changes.

Figure 4.1 illustrates the Make-A-Wish UK ToC – Disneyland Paris for the wish child, their siblings and their parent/guardian. The ToC details the material outcomes and the negative outcomes that would have been experienced without the wish experience. The following outcomes were verified through the interviews.

## Outcomes for the child

**Positive emotions**

All the children enjoyed the trip, with two of the wish children reporting that going to Disneyland was their one true wish.

**Respite** from the families' daily struggles led to happiness and excitement. The excitement about the Disneyland trip started before the families went on the trip. Families had started sharing the news with friends and other family members as soon as their Make-A-Wish UK application was accepted. One family had a countdown to Disneyland on their Facebook page.

The family found the experience exceeded their expectations. What made their experience enjoyable was the variety of activities they were able to take part in; these included not only the rides, meeting Disney characters, and obtaining their autographs, but also accessing different types of restaurants, watching entertainment shows, and seeing the fireworks. Disney's staff support together with the provision of the Disney Lanyard also made the family feel special and catered for and enabled them to take advantage of everything Disney had to offer.

> "It was amazing…the only downside to it was it would have been nicer if [daughter] had been taller, because she could not go on some of the rides she wanted to go on." (Mum)
>
> "We were shown around, went backstage to the Buffalo Bill's wild west, watched fireworks, [there were] really nice restaurants, everything seemed to be over the top in a good way." (Dad)
>
> "It was incredible, the merlin pass, genie pass and it just honestly it was incredible. You get to go to the front of the queue, it was embarrassing at times, these massive queues and they drop everything…there is no way we would have done everything and got signatures without that [lanyard]." (Mum)

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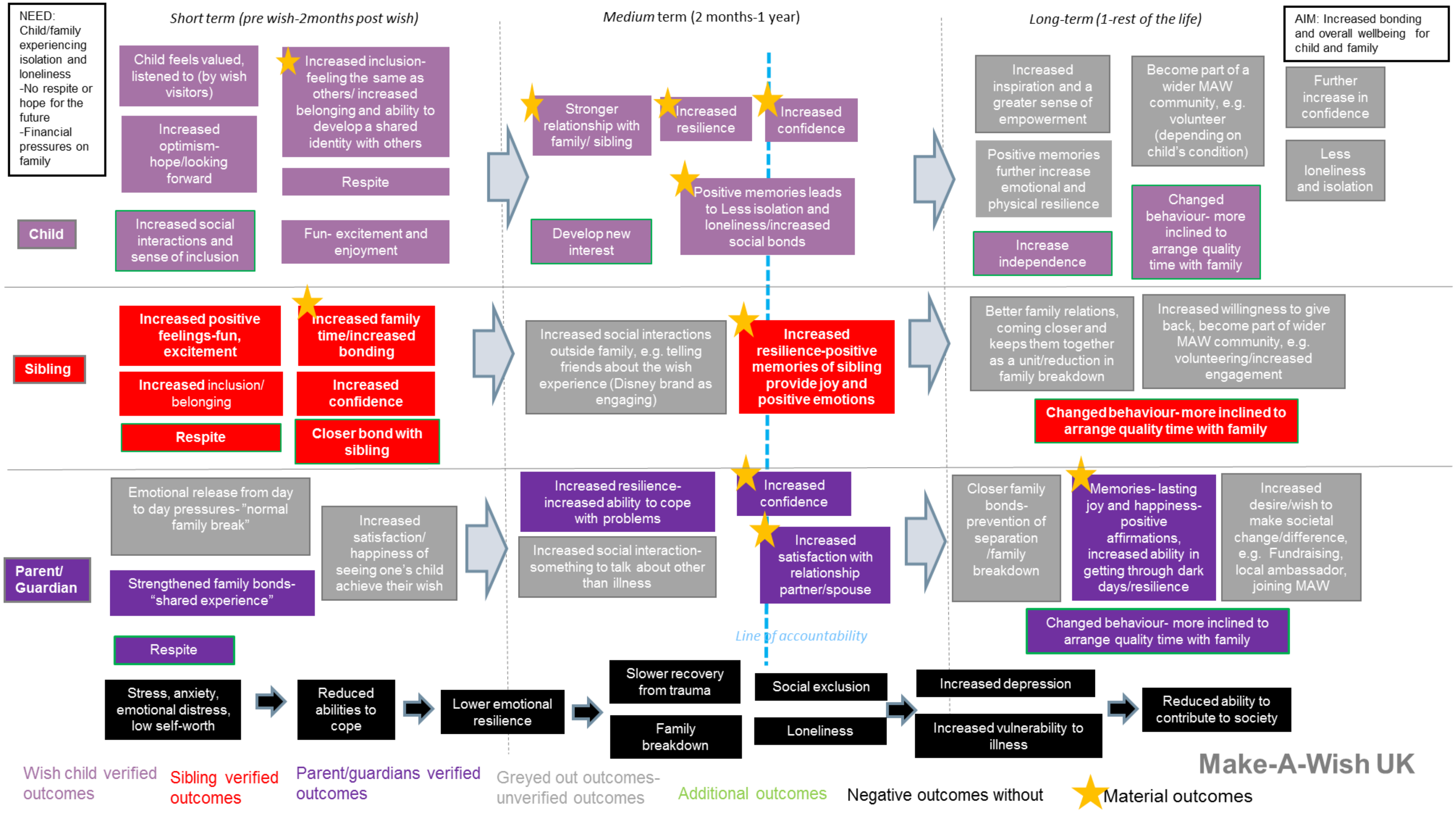
*Figure 4.1: Make-A-Wish UK Theory of Change – Disneyland Paris*



NEED: Child/family experiencing isolation and loneliness
-No respite or hope for the future
-Financial pressures on family

*Short term (pre wish-2months post wish)*

*Medium* term (2 months-1 year)

*Long-term (1-rest of the life)*

AIM: Increased bonding and overall wellbeing for child and family

**Child**

Child feels valued, listened to (by wish visitors)

Increased optimism- hope/looking forward

Increased social interactions and sense of inclusion

Increased inclusion- feeling the same as others/ increased belonging and ability to develop a shared identity with others

Respite

Fun- excitement and enjoyment

Stronger relationship with family/ sibling

Increased resilience

Increased confidence

Develop new interest

Positive memories leads to Less isolation and loneliness/increased social bonds

Increased inspiration and a greater sense of empowerment

Positive memories further increase emotional and physical resilience

Increase independence

Become part of a wider MAW community, e.g. volunteer (depending on child's condition)

Changed behaviour- more inclined to arrange quality time with family

Further increase in confidence

Less loneliness and isolation

**Sibling**

**Increased positive feelings-fun, excitement**

**Increased** inclusion/ belonging

**Respite**

**Increased family time/increased bonding**

**Increased confidence**

**Closer bond with sibling**

Increased social interactions outside family, e.g. telling friends about the wish experience (Disney brand as engaging)

**Increased resilience-positive memories of sibling provide joy and positive emotions**

Better family relations, coming closer and keeps them together as a unit/reduction in family breakdown

Increased willingness to give back, become part of wider MAW community, e.g. volunteering/increased engagement

**Changed behaviour- more inclined to arrange quality time with family**

**Parent/ Guardian**

Emotional release from day to day pressures- "normal family break"

Strengthened family bonds- "shared experience"

Respite

Increased satisfaction/ happiness of seeing one's child achieve their wish

Increased resilience- increased ability to cope with problems

Increased social interaction- something to talk about other than illness

Increased confidence

Increased satisfaction with relationship partner/spouse

*Line of accountability*

Closer family bonds- prevention of separation /family breakdown

Memories- lasting joy and happiness- positive affirmations, increased ability in getting through dark days/resilience

Increased desire/wish to make societal change/difference, e.g. Fundraising, local ambassador, joining MAW

Changed behaviour- more inclined to arrange quality time with family

Stress, anxiety, emotional distress, low self-worth

Reduced abilities to cope

Lower emotional resilience

Slower recovery from trauma

Family breakdown

Social exclusion

Loneliness

Increased depression

Increased vulnerability to illness

Reduced ability to contribute to society

**Make-A-Wish UK**

Wish child verified outcomes

Sibling verified outcomes

Parent/guardians verified outcomes

Greyed out outcomes- unverified outcomes

Additional outcomes

Negative outcomes without

★ Material outcomes

### Increased inclusion and social interaction

Families used words associated with 'normality' to denote the increased sense of belonging their wish children felt during and since the trip to Disneyland Paris. Taking part in activities like other children their age has had an impact on their child's sense of self, making them feel they belonged where previously they were often isolated in hospitals. As a result of this sense of inclusion, the children became more open to social interactions both with others on the trip and afterwards, as they had something fun and positive to talk about.

One child was often nervous and would usually not be willing to take part in new activities. The Make-A-Wish UK staff visited the family to ensure he was comfortable, and as a result, he was able to take part in the experience with the rest of his family and enjoyed it.

> "It made her feel normal for that week. She felt like any other child having fun, rather than a sick a child." (Mum)
>
> "She loves showing the photos to everybody, all the nurses. She opens up and starts a conversation. Every now and then she will flick through [the photos]. She is generally talking more now." (Mum)
>
> "She threw herself into it really…she was made so welcome at Disney. People took their time .People held her hand. They made her feel Mickey Mouse's face. She met [other Disney] characters; they were good with her." (Mum)

### Increased confidence

Families reported that their children became more comfortable with trying new things such as new food and they developed new interests as a result of the trip. Two families had concerns about their children's reaction to the trip, as they often were not open to new experiences; however, none of their concerns have come to pass. One family reported that their child had lost her confidence and had become shy and withdrawn as a result of spending a long time in the hospital. However, the trip has helped the children to either regain their confidence or develop confidence by developing new interests.

> "She became shy, embarrassed, withdrawn…she was embarrassed about her body; that all comes from her being prodded and poked. [Disneyland trip] was the point she started feeling confident…she came out of her shell." (Dad)
>
> "She is a little star. She took everything in her stride. It was an unknown for her: new sights, new smell. Even though visually impaired, she got the full benefit of [the] Disney experience without having her sight; you don't need sight to have [a] Disney experience." (Mum)

### Additional outcome: developing new interests and increasing independence

One family reported their daughter's increase in independence as a result of the trip. Both parents were apprehensive about the trip and their daughter's reaction to it. However, the trip had a significant impact on her confidence. As a result of this experience, their daughter, despite her condition and visual impairment, continues to experience new opportunities; her parents got her passes to go on rides at different places throughout the year.

> Because of her visual impairment, she is wary about any new situations, but she took to new situations to Disney very well. She threw herself into it really. She wanted to be a princess in a Disney castle (her wish). It was lovely… it has given her confidence to go on and try new things out… [our daughter] went as a princess but came back as a rollercoaster junkie." (Mum)

**Increased resilience/coping**

Families reported that their children were better able to cope with their feelings as a result of the trip; it provided an opportunity to have fun together, when often some of the siblings were often isolated in hospital. The trip was a form of distraction from their medical conditions and negative feelings. Families reported that Disneyland made them realise the importance of positive feelings and fun activities for their children, and for the family as a whole.

> "It was really difficult…so many things going on. You get caught up with all the hospital appointments. E got every infection under the sun. It was touch and go [in the beginning]…[the trip] was a form of escapism. Having fun with her sister was good. It put her in a **different state of mind.**" (Mum)

One family reported that the visit to Disneyland for K was the first opportunity they'd had to go abroad. This was a worry for the family as their child "is a creature of habit, understands routines, and has also been nervous about people in costumes in the past". However, the process of Make-A-Wish UK staff coming to the house, building trust, and helping him to be comfortable with people, as well as making his own decision to go, really helped him to feel comfortable with new experiences.

> "K has only 5 'safe foods' and had reduced his range to t3 since recent treatment before the trip to Disneyland. Being in a new place and sharing an experience with his sister of getting food allowed him to try something new. When they got back home, he showed his grandparents. I think it was his way of saying 'thanks for pushing me out of my comfort zone'. It was magical." (Mum)

**Positive memories**

The visit gave families positive memories to look back on. They often recall those memories as a family whenever something triggers it, such as "when the [sisters] have got their Disney outfits on or after watching Disney movies on telly". One parent reported that her son looks back over the photos regularly, both alone and with his siblings and parents. His sister speaks with him about their holiday, which helps to strengthen their bond.

One family reported that despite their child's condition of cerebral palsy, she was able to recognise and positively react to any reference of the trip or the mention of rollercoasters. This demonstrates the impact positive memory has in bringing about positive feelings long after the trip has taken place (two years ago).

> "Yes, we all talk about the trip. When we do, when we say 'rollercoaster', or when we talk about it with others, we ask her 'what did you do on [the] rollercoaster ride?' She puts her hand in the air and goes "whee". She understands. That has given her a lot of confidence." (Mum)

**Quality and increased time spent with family/sibling (increased bonding)**

All the families reported that the trip provided a wonderful holiday. One family reported that Make-A-Wish UK enabled their carers to join them so that they were able to focus on enjoying their time together as a family. Families appreciated their child spending time with the whole family as usually they are often isolated in hospitals, and do not get to see their siblings often.

> "It was amazing. I did not know what we were expecting apart from what you see on telly - the big castle - but it was way more than we expected…E [child] went on stage and did this shooting thing and won. She was excited about it. She was in a nice place then. She was not poorly. She was able to enjoy it…" (Dad)

> "It was magical. Disney is a magical place. The characters, everybody, were so lovely to the kids… [the trip] gave us time as a family to do normal things like other families." (Mum)

Families reported that their children had very strong relationships to begin with but did not get to spend quality time together as a result of the diagnosis.

> "The girls enjoyed the rollercoaster the most…E spent a lot of time in the hospital…she often could not see her sister…the trip gave us the opportunity to spend time together." (Dad)

## Outcomes for the siblings

**Positive feelings**

Having fun with their siblings and parents was very much appreciated by the siblings. Usually the siblings had missed out on many experiences due to the treatments of their (wish) siblings and had also not been able to spend quality time with them. One sister reported feeling "excited and happy" once in Disneyland, but also on her way to Disneyland Paris as she "loved the [Eurostar] train."

**Increased family/sibling bonding and social interactions**

The experience of most families revolved around medical treatment like hospital appointments and monitoring the conditions of the wish child. One mother also reported that their daughter had developed a sense of anxiety about her sister's illness often asking whether her sister was "going to die". The trip enabled siblings to make positive memories together away from the hospital.

Furthermore, one family used the Disney experience to create some activities they could share together, for example through buying an autograph book. B (child) took a photo with every single character at Disneyland Paris and made a book together; she often uses the book to engage with her brother.

### Positive memories provide joy and positive emotions which help with coping mechanism/resilience

Reminiscing about the trip is a key mechanism to enable the families to re-experience positive feelings; this helps to boost general wellbeing and enables the family to cope more effectively during difficult times. Evidence suggests that positive emotions contribute to psychological wellbeing via more effective coping by enhancing coping resources in the face of negative events.[4]

One family reported that recounting their experiences as a family started whilst they were still in Disneyland. It was always at the end of the day when they returned to their hotel room and recounted together the fun time they had had during the day.

> "[A favourite memory would be] the family time, in the hotel room. We would have a debrief about the day, seeing everybody having the same emotion, everybody happy." (Mum and Dad)

## Outcomes for the parents/guardians

### Increased quality time spent with family and increased social interactions

The families had a wonderful holiday together, despite some concerns. Some families had concerns about their children's reactions to new experiences, while another was worried about their child's health problems. For example one family reported that they were worried that their son's phobias (which had made other holidays difficult) would pose an issue in terms of travel and then getting out. But this was not the case.

Another family was also worried their daughter would "scream the whole place down" but the mother reported feeling "happy seeing [her daughter] actually enjoy it". Another family reported feeling happy "seeing her feel like a normal child" enjoying the trip together with her sister.

> "It was amazing, absolute amazing. The trip there was brilliant. All family, all together, on an adventure… It was great to be together as a family. It was special just to be together." (Mum and Dad)

The families reported feeling more confident engaging with others such as friends as a result of the trip. One mother reported often recalling the trip and talking about it with her friends.

### Increased satisfaction with relationship partner/spouse

One family in particular reported that the trip brought the parents closer together. They were often apart since they split the care responsibilities. This often meant one parent looking after the wish child at the hospital, whilst the other parent took care of their other daughter at home.

> "It gave us chance to spend time together. For months on end we did not see each other. We were like ships passing at night…there was a lot of strain on us as a family. [The trip] gave us time to be together again." (Mum)

### Respite

The trip provided a break from focusing on the daily struggles. Parents reported the very difficult nature of their role as a parent of a child with complex needs and a life-limiting illness, and the relentless nature of their caring role; it is "24/7 with no break". Parents enjoyed spending quality time as a family together with one mum reporting the trip helped "take [her] mind off what was going on".

### Increased confidence

As a result of the holiday, families reported feeling more confident about the future. One family reported increased confidence in relation to travelling abroad and trying different accommodation and transport options. Others reported more confidence to take their daughter to new social settings for her to enjoy.

> "Disney gave her and us the confidence to take her to rides regularly. We know we can go to local parks, Alton Towers and Thorpe Park." (Mum)

### Positive memories

Like the other stakeholders, reminiscing about the trip brought the families together and enabled them to re-experience positive feelings. For example, one family reported recalling memories helped with discussing how the trip could contribute to future things that they could do together (implying an increased ability to seek positive experience as a family).

Another family reported that the trip provided them with more opportunities to interact with their friends. The parents reported often talking about the trip with one another as well as with their non-communicative children. One mum found the trip "fantastic, a special memory, that [we] will never forget".

### Increased resilience and better coping mechanisms

Parents reported feeling more confident and being better able to cope with their feelings as a result of the trip.

> "It makes us realise [that we need] to spend more time as a family. It can be quite a strain on relationships, it can get so stressful as me and [my partner] spend a long time not with each other.". (Mum)

One parent reported not feeling more resilient as a result of the trip. This could be because at the time of the interview their child had relapsed and was back in hospital.

### Long-term impact: behaviour change leading to better coping mechanisms

All families reported that they are more inclined to travel, recognising the benefit this has on their family's wellbeing. One family reported that introducing more travel in their routine would help them to "get back to normality" as they were a family who often travelled prior to their daughter's diagnosis.

> "We always liked to travel anyway, before her illness…that trip was an opportunity to do that once again, [to do] what we liked to do… I think it gave us the chance to sit down [and] made us realise how much we have missed being as a family together. It made us realise we need to do more [of this] and it is easier now, as E still needs to be checked, but is not on medication." (Mum)
>
> "We weren't able to fly. Now that we can, we go on loads of trips to Cornwall." (Dad)

Another family reported that prior to the trip they were often protective of their children due to their condition and were apprehensive about letting them explore new opportunities, often because the children did not react well in such conditions. However, since the trip the family reported increased trust in their daughter's capabilities and confidence, and they are more inclined to let her become more independent.

It was not possible to determine from the interviews the duration of most of the outcomes. We know families re-experienced positive feelings whenever they recalled a memory, such as flicking through photos or watching a Disney film.

### Attribution

Some families reported receiving support from grandparents and local friends which also contributed towards their emotional wellbeing. Despite the support from other family members, the families largely attributed the changes they experienced to the Disneyland trip. On average, the families attributed 87.5% to the Disneyland trip.

### Counterfactual

One family reported that their feelings would have worsened slightly had they not taken part in the Disney trip. They also reported that the relationship with their partner and children would have slightly worsened, as the trip helped bring them closer together.

# 5. MediCinema

MediCinema is a service providing free cinema screenings for patients and the families caring for them. MediCinema aims to improve the experiences of patients in hospitals and the families caring for them by providing opportunities to spend quality time together watching a film. Currently there are six MediCinema sites:

- MediCinema in St Thomas' Hospital, London
- MediCinema in the Royal Victoria Infirmary, Newcastle
- Yorkhill MediCinema in Southern General Hospital, Glasgow
- MediCinema at the Serennu Children's Centre, Newport
- ICAP in Guy's Hospital, London
- CW+ MediCinema in Chelsea and Westminster Hospital, London

Cinemas screen the latest films including Disney movies. During our research, families mentioned films such as Dumbo, Aladdin, Frozen, and Mary Poppins among others.

## Key findings

**MediCinema provides a sensory and engaging experience,** escapism from a medical environment, and an opportunity to bond and interact for many children and their families.

**Most of the families interviewed reported positive feelings, increased social interactions,** and **closer bonding between families** as direct result of attending MediCinema. They also reported an increased sense of belonging and feelings of normality every time they visited MediCinema.

**Some families reported that MediCinema contributed to the children having an increased ability to cope with their illnesses and treatments as well as experiencing a better engagement with their health**. MediCinema enabled children to better comply with their treatments, provided stimulation and distraction from pain, and reduced negative feelings or anxiety levels, which supported children to cope better with their conditions. Some families reported their children having a much better response to their treatment and recovery than expected. One parent in particular reported that their daughter had a higher chance of remembering MediCinema despite her cognitive impairment and memory problems.

**Families reported that siblings experienced an increase in social interactions as well as an increase in quality time between family members and friends.** This was through siblings watching Disney movies together, but also through finding common interests and enabling the siblings to talk about the films they had watched with one another.

**Parents reported feeling resilient as a result of having some time dedicated to respite**. Some parents also reported a change in behaviour through introducing regular family times for their children, respite for themselves, and giving time through volunteering.

**All families reported recalling positive memories on a regular basis ranging from every day to a few days either on their own or with their family members and friends** leading to closer relationships with one another as well as enabling them to re-experience positive emotions.

Figure 5.1 illustrates the MediCinema ToC for children aged 2–6 and 8–12, siblings, and parent/ guardian. The ToC details the material outcomes verified through the interviews.

## Outcomes for the child

### Respite leads to positive emotions

Most families reported that their children experienced positive feelings from attending MediCinema. MediCinema provided a **break/ some respite,** and a form of escapism from the ward for the children. One child, M, reported that MediCinema made him "happy and a little better" whenever he visited. S who has been attending MediCinema since she was four years old and has visited it about "ten or eleven" times over the last two years reported that she felt happy about "leaving the hospital ward" to watch a movie and often collects tickets as a keepsake which could be used to evoke positive emotions in the future.

> "I enjoyed [MediCinema]; it made me smile…I enjoy watching the movies. I always get to keep a ticket." (Child)

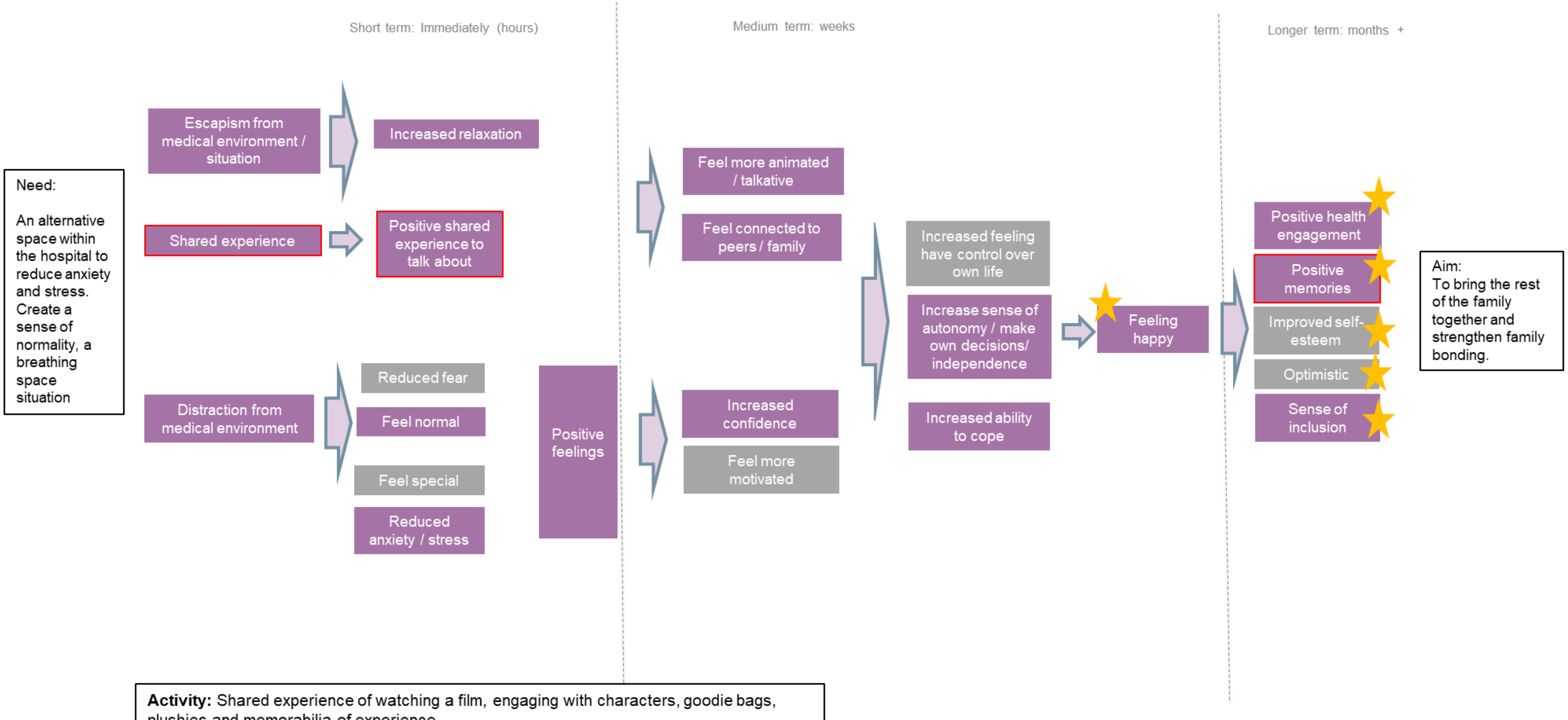
Both K and C reported that MediCinema boosted their daughters' moods as they had something to look forward to amidst all their medical treatments. C's daughter, P, was able to break up her week twice for a couple of hours to watch something and have fun in the process. Additionally, on the weekend, her sister and dad would visit to watch a film together as family to spend quality time together.

> "Without MediCinema, morale would have been a lot lower; each day would have gone slowly." (Mum)

> "It added a bit of looking forward to as a family. It has become part of her routine which helps with her social skills. For me seeing her, watching her face lights up, her being happy, that is quite great." (Mum)

> "Every Saturday morning they wait impatiently for those who bring them their tickets…this whole building is filled with things they hate like needles. Having one day to go to MediCinema is nice. They get out of their pyjamas and get dressed…[it] makes better memories of the building." (Mum)

*Figure 5.1: MediCinema theory of change*



Short term: Immediately (hours)

Medium term: weeks

Longer term: months +

Need:

An alternative space within the hospital to reduce anxiety and stress. Create a sense of normality, a breathing space situation

Escapism from medical environment / situation

Increased relaxation

Shared experience

Positive shared experience to talk about

Distraction from medical environment

Reduced fear

Feel normal

Feel special

Reduced anxiety / stress

Positive feelings

Feel more animated / talkative

Feel connected to peers / family

Increased confidence

Feel more motivated

Increased feeling have control over own life

Increase sense of autonomy / make own decisions/ independence

Increased ability to cope

Feeling happy ★

Positive health engagement ★

Positive memories ★

Improved self-esteem ★

Optimistic ★

Sense of inclusion ★

Aim:
To bring the rest of the family together and strengthen family bonding.

**Activity:** Shared experience of watching a film, engaging with characters, goodie bags, plushies and memorabilia of experience.

**Why:** The activities around the film showing deepen experience and deepen the memory e.g. reference to toys from the session kept by the child.

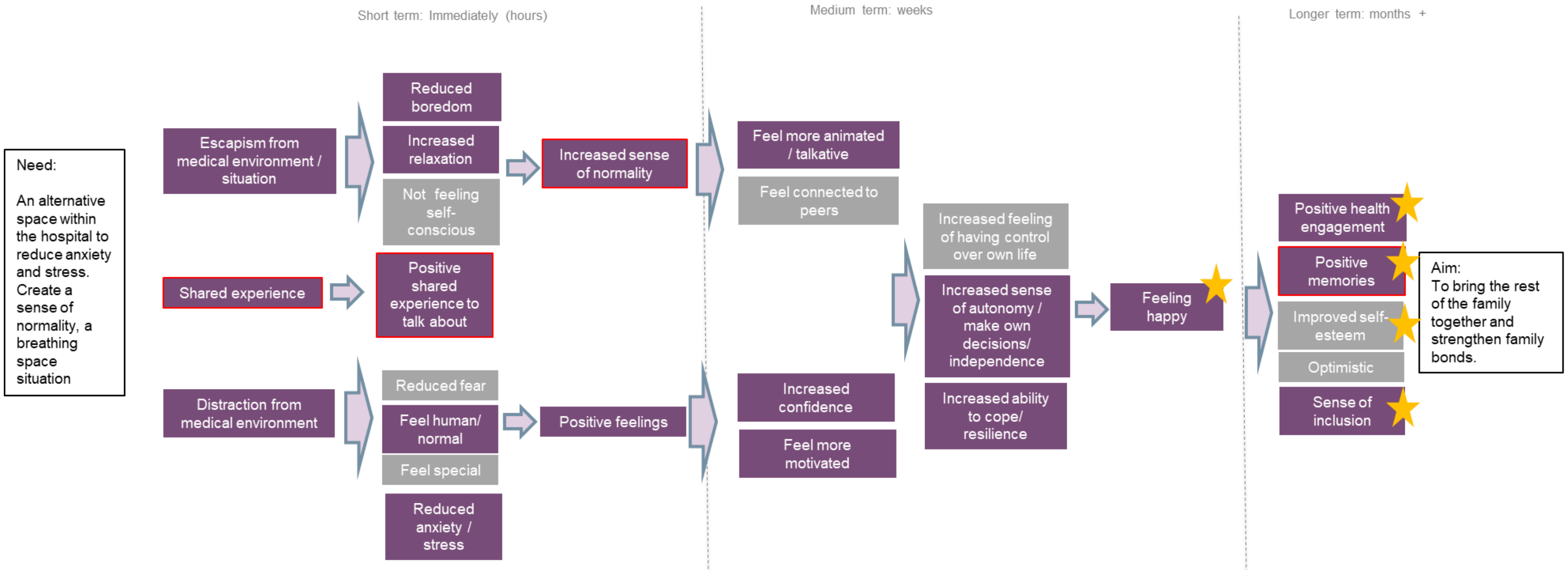
Deepening experience of Disney film shown with red border

Greyed out outcomes- unverified outcomes

★ Material outcomes

## MediCinema

## Stakeholder: Children 2-6 years old



Short term: Immediately (hours)

Medium term: weeks

Longer term: months +

Need:

An alternative space within the hospital to reduce anxiety and stress. Create a sense of normality, a breathing space situation

Escapism from medical environment / situation

Shared experience

Distraction from medical environment

Reduced boredom

Increased relaxation

Not feeling self-conscious

Positive shared experience to talk about

Reduced fear

Feel human/ normal

Feel special

Reduced anxiety / stress

Increased sense of normality

Positive feelings

Feel more animated / talkative

Feel connected to peers

Increased confidence

Feel more motivated

Increased feeling of having control over own life

Increased sense of autonomy / make own decisions/ independence

Increased ability to cope/ resilience

Feeling happy ★

Positive health engagement ★

Positive memories ★

Improved self-esteem ★

Optimistic

Sense of inclusion ★

Aim:
To bring the rest of the family together and strengthen family bonds.

## MediCinema

## Stakeholder: Children 8-12 years old

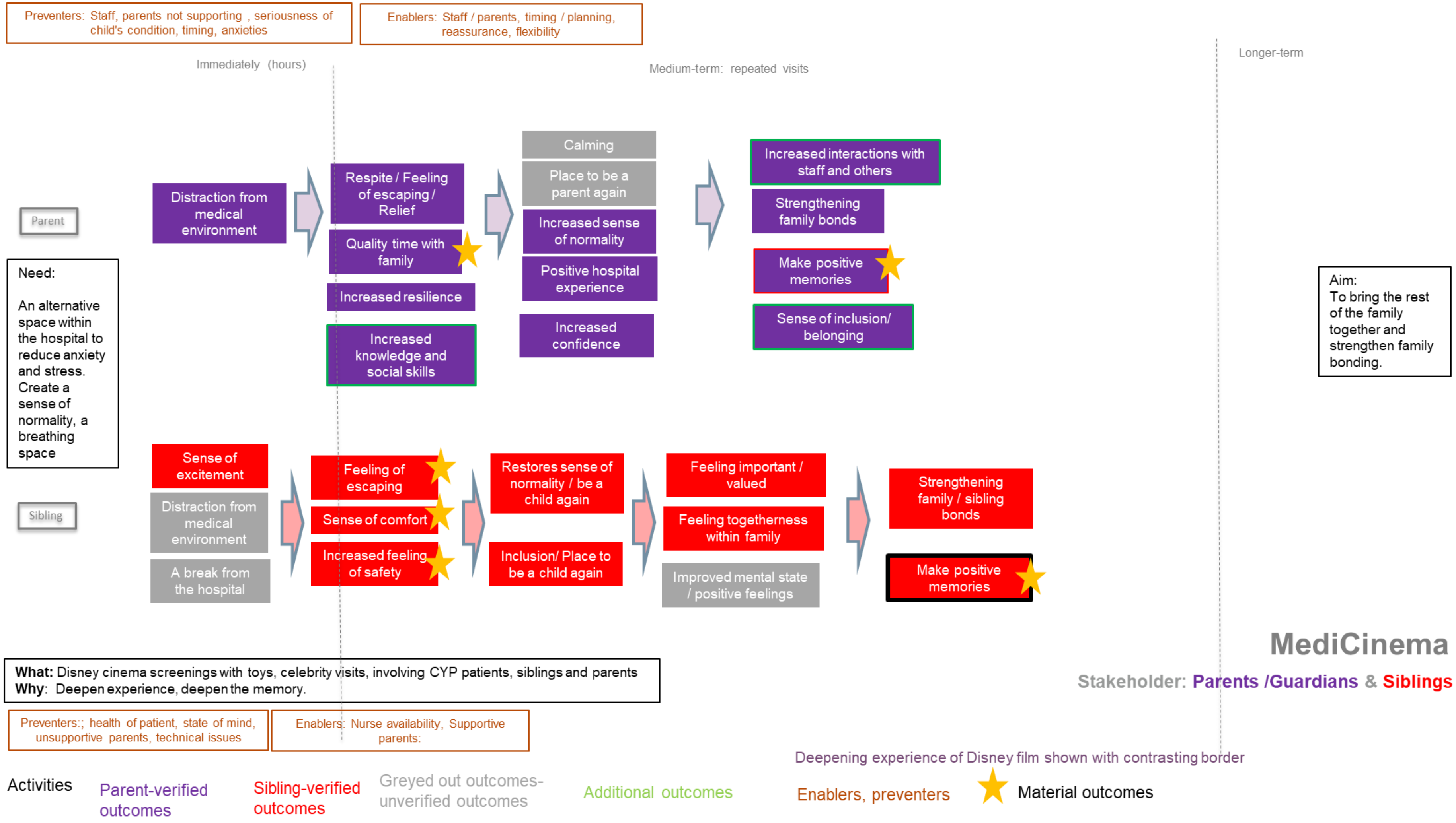
**Activity:** Shared experience of watching a film, engaging with characters, toys and memorabilia of experience.

**Why:** The activities around the film showing deepen experience and deepen the memory e.g. toys from the session kept by the child.

Deepening experience of Disney film shown with red border

Greyed out outcomes- unverified outcomes

★ Material outcomes



Preventers: Staff, parents not supporting , seriousness of child's condition, timing, anxieties

Enablers: Staff / parents, timing / planning, reassurance, flexibility

Immediately (hours)

Medium-term: repeated visits

Longer-term

Parent

Need:

An alternative space within the hospital to reduce anxiety and stress. Create a sense of normality, a breathing space

- Distraction from medical environment
- Respite / Feeling of escaping / Relief
- Quality time with family ★
- Increased resilience
- Increased knowledge and social skills
- Calming
- Place to be a parent again
- Increased sense of normality
- Positive hospital experience
- Increased confidence
- Increased interactions with staff and others
- Strengthening family bonds
- Make positive memories ★
- Sense of inclusion/ belonging

Aim:
To bring the rest of the family together and strengthen family bonding.

Sibling

- Sense of excitement
- Distraction from medical environment
- A break from the hospital
- Feeling of escaping ★
- Sense of comfort ★
- Increased feeling of safety ★
- Restores sense of normality / be a child again
- Inclusion/ Place to be a child again
- Feeling important / valued
- Feeling togetherness within family
- Improved mental state / positive feelings
- Strengthening family / sibling bonds
- Make positive memories ★

## MediCinema

Stakeholder: Parents /Guardians & Siblings

**What:** Disney cinema screenings with toys, celebrity visits, involving CYP patients, siblings and parents
**Why**: Deepen experience, deepen the memory.

Preventers:; health of patient, state of mind, unsupportive parents, technical issues

Enablers: Nurse availability, Supportive parents:

Deepening experience of Disney film shown with contrasting border

Activities

Parent-verified outcomes

Sibling-verified outcomes

Greyed out outcomes- unverified outcomes

Additional outcomes

Enablers, preventers

★ Material outcomes

### Increased confidence

Most families reported that their children had increased their confidence as a result of attending MediCinema. Furthermore, this increase in confidence then led to other outcomes such as **increased social interactions** and **increased independence**.

### Increased social interactions

Many of the children used the films they had watched as a trigger to start conversations with others including with hospital staff members. One mother reported that MediCinema has had a significant impact on her daughter's confidence and emotions. As soon as she watches a movie, she opens up and engages with people discussing what she has watched. She also reported that her daughter continues to be confident in other scenarios such as when they go to theatres outside of MediCinema. This was also true of the other families who reported their children feeling "less shy" and increased social interactions both within and outside hospital.

> "It is hugely positive. She goes [to the cinema] on the day, [and afterwards] she speaks about it for days if not weeks. She feels clearly grown up… it is a very special event. She gets a level of joy out of it…she is more confident [about] meeting new people. She was terribly shy when I first took her there…she met with other children, [like] Lidia. They got on like a house on fire. In paediatric wards the children cannot mingle. It is rare for her to meet other children in hospital. She was [a] great buddy." (Mum)
>
> [MediCinema] breaks the ice between the children in the ward. In the ward, children don't talk with one another, in the cinema they do, and seeing other children makes them believe that hospital is not quite [as] scary." (Mum)

One child reported that he became more confident in approaching people due to being able to build relationships with others when visiting MediCinema.

> "[I became] less shy, because I got to know the people there better. People are really friendly and make sure I belong there." (Child)

### Increased independence

Families reported their children's increased confidence, and this had a knock-on effect on their independence

> "At first [my daughter] was very scared of the cinema. We would never get through the door, and now each time we take her she gets more and more confident, and last time she went without [mum] and sat through the entire movie Dumbo [on her own]" (Mum)
>
> "[My daughter] became more confident and her confidence actually carried on outside [MediCinema]. She actually feels comfortable [at MediCinema]; she is

> confident and if she wants to go to the toilet, she does knowing that she will be safe. I would never allow her to do that [go to the toilet on her own] in other cinemas outside. I think she is quite vulnerable, but I feel a lot safer in [MediCinema]. MediCinema gave her more independence." (Mum)

**Quality time with family, siblings, and friends (increased bonding)**

MediCinema enabled families to spend quality time together. This was particularly important for those who had to be in isolation for a period of time due to their condition. MediCinema enabled both a closer bonding of families as a whole, as well as of siblings specifically.

For example, one child was very poorly when she was first diagnosed and had to be isolated in her room for six weeks. She could not see her sister during that time. The child reported that she was sad during this time: "I could not do much when I was poorly." Her mother reported that her daughter "had chemo, and none of it was pleasant. When she was able to leave the room, and the [doctors] said [she could] go out, it was such as countdown all week till Saturday." The child's sister and father would come to visit at weekends and the family introduced MediCinema into their routines. MediCinema provided an escape from the day-to-day difficulties for their daughter, and it helped to make up for the time the sisters stayed apart. The mother reported that she and her two daughters spent the time watching movies as well as "singing along to the Mary Poppins song the whole night".

Similarly, K (mother) reported her daughters using MediCinema to come closer together.

> "[MediCinema] is actually for them to go and watch [a movie] together. They look forward to going to the cinema, which is something they can bond over. Every Wednesday both kids, they bond a bit more" (Mum)

Furthermore, MediCinema has also enabled closer bonds between extended family members as well as friends.

> "I went with my brother, my cousins, my family friends, and sometimes with the other kids in the ward" (Child)
>
> [I went] with mum and other friends from the ward. Everyone gets to go to the cinema. I watched it with my friends [from school] and I sat right next to my friend" (Child)

**Increased sense of belonging leads feeling of normality**

Many of the families reported that their children had felt an increased sense of belonging as a result of MediCinema. MediCinema was something that grounded the families and provided them **with something familiar,** an environment where they felt they belonged.

> "We go [to the cinema] regularly at home [Leeds]. We had a movie night. [MediCinema] felt like an extension of what we do at home…the hospital became a

> second home for us. [MediCinema made [daughter] feel as normal as possible].” (Mum)

Similarly, one father reported that his son had always liked going to the cinema and the opportunity to continue to do this during a time when everything has changed was significantly important.

> “He liked watching any films; he is interested in Disney [and] used to go twice a week [to MediCinema]” (Dad)

**Increased resilience and better health engagement**

Some families reported MediCinema has contributed to an increased ability to cope with their illnesses and treatments, which led to a better engagement with their health. P’s mother reported that MediCinema helped P become more resilient and better able to cope with all the treatments. MediCinema was used as a reward when P complied with treatments and doctor’s recommendations.

> “It was used as some form of bribery. [I' say] if you drink this water today we can go to the cinema; if you are well and you drink water, we can go out” (Mum)

Other families reported that MediCinema helped their children cope better through experiencing positive emotions when watching films; it was a form of distraction from pain or lifted their mood. M reported being better able to cope with his feelings and health as a result.

> “When I watch the movie my pain starts to go away” (Child)

> “After the surgery, [my son] was sad and in pain. Staff then took him to the cinema [to watch Dumbo]. He became very joyous, [and had] wonderful time. We will never forget that time…he almost forgot about his pain, he was happy… [MediCinema] kind of removes your tension and your pain. You forget all about it when watching” (Dad)

> “The kids love it up there [MediCinema]. They get a bit of freedom from first floor [ward] to fourth floor [MediCinema]. It changed her hospital life. I think she would not have been able to cope in another hospital if they did not have one [MediCinema]” (Mum)

Two families reported that their children were able to cope better with their health and feelings through learning about how to handle and manage their emotions from the movies they were watching.

> “Her treatment makes her very tired and watching a movie makes her relax. Watching a film is not about the film, but also about emotions, the storyline Those films become part of her fairy tale. They provided another thing to think about… Some of the things brought up in films, the big emotions brought up in films,

> learning it is OK, that sometimes you are sad and sometimes things are bad. She was learning about emotions and managing [her] emotions as a result" (Mum)
>
> "All the films [she watches] allow her to express herself. She was singing and dancing on the way home from watching Aladdin, and [is] sad when we watch sad movies" (Mum)

**Better health engagement**

Some families reported their children having a much better response to their treatment than expected. The families attributed this to MediCinema and the positive emotions it enabled them to experience when watching films. Some of the children were in hospital and ICU for prolonged periods and the parents reported that the wards, although well run, did not provide a lot of stimulation. For one child this manifested itself in appearing sleepy and lax.

> "There's not a huge amount of stimulation or things to engage them on a ward. He benefits from all additional experiences, so we go and grab them." (Mum)

However when the children were taken to a more stimulating environment, they brightened up: "It's a sensory change from the clinical bright lights – night time, soft lights and a movie." For one child, this helped to increase their engagement levels. The parents also reported that being out of the ward seems to make their children healthier, need less medication. When they are out for prolonged periods (other respite care), they see results that are sustained.

For one child, this helped with checking the extent to which they had permanent damage from their illness:

> "He lost his speech and mobility; he had to learn his social skills again. Fatigue was a big factor. He had a brain injury and was very sensitive to sound. The cinema was a way to see how he would interact with sound. The staff gave him ear defenders to see how long he would last. He saw Peter Rabbit 2x [but] didn't see the full movie: the first time, he fell asleep but the second time he took off the ear defenders. The hospital then knew that he wasn't hyper-sensitive to sound and that he would recover."

MediCinema has provided opportunities for increased stimulation and learning associations to support a child with their memory problems.

> "Every time she goes there, she makes sure she brings something about the movie. Last night with Aladdin she knew there was a monkey, so she brought a monkey cuddly toy to watch Aladdin. For Peppa she brought a cat; MediCinema makes her think and prepare before getting there to watch the movie. She gets prepared for Wednesdays" (Mum)

Regular visits to MediCinema enables children to experience the hospital as a positive space leading to a reduction in anxiety levels. Positive associations with a hospital may lead to a better health engagement.

> "Going to a regular cinema, it is really nice to go to a hospital for something positive, not being about needles and blood that was important for her and for us. [MediCinema] changes her mind-set about what a hospital is about. She thinks of it as a place of treatment, [a] cinema, [a] pizza"(Mum)

**Increased knowledge/social skills**

One mum reported her daughter exhibiting increased independence because of feeling safe when at MediCinema. Furthermore, she stated that MediCinema played a role in teaching her daughter new rules and social skills and how to behave in public.

> "[MediCinema] is a safe environment. [She] is confident, speaks to nurses, [shows] independence through asking for water and going to the toilet [on her own]…[She] understands there are rules to follow like we are not allowed to eat, because another patient cannot have anything [at MediCinema]" (Mum)

**Increased physical activity**

One family reported that a movie they had watched with their daughter had a marked impact on her; she regularly attends ballet lessons as a result of a movie she had watched.

> "When we went to watch ballerina, she came out of ICU…she just shone to dancing. She was copying the dance on the screen. She made us laugh for half hour. It was nice to see her up and about and enjoying something….Six months later S attended ballet lessons and it is her favourite thing in the world" (Mum)

**Positive memory**

Most families reported recalling positive memories relating to MediCinema which continue to bring them closer to their families. The positive memories ranged from Disney movies they had watched at MediCinema such as Aladdin, Ballerina, Acquaman, Paddington Bear, and Peter Rabbit, and singing along to Mary Poppins with family member. All reported recalling these memories on a regular basis ranging from every day to a few days either on their own and/or with their family members and friends. This brought them closer to one another as well as enabled them to re-experience positive emotions all over again. Two families reported the impacts positive memories of MediCinema have made on their children who have cognitive impairment.

> "Even now, he still talks about Peter Rabbit. He can remember one scene where he sticks a carrot down Mr McGregor's trousers- he talks about this part which was 20 minutes in. His short-term memory was bad with the illness. We needed to see how it would recover. [It's] comforting to see he was talking about it in the short term and now the long term." (Dad)

Other families reported how MediCinema offers a sensory and engaging experience for the children, and offers the children the opportunity to be stimulated as well as to create memories together as a family. One family in particular reported their child going to the cinema from ICU with two other children.

> "The three of them had an absolute ball. The darkness with the lights, the colourful images, the chairs [they] were beautiful." (Mum).

## Outcomes for the siblings

**Family and sibling bonding which led to positive feelings and an increased sense of belonging**

All the families with siblings reported that MediCinema provided them with opportunities for their children to have fun and bond together. Most families reported that watching films was a form of escapism for the children. They enjoyed their time, with an increased sense of belonging/ normality at MediCinema. M reported she had not seen her sister for a month when her sister was taken to hospital. M always looked forward to visiting her sister at the hospital and would get excited about watching films at MediCinema

> "I was very excited to watch Bohemian Rhapsody…we were split up and seeing it with my family was like a normal thing to do" (Sister)

**Positive memory**

All families reported siblings often using the films they had watched in MediCinema as points of discussions with their siblings outside. Two siblings reported recalling the movies they had watched and talking about them with their siblings most days, while another two reported this happening occasionally/on a few days. One sibling, M, reported that her favourite memory about MediCinema was watching with the whole family together. She appreciated spending time with her mum and sister again: "We were all together, the atmosphere was nice, we were all excited." She reported often talking with her sister about MediCinema or the films they watched outside of MediCinema.

**Increased social interactions (with staff and others) and feelings of inclusion/belonging**

Increased social interaction and feelings of inclusion came through watching Disney movies together, but also through finding common interests and enabling siblings to talk about the films they had watched with one another. One sister reported she usually spoke to friends about MediCinema especially when she went to the cinema with them. She had also started encouraging her friends to donate to MediCinema.

> "I say there is a cinema in the hospital. Whenever they see [the MediCinema] advert in a cinema, my friends shout [in excitement]. I try to make them donate" (Sibling)

M reported she had a better relationship with staff and discussed the films she watched with the doctors sometimes, as they asked her about them; she found the doctors to be “a lot more friendly”.

## Outcomes for the parents /guardians

### Quality time with family (bonding) and positive feelings

Parents spoke of enjoying watching their children enjoy themselves, especially in contrast to being on the ward. They were able to watch films together and feel normal. One of the families does not know how long their son will be around: “We just do as much as we can with him.” For them, going to the cinema and other activities is a way of making the best of their time together.

Similarly, other families reported spending quality time as a family because of MediCinema and having an opportunity to take part in something normal. One mum noted: “MediCinema made sure we make that time as a family as well.” Another mum reported that every Wednesday was a “family time” because of MediCinema. “We actually watch it together with her. We love it. It is family time, every Wednesday.”

### Respite

Most parents reported that the break MediCinema provided was invaluable and that they looked forward to it. Parents who were interviewed talked about their personal experiences of attending the adult screenings. One parent described finding the cinema not long after their son’s diagnosis and watching *It’s a Wonderful Life*, part of their Christmas ritual. Although this wasn’t the ideal environment, they described finding it as delightful, and giving them 90 minutes of time out from what was happening all around them.

One mother reported that MediCinema provided some escapism for a couple of hours twice or three times a week. She would go to MediCinema twice with her daughter and on the weekend with the entire family. She also made arrangements so that the parents took turns to watch a film, targeted at adults, on their own.

> “[It was] amazing to go off for couple hours and not think about tubes, transplants, drugs. It was something to look forward to” (Mum)

### Better relationship with staff and increased interactions with others

Most families reported always having had a good relationship with staff; however, MediCinema provided them with opportunities to talk about issues outside of medical procedures. Similarly, watching the films at MediCinema also provided some parents with the opportunity to increase their interactions with others

> “It makes a difference. Doctors ask about the movies and you talk about it.” (Dad)
>
> “We get to know the nurses better; if [my daughter] needs something, the specific nurse comes to the cinema. [One time] my daughter had a blood clot in her leg, so

> the nurse came to the cinema to keep an eye on it. [It] is nice to have relationship that is not about being treated. [MediCinema] also improves her relationship with doctors, as they have something to talk about that." (Mum)

**Increased resilience**

Most parents reported they had a greater understanding of the importance of spending time on positive activities to improve their health as a result of the positive experiences they felt watching films at MediCinema. Additionally, one mum also reported she was better able to cope with her emotions as she had a greater understanding of the different medical conditions of other families at MediCinema and had started to put things into perspective.

> "I understand the need for everyone to have fun, downtime, a little boost. Treatment is a slog for all of us. [MediCinema] is a break for us, having a special time. It gives you excitement, and you recuperate;[it] gets you to keep going" (Mum)
>
> "It puts it in perspective, especially being in that environment. We are all enjoying the same thing even though we are all going through different issues health wise. I appreciate more what I have and appreciate my health a lot more" (Mum)

**Feeling of normality; increased sense of inclusion/belonging**

Some families reported that MediCinema is a very welcoming and safe environment enabling parents to feel normal, ensuring they do not miss out on experiences many take for granted. This has led families to experience an increased sense of belonging.

> "As a parent you see others in social media doing lots of things and you wish you could do some of that with your child. MediCinema allows you to do that. it gets everyone off that ward and have some fun" (Mum)

Families also felt a sense of inclusion due to the welcoming and accommodating environment of the cinema.

> "It is very special and lucky to [have] access it. The commitment of the staff is extraordinary. Whenever we are in the hospital, they come to tell her what is available [to watch] and encourage people to go. [MediCinema] is extraordinarily clean, well done and welcoming, especially because a child's immune system is easily compromised." (Mum)

**Positive memory leads to positive emotions**

Most families reported often recalling positive memories such as seeing their children have "fun or be happy" at MediCinema either on their own or with their family members and at times with friends.

One mother and her daughter had spent a lot of their time in the hospital away from their family who were based in Leeds. Time spent at MediCinema was even more important during Christmas holidays or birthdays. She stated that she cherished those memories, and reported she often reminisced about the special occasions she spent at MediCinema with her family, such as her own birthday, as well as with her friends, although to a lesser extent.

Another mother reported that watching her daughter get dressed up for Frozen was one of her favourite memories from MediCinema; she reported that her memories are sometimes triggered by things around her such as seeing a poster. Furthermore, she reported often looking forward to watching films at MediCinema as it triggers positive memories from her own childhood.

> “[I remember] Frozen. A dressed up for it. They also had people do face painting and balloons…MediCinema is something I also look forward too, like last night I too was singing along [to Mary Poppins]. It brings back happy memories from childhood even for me.” (Mum)

**Change in behaviour**

Three mothers reported  having changed their behaviour as a result of the positive impact they had experienced at MediCinema.

**Spending quality time as a family** has become a routine part of life.

> “We made an effort to do more movie nights, [to] make that a thing; we decided to have a day a week as a family. [It could be] a day of nothing. We will do stuff but do it together…a day of being together [The] kids make popcorn, re-enact [a] MediCinema experience, be cosy.” (Mum)

One mother reported she has started volunteering while another mother reported that MediCinema gave her the confidence to believe in her daughter’s independence and make time for herself.

> “I started volunteering in school ever since I found out about [my daughter’s condition] but in MediCinema I see so many different people and people with so many different conditions you become a lot more understanding and a lot more aware.” (Mum)

**Attribution**

On average, families attributed most of the change (74%) to MediCinema with four families fully attributing (100%) the changes to MediCinema. Some of the families also reported that they were also supported by nurses “who became family and friends than nurses”, staff at the hospital, friends, family, and other charities.

**Counterfactual**

Most families reported their feelings would have worsened with some families reporting that their confidence and their relationship with their family would have slightly worsened.

> "Whenever in hospitals you miss out on bonding moments. All I'm for her is a nurse. MediCinema enables us to have a mum and daughter thing [relationship]." (Mum)

Most reported that their relationship with their siblings would have stayed the same indicating the close relationship with them anyway.

# 6. Great Ormond Street Hospital Children's Charity

The research focused on the play team at GOSHCC. The play team provides a therapeutic service with a core aim of reducing anxiety and improving cooperation with treatments and interventions. The play specialists' knowledge of child development informs interventions for the therapeutic use of play in the child's experience of inpatient admissions, and the understanding of their condition and the treatments required. The stated core functions of the play team are to[5]:

- Create an environment where stress and anxiety are lessened.
- Help children and young people to understand why they are in hospital, and what will happen.
- Assist them to cope with illness, with being in hospital, and with treatment.
- Help them to regain confidence, independence, and self-esteem.
- Aid in assessment and appropriate treatment approaches especially in children with an autism spectrum disorder and learning disabilities.
- Speed up recovery and rehabilitation.
- Enhance a family's involvement in their child's care.

## Key findings

**GOSHCC interviewees have had difficulties speaking about activities that focused on Disney as most thought of the play team interventions as a whole.** Some interviewees reported Disney-specific activities such as games, which focused on Star Wars, watching movies on tablets, and visiting the reef.

**All the children interviewed mentioned both the reef and the activities they did with the play team as the source of their happiness and excitement when visiting the hospital.** Three of the children had Cystic Fibrosis, which meant they had times when they were isolated, and confined to their room; as such, they had missed out a lot on fun things. This made going to the reef when they got better even more exciting.

**All the children interviewed reported feeling happy about the play team. The staff in the play team became a focal point for children in managing tensions, supporting complex medical procedures, and providing a distraction to the ward**. Many of the children have known some of the play team workers since they were very young and have developed a strong relationship with some member of staff in particular. The children have also come to associate the hospital with fun activities.

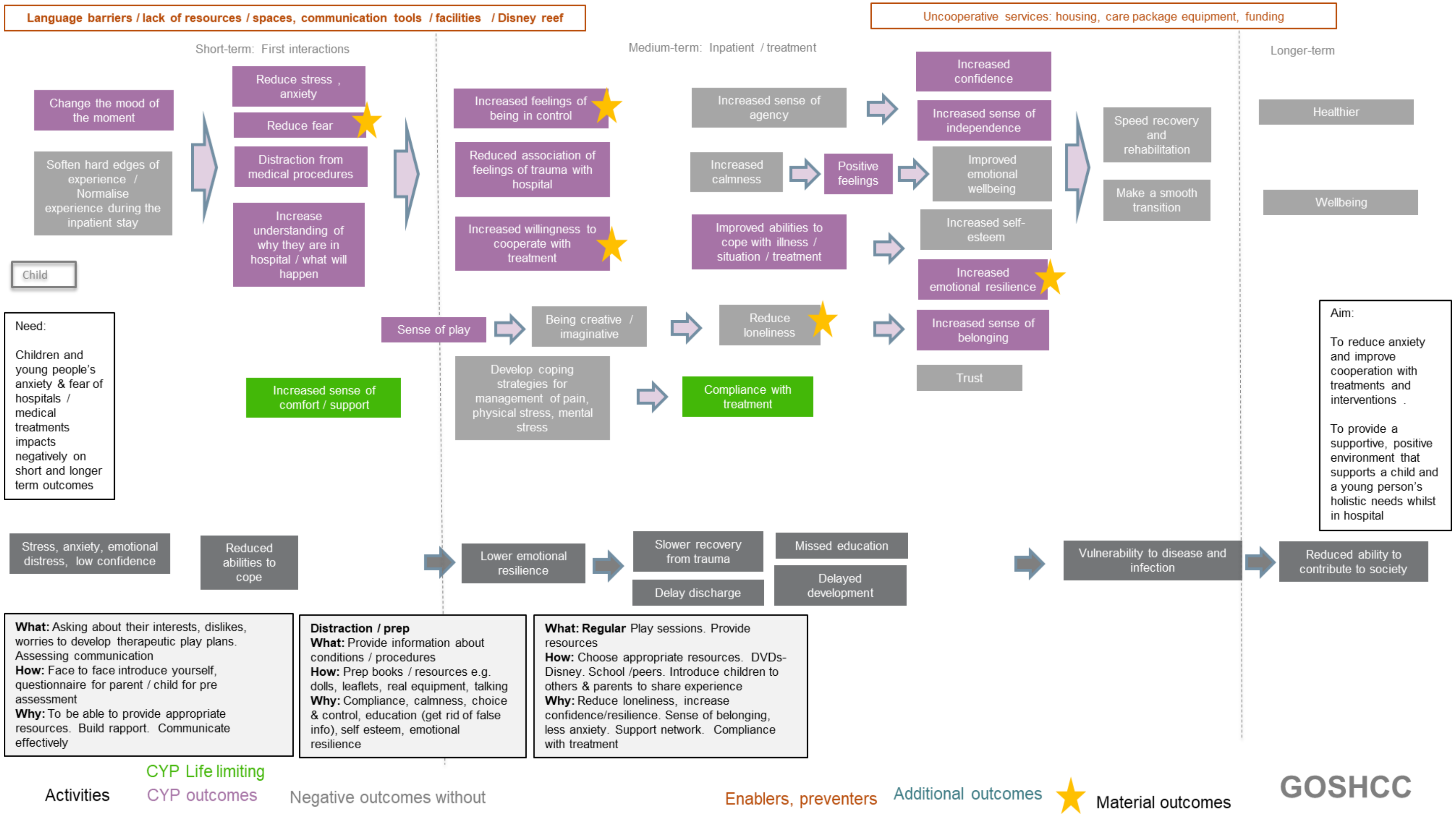
**Increased resilience or being better able to cope with treatments and emotions was highly dependent on the child's level of understanding and their condition.** For those children whose life-limiting conditions affected their cognitive ability, it was difficult to assess whether the interventions had an impact on their coping mechanisms. Other children reported being better able to cope with their treatments, as well as their feelings, as a result of increasing their understanding and reducing their fears about their treatments. Parents also stated that their children associated the hospital with fun things; this has reduced their stress levels and increased their ability to cope.

**The reef, the Disney tablet, and the fun Disney activities provided by the play team enabled the children to bond** with one another and feel an increased sense of belonging at the hospital.

**Most families reported recalling positive memories about their children's happiest moments at the reef** or when using the tablet to play games or go to parties organised by the play team. They talk about these experiences with their children, partners, and friends from time to time.

Figure 6.1 illustrates the GOSHCC ToC for the child, siblings, and parent/ guardian. The ToC details the material outcomes verified through the interviews.

*Figure 6.1: GOSHCC Play team Theory of Change*



**Language barriers / lack of resources / spaces, communication tools / facilities / Disney reef**

Uncooperative services: housing, care package equipment, funding

Short-term: First interactions

Medium-term: Inpatient / treatment

Longer-term

Change the mood of the moment

Soften hard edges of experience / Normalise experience during the inpatient stay

Child

Need:

Children and young people's anxiety & fear of hospitals / medical treatments impacts negatively on short and longer term outcomes

Reduce stress, anxiety

Reduce fear ★

Distraction from medical procedures

Increase understanding of why they are in hospital / what will happen

Increased sense of comfort / support

Sense of play

Increased feelings of being in control ★

Reduced association of feelings of trauma with hospital

Increased willingness to cooperate with treatment ★

Being creative / imaginative

Develop coping strategies for management of pain, physical stress, mental stress

Increased sense of agency

Increased calmness

Positive feelings

Improved abilities to cope with illness / situation / treatment

Reduce loneliness ★

Compliance with treatment

Increased confidence

Increased sense of independence

Improved emotional wellbeing

Increased self-esteem

Increased emotional resilience ★

Increased sense of belonging

Trust

Speed recovery and rehabilitation

Make a smooth transition

Healthier

Wellbeing

Aim:

To reduce anxiety and improve cooperation with treatments and interventions.

To provide a supportive, positive environment that supports a child and a young person's holistic needs whilst in hospital

Stress, anxiety, emotional distress, low confidence

Reduced abilities to cope

Lower emotional resilience

Slower recovery from trauma

Delay discharge

Missed education

Delayed development

Vulnerability to disease and infection

Reduced ability to contribute to society

**What:** Asking about their interests, dislikes, worries to develop therapeutic play plans. Assessing communication
**How:** Face to face introduce yourself, questionnaire for parent / child for pre assessment
**Why:** To be able to provide appropriate resources. Build rapport. Communicate effectively

**Distraction / prep**
**What:** Provide information about conditions / procedures
**How:** Prep books / resources e.g. dolls, leaflets, real equipment, talking
**Why:** Compliance, calmness, choice & control, education (get rid of false info), self esteem, emotional resilience

**What: Regular** Play sessions. Provide resources
**How:** Choose appropriate resources. DVDs-Disney. School /peers. Introduce children to others & parents to share experience
**Why:** Reduce loneliness, increase confidence/resilience. Sense of belonging, less anxiety. Support network. Compliance with treatment

Activities

CYP Life limiting

CYP outcomes

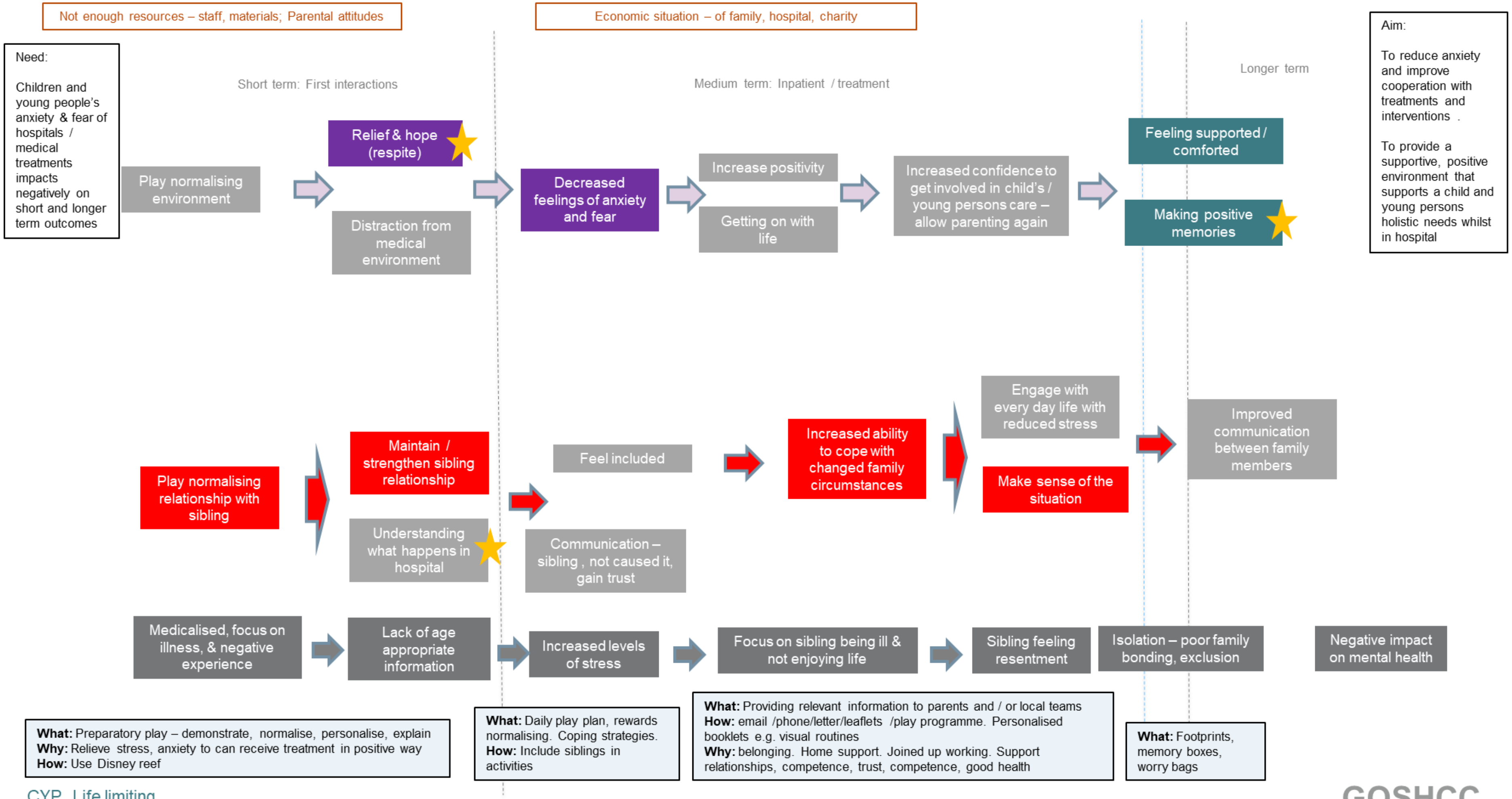
Negative outcomes without

Enablers, preventers

Additional outcomes

★ Material outcomes

GOSHCC



Not enough resources – staff, materials; Parental attitudes

Economic situation – of family, hospital, charity

Need:

Children and young people's anxiety & fear of hospitals / medical treatments impacts negatively on short and longer term outcomes

Short term: First interactions

Medium term: Inpatient / treatment

Longer term

Aim:

To reduce anxiety and improve cooperation with treatments and interventions .

To provide a supportive, positive environment that supports a child and young persons holistic needs whilst in hospital

Play normalising environment

Relief & hope (respite) ★

Distraction from medical environment

Decreased feelings of anxiety and fear

Increase positivity

Getting on with life

Increased confidence to get involved in child's / young persons care – allow parenting again

Feeling supported / comforted

Making positive memories ★

Play normalising relationship with sibling

Maintain / strengthen sibling relationship

Understanding what happens in hospital ★

Feel included

Communication – sibling , not caused it, gain trust

Increased ability to cope with changed family circumstances

Engage with every day life with reduced stress

Make sense of the situation

Improved communication between family members

Medicalised, focus on illness, & negative experience

Lack of age appropriate information

Increased levels of stress

Focus on sibling being ill & not enjoying life

Sibling feeling resentment

Isolation – poor family bonding, exclusion

Negative impact on mental health

**What:** Preparatory play – demonstrate, normalise, personalise, explain
**Why:** Relieve stress, anxiety to can receive treatment in positive way
**How:** Use Disney reef

**What:** Daily play plan, rewards normalising. Coping strategies.
**How:** Include siblings in activities

**What:** Providing relevant information to parents and / or local teams
**How:** email /phone/letter/leaflets /play programme. Personalised booklets e.g. visual routines
**Why:** belonging. Home support. Joined up working. Support relationships, competence, trust, competence, good health

**What:** Footprints, memory boxes, worry bags

CYP Life limiting

GOSHCC

Parent outcomes Sibling outcomes Negative outcomes without Greyed out outcomes- unverified outcomes Additional outcomes ★ Material outcomes Enablers, preventers

## Outcome for the child

### Positive feelings

All the interviewed children mentioned both the reef and the activities they did with the play team as the source of their happiness and excitement when visiting the hospital. Three of the children had Cystic Fibrosis, which meant they were isolated, confined to their room when they were poorly; as such, they had missed out a lot on fun things. This made going to the reef when they got better even more exciting. One parent described the reef as a safe and relaxing place, away but not too far from support.

> "After the reef had been created, she loved it. She loved the colours. [We] spent quite a long time taking photos. Every time we go to hospital, she wants to visit the reef." (Mum)

Similarly, all the children reported feeling happy about the play team. The staff in these teams became a focal point for children in managing tensions, supporting complex medical procedures, and providing a distraction to the ward. Many of the children have known some of the play team workers since they were very young and have developed a strong relationship with some members of staff. The children have also come to associate the hospital with fun activities. B, a mother reported her son used to watch movies and play games on the tablet that was provided to him by the play team at the hospital. E reported that he enjoyed playing Lego Star Wars games with the play team and feeling happy during that time.

> "They gave him [a tablet] to play games. Once he was out of surgery they gave him that to play and have fun and make him happy…he watched movies and played games on it. The app made him feel well and happy when he used it." (Mum)
>
> "[I liked] playing games, Star Wars…they [the play team] are fun, funny and nice. They let me use tablets. They are always nice to me…[my favourite thing] was playing Lego Star Wars. [It made me feel] happy." (Child)
>
> "He loves [the play team]. You see a big smile on him as soon as they come into the ward. The play team are always consistent, so he knows them really well. He knows that [seeing] the play team means he is going to have fun, not just horrible thing being done to him." (Mum)

The play team also organise birthday parties for the children, and sometimes the siblings as well. This is appreciated not only by the children but also by the parents/guardians making the whole family feel valued and included.

> "Her birthday party was organised by the play specialists. She had a very big party in the play area with the doctors and nurses. We were close to the team." (Mum)

### Increased resilience, increased feeling of control, and better engagement with their health

Increased resilience or being better able to cope with treatments and emotions was highly dependent on the child's level of understanding and condition. For those children whose life-limiting conditions affect their cognitive ability, it was difficult to assess whether the interventions had an impact on their coping mechanism. Other children reported they were better able to cope with their treatments as well as their feelings; having better coping mechanism as a result of accessing positive, fun experiences has supported the children to better engage with their health. This may have also given them a feeling of increased control over their lives. The children mostly reported two reasons for being able to cope better:

### Coping better through increased understanding which leads to getting over their fears

The play team made a significant impact on the children's lives enabling them to better engage with their treatments by reducing their fears and increasing their understanding of their treatments.

Parents were able to describe how members of the play team helped the children to be less fearful of tests and procedures. They sat with them through procedures and were able to reduce fear and increase willingness, something that the parents didn't feel able to do.

> "[Having them there] takes the anxiety away. [They] know it's going to be okay. At home we have a battle with the tablets; when we're going there, we don't worry about it as [they] have entertainment." (Mum)

The play team often uses stories the children care about, such as Disney movies, to engage them with their treatment. One example is with E, a 9-year-old who had undergone a brain surgery to remove his tumour. The play team had a key part in his preparation for surgery to lessen his fears. E has always been into Star Wars and the play team used the movie as an analogy to explain what the doctor would be doing during the surgery. The bad cells in E's brain were likened to the Stormtroopers and the good cells were Yoda trying to fend them off, but Yoda got tired and needed the doctor's support. E got into the story and was prepared for his surgery. He ended up having further treatment and another surgery. At the time of the research, E could not remember this incident, but remembered the games that he used to play with the play team which still centred on Star Wars, in particular Lego Star Wars, which continued to help him in his recovery.

> "They keep playing with him. They make him happy. They helped him recover from being down, recover quick from the pain. They made him stand up from his lying bed, and he was really happy. They used some toys. I am not really good with Disney and all that, [but] he was so happy." (Mum)

> "[The play team] make me laugh, be strong and happy. They make me strong by making me walk to the play room and have fun." (Child)

> "[The] play team would come to the room where he was lying and encourage him to get off [the bed]. [They'd say] 'oh, let's go to the play room, you are going to play all kinds of play', so he has more courage to get off and play. What they do [has an]

> impact on the medication and his medical stuff. It had [a] positive impact on him, because if he is having medication without trying to do stuff, it cannot work. It has really given him confidence." (Mum)

Other families also reported that their children were better able to cope through reducing their fears.

> "They are far more able to do things that the doctors need them to do [because of the play team]. The play team supported the doctors and nurses. My daughter used to scream and scream, and [the play worker] worked with her. Now she no longer screams, now it is bearable for her." (Mum)

> "They don't feel scared. [The play team] have been with us." (Mum)

**Coping better through distraction from pain**

The play team distracting the children while they are getting their treatment or the children's anticipation of fun such as playing at the reef once they comply with treatment has led children to better engage with their health.

> "She got over [her] needle phobia [and fear of] swallowing tablets. Cinderella came when she got her PICC line out. She felt special when [that] horrendous thing was being done to her." (Mum).

> "When I have tests, I don't enjoy them…I know the play team are there for me, and there is something to enjoy after." (Child)

> [The play team] are very good with their techniques. [They help] through play and distraction, using their imaginations. Emotionally it helps [the children] deal with what they have to go through at the time. They go through adult things at a young age. [The play team] help motivate, and cope, come to terms with it…play specialists are vital for the kids" (Mum)

**Increased confidence**

Some parents reported the children were able to improve their confidence through taking part in fun activities leading to a reduction in their anxiety and experiencing the hospital as a positive space. E also reported that he felt confident when spending time with the play team as a result of not being left alone in his room and "getting silent all the time", while another child reported his confidence would have significantly worsened if he had no opportunity to play in the reef.

> "F has always been with me because of her long-term condition. She has never been to a mainstream school; she has been in protective isolation. The play team were making her feel confident away from me. She was proud of cooking, learning how to offer food on trays, how to share [her] cooking. She increased her independence and her confidence in herself." (Mum)

**Increased family/sibling bonding**

Families reported they were able to have better communication and quality time together thanks to the reef, the tablet/Disney life app, and the play team's interventions. For example, two children reported they enjoyed spending quality time together at the reef with their mother. The reef enabled them to play and have fun together, which led to a reduction in stress for them as well as their mother. One mother reported the relationship between her children improved thanks to the play team who organised activities and helped them interact; this was significant as the sibling had been apart from months due to hospital stays and the play team ensure "they have a normal brother sister relationship".

> "Every time we are in hospital, we visit the reef, and we see the play team at least once a month. Both children love playing games with the play workers and volunteers. They love the reef. [The] play team comes around daily; they are our life line for us." (Mum)
>
> "We used to watch Disney movies on the tablet; both were sharing it, it made them have fun together and happy." (Mum)

**Increased sense of belonging**

Families reported their children feeling valued by the play team. They not only organised fun activities but also tried to determine what the children enjoyed the most. One child reported his favourite movie was Star Wars and as a result he was able to play the Star Wars game on the tablet as well as play Lego Star Wars with the play specialists. One parent suggested the consistency of seeing the same faces all the time is valuable for the children, as it gives them an increased sense of belonging.

> "One play worker, Lizzie, knows both children since they were little, nearly 10 years. The children look forward to seeing her, the consistency is good." (Mum)
>
> "[My daughter] looks forward to play with [the play worker]. It is an instant smile when she comes in. Even a short visit is worthwhile. She feels like she is listening to her and her needs and feelings are respected." (Mum)

**Positive memory**

Most families appreciated the play team not only in providing them support at the hospital but also making nice memories for them. Two mothers reported the play team organising birthday parties for their children, referring to them as "magical", whilst two children reported their favourite memory as playing in the reef.

> "[My fondest memory is] the reef. I love the reef. It is pretty. I like the colours. Maybe we can make more heroes like more princesses, Moana, Frozen, Moana's pig, Maui beach." (Child)

E reported his happiest memories as when he spent time playing Lego Star Wars with the play team. He reported that he missed the play team and recalled those memories "every day" on his own. Another child recalled a memory from when she was much younger. Two siblings and another child reported often recalling those memories and talking about it with one another, as well as their parents and friends.

One family were visited on the ward by Disney characters which the child loved, as it was her favourite character at the time. They still have a picture of this day. They were able to describe in-the-moment enjoyment.

### Hospital as a positive space

Some parents reported their children experiencing the hospital as a positive space often "associated with fun", including for siblings, due to the positive feelings they are able to experience. One child reported inviting her friends to the hospital to have fun with them at the reef, while another reported being always made to laugh and have fun which "[made] everything easier".

> "The play team made the hospital not a scary place. When she leaves, she does not remember the treatment, she remembers a cool place. She forgets all her pain and says can we stay in the hospital again. It is incredible." (Mum)
>
> "My friends come to visit me at the reef on Sundays and Saturdays; they love it." (Child)
>
> "Everything is less stressful as [the] children are looking forward to coming to the hospital." (Mum)
>
> "When we go to other hospitals, F hates it. She loves GOSHCC because of the play team and the reef." (Mum)

## Outcomes for the siblings

### Increased inclusion and positive feelings

All of the families with siblings appreciated that siblings were fully included and had access to the same interventions and activities available for the children with life-limiting condition, making them part of the "ward family", and leading them to feel valued and included. Siblings had opportunities to experience positive feelings such as happiness, excitement, and relaxation. This was mostly through visiting the reef, meeting Disney characters, using the Disney life app, and playing games with the play teams.

> "I like the ship in the reef. I like climbing up it." (Child)
>
> " F uses the Disney app quite a lot when I am in meetings just to chill for an hour and watch movies and play games." (Mum)
>
> "They met with characters lots of time. At Christmas she saw Winnie the Pooh and Snow White. She loved it." (Mum)

**Increased resilience and positive feelings leads to better coping mechanisms**

All families with siblings who took part in the research reported the play team were vital not only for their children with life-limiting conditions, but also their other children who often felt left out, believed the focus was on the other sibling, and felt isolated and anxious about what was happening with their siblings. The siblings were able to cope better with staying in the hospital and deal with their sibling's treatments as a result of the **positive** distraction and escapism provided through the Disney app. They used it to watch movies and play games. They visited the reef took part in fun activities with the play team. Siblings reported a reduction in their anxiety and fear through an increased understanding of what was going around them.

> "The play team were important, particularly for F. They were so important in helping her to learn to cope with her brother's needs. There is no team to do this in this kind of way. When [my son] had problems and had a cardiac arrest, the play team would come and take [my daughter] away and play with her." (Mum)

One mother reported that her daughter was able to better cope with her brother's condition as a result of an increased awareness of it. This led her to become less nervous and increase her confidence and become happier.

> "When a PICC line or different things need to be done…, the play team brings dolls to explain what is about to happen, or the tablet to try to make the kids laugh. When we are going through something difficult, they are holding our hands through it." (Mum)

**Increased bonding with family/sibling**

The opportunity to have fun and find happiness during a difficult time as well as increase their understanding has enabled siblings to have better relationships with their family. Families reported that their children would have "felt resentful" and jealous and the relationship between their siblings and their parents would have worsened without the opportunity to access positive experiences in the hospital.

Examples of accessing positive experiences which enabled closer bonding between families and siblings included playing in the reef together as well with their mother which they often do every time they visit the hospital.

> "We play together in the reef [with my little brother]. It makes us a bond better." (Child)

**Hospital as a positive experience**

Some parents reported their children experiencing the hospital as a positive place, including for siblings. One child reported that his favourite activity and fondest memory was going to the reef and playing with his sister. He reported he was neither happy nor sad before the reef, but very happy after visiting the reef. One mother reported her daughter enjoying herself at the hospital with the help of the play team as well as the Disney app, without it, her experiences would have been "stressful".

## Outcomes for the parents /guardians

### Respite leads to positive feelings and reduce stress/increased coping mechanism or resilience

Some families reported the designated areas for play such as the reef or the fun interventions by the play team provide some respite for the families from their daily struggles, leading them to be calmer, reduce stress and experience positive feelings when they see their children having fun.

> "Every time we are in hospital, we visit the reef, and we see the play team, at least once a month. Both children love playing games with the play workers and volunteers. They love the reef. The play team come around daily; they are our lifeline for us. I know the hospital experience would be completely different without the play intervention. It is just as important as the medical intervention."

### Better communication with staff and others

The majority of families reported that when their children were distracted with fun activities, they were also able to become calmer and less stressed and this in turn enabled them to improve their relationships with others. It mainly improved their ability to have a better relationship with the staff as they were able to communicate effectively.

> "The positive thing [is] it helped us to have better communication [with others], because we are more relaxed and happier and as a consequence you have a better relationship with everybody else." (Mum)
>
> "When I am calmer, I have positive things to talk about with others; everything is a little better." (Mum)

### Increased family bonding

Families were able to spend quality time together with their children leading them to create positive memories together. Two mothers reported that they regularly spend time at the reef with their children, while another two reported that the play team gave them the opportunity to spend quality time with their children.

> "Our [daughter and mother] relationship changed for the better. No one can be switched on happy [given] such extreme circumstances." (Mum)

### Positive memories

Most families reported recalling positive memories about their children's happiest moments at the reef or when using the tablet to play games or attend parties organised by the play team and talk about them with their children, partners, and friends from time to time.

> "F's first birthday party on the ward [was] the best ever, and it was not the only one [the play team] organised. There were more. It is a memory I will never forget." (Mum)
>
> "[The play worker] coming in when Ava was three. Lizzie was sat with Ava with the tablet. Ava was amazed by it and I loved it. [It] was a special moment." (Mum)

### Attribution

On average, the families attributed 75% of the changes they experienced to the play team. Families mentioned that other staff members such as "the nursing staff's caring manner" had also brought many positive changes to her children's lives.

### Counterfactual

The majority of the families reported that their feelings and relationships with their families would have worsened without the support provided by the play team.

Two children reported that their relationship with one another would have slightly worsened as they enjoy playing at the reef together. One child also reported that her relationships with her friends would have slightly worsened as they currently enjoyed getting together with them in the reef. Four children reported that their feelings would have worsened significantly without the play team.

Two mothers also reported that their children's confidence would have worsened without the play teams.

> "Her confidence would have significantly worsened. [My daughter] is shy and nervous with strangers, but knowing the same people in the play team helps. She becomes more positive. Even if something bad happened, she knows she has Lizzie." (Mum)

# 7. Together for Short Lives

Together for Short Lives is a UK charity supporting seriously ill children and their families to make the most of every moment they have together.

Four families took part in the research, one of whom attended a Disney party, while the others reported that the hospice events and parties they had attended had Disney themes and characters. Two of the families had lost their child in 2010 and 2014. Of the four families, one predated Together for Short Lives Disney-themed parties, and started attending the hospice events and parties after their child had passed away in 2010. The second family attended the hospice parties and events between 2005 and 2014 when their child son was alive.

## Key findings

**The families reported the parties had provided opportunities for a break and an escape from the daily struggles and medical procedures the family were going through.** Despite the children's cognitive abilities, the parents could tell the positive impact the parties had on their children by assessing their children's body language such as "smiling" and "looking comfortable". The families are going through a challenging time and despite this, the parties offered them the opportunity to experience some semblance of normality.

**It was difficult to assess the resilience/better coping mechanisms outcome due to the condition of the children; however, some of the families reported their children experiencing a break from a focus on constant pain and negative feelings** such as "screams" to experiencing positive feelings. This inadvertently may reduce their stress level leading to better coping mechanisms in their day-to-day lives.

**The majority of the families reported that the siblings benefited the most from these parties.** They are often isolated and miss out on many things due to their sibling's medical condition.

**Siblings also spent time with other children going through similar circumstances, leading them to feel an increased sense of belonging and less alone**. This can support them to adopt a better coping mechanism with the loss of their sibling through attending the hospice events.

**One of the driving forces of attending these events for most families was to make as many good memories as possible before their loved one passed away**. The photos and gifts they receive at these parties are often used to recall positive memories and used as an engagement method to keep a close relationship with one another.

Figure 7.1 illustrates the Together for Short Lives ToC for the child, siblings, and parent/ guardian. The ToC details the material outcomes verified through the interviews.

## Outcomes for the child

### Uncertainty of outcomes

Assessing the children's outcomes was challenging due to the children's conditions.

K explained her child's condition is quite severe which means she is significantly delayed in her cognitive development; as such, it is very hard to tell what S is thinking. Similarly, C also had a severe cognitive disability, and his mother reported observing her child's body language to assess whether he was enjoying his time.

### Positive feelings and feeling valued and included

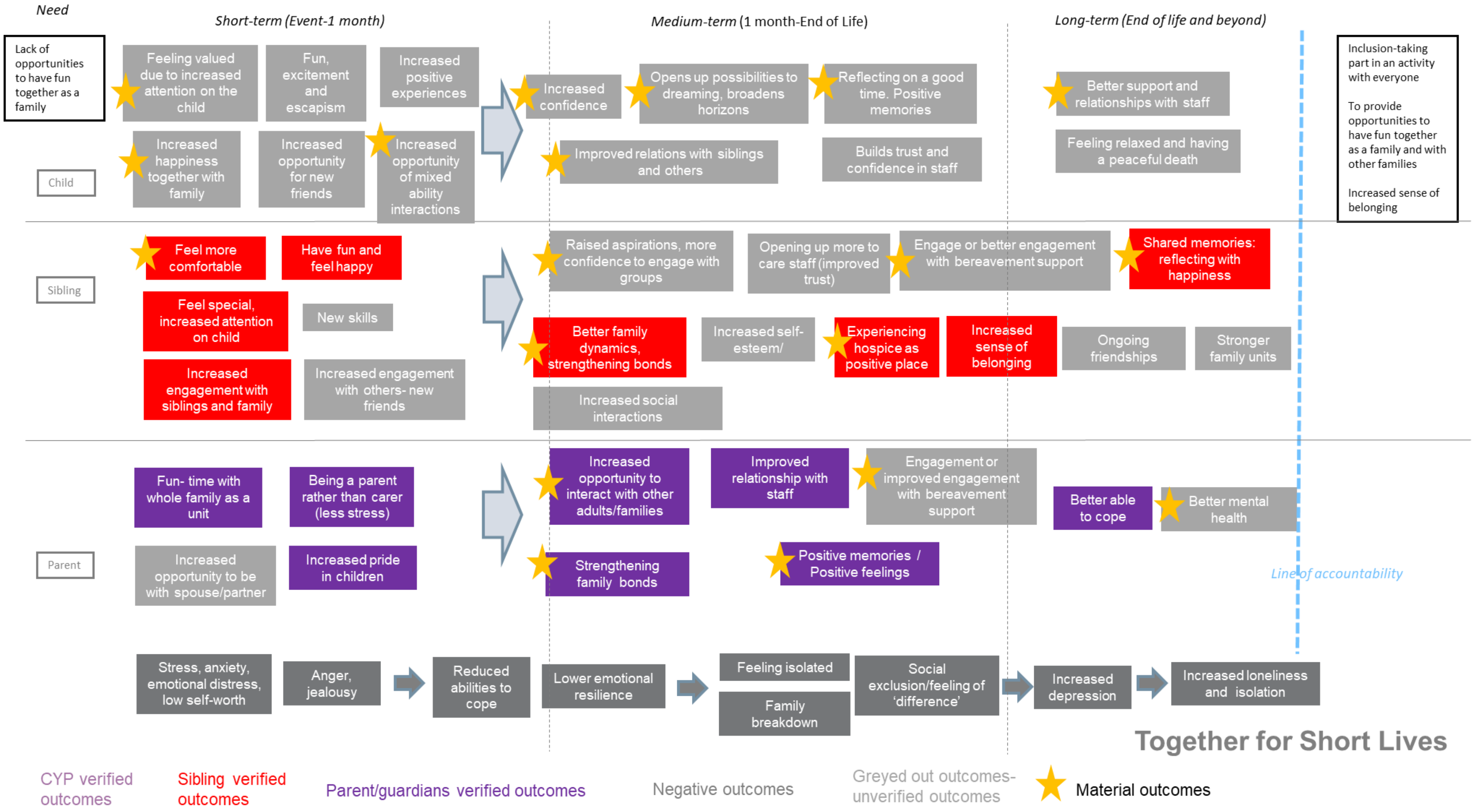
Hospices put on multiple events over the year where children and their families have a chance to play, relax, and spend time with others. The families reported these parties provided opportunities for a break and an escape from the daily medical procedures. Two families had Disney-themed parties, while the third family reported that although they did not attend Disney-themed parties, most of the parties they had attended had gifts, toys, or characters associated with the Disney brand.

Two of the families reported that their children had a severe cognitive disability so while it was difficult to properly assess their feelings, both parents reported that the parties brought comfort and contentment to their children.

They reported that the positive feelings their children were able to experience despite their cognitive abilities and provided opportunities of feelings of 'normality' despite the context. One mother reported that it is difficult for her daughter to demonstrate emotions like excitement or "express great joy" due to her severe cognitive disability. However, her daughter, S, "looked content" at the party and was comfortable. Similarly, J reported that her son had a severe cognitive disability before he passed away, yet despite this, she could tell he enjoyed the parties he had attended "through his body language such as smiling".

> "C was ill all the time. He did not get any chance to be a little boy. [The parties] meant I could watch him enjoying himself. He would smile. I knew he was having a good time." (Mum)
>
> I could watch them [both sons]. It was our normal. Things like that [events] meant we could do it [take part in normal things]. We probably would not be sane if it had not been for that [the event]."
>
> "It felt like there was light at the end of the tunnel, one that did not involve invasive procedures, just being a kid. [He had] become a medicalised patient, so seeing him being a kid and smile and relax is huge. You cannot buy that. That is why it is so special." (Mum)

*Figure 7.1 Together for Short Lives*



### Increased family bonding

All families reported that the events accommodated them and enabled them to bond over fun activities or positive experiences. One mother reported that these events provided opportunities for her child to be the centre of attention and feel special. Additionally, the whole family got to take part in fun activities together as a family.

One of the families who had attended a Disney-themed party stated the event was fun for the family. The party included the volunteers dressing up, themed cakes, a film, and a gift pack. The family described how this party, and other days are a lot of fun for all of them. Offering a chance to relax together, these events are for all of the family and each person is aware of that.

> "Events grab the whole family; it's not just mum and baby. It's a treat. That [event] was a couple of years ago, but [the children] still remember the gift pack, the teddy, the Frozen DVD, stickers. They've all been used since." (Mum)
>
> "We get to do nice things. It [is] not all doom and gloom. It adds lovely things into our lives." (Mum)
>
> "If events like these weren't happening, it would make our lives less rich. Having these things is like everyone is out there doing it with you. You got support if you were just battling away. I got friends in other countries. They don't have support. I got a friend in Luxemburg. She has [not] got anyone to help her with her son who is even sicker [than S] and her mental health is suffering. She does not have all these nice things to go to; she is going downhill, depressed. [The parties] just make your life happier. Life is made up of nice moments. It is important to me. Those moments, I am capturing them you know. Those are the most important things. It is not about money; it is about people enjoying each other, having fun and knowing you are supported." (Mum)

## Outcomes for the siblings

### Positive feelings/escapism

Most families reported that the events were a place for children, including siblings, to enjoy the space. One mother reported the events had mostly impacted on her other son (sibling) who would enjoy himself and "had no care in the world" at these parties. She also reported that her daughter had missed out on a lot of things when she was his age and these parties remedied this. The parties provided a form of escapism from the day-to-day routines, which centred on their sibling's medical procedures

> "P got stuck in [and] enjoyed having fun. There [were] other siblings as well [at the party]… he did not have to think about what was going on [medically with his brother]. Just for a minute, he could just be a kid…it was quite often I had to whisk

> him out of bed at 4 am because C was unwell and that was unfair. [At the party] P had no care in the world at that point. That sums it up." (Mum)
>
> "E looked happy and excited [and] calm. She loves being around people, having her sister there. We got lovely photos of the day… there was lovely food with [a] Frozen cake on it [and] balloons. We got [a] few toys and we still put [the] Frozen [toy] one in her bed." (Mum)

**Increased sense of belonging and social interactions**

All four families reported the importance of their children spending time with other children in similar circumstances, particularly for those who had lost their sibling. The parties and events provided the opportunity to be understood and feel less isolated during a difficult time. They also increased their sense of belonging.

Such events help siblings to build friendships with other children in similar circumstances. Additionally, the hospice events are a place for siblings to engage with what it means to have disabilities or different abilities. It can help them to better understand their siblings and be less conscious of what it means to be with someone with additional needs: in the hospice, it is normal.

> "On the first visits she saw a teenage girl in a wheelchair who was blind. She ran over, touched her wheelchair and spoke with her. In that environment, she met other kids with disabilities, and it becomes normal. She knows S is disabled and a bit different. But when go to the hospice, it's normal. [I] feel a lot of her relaxes; [she is] not conscious of her sister. She can relax in the environment and be herself." (Mum)
>
> "The kids, they understood [one another]…it was a bit of solidarity." (Mum)
>
> "[At these events] you can chat to people, other children who understood when back at home the people who understood were the staff, mum, and dad. It [losing a sibling] was a lot easier to deal with having people to chat to." (Sibling)
>
> "There were a lot of children; it was really nice, felt special for us" (Mum)
>
> "One of her best friends is C who is in a similar situation. He lost his sister. The bond they have is so special. They have been there for each other. They are only 5 but the depth of their relationship – [you] can't match it. They will be lifelong friends." (Mum)
>
> "Just being around other kids going through the same thing, knowing they are in the same boat as me, brings in something of a normality. They bring photos [of their terminally ill siblings who cannot attend the event] to talk about them. Some kids have lost their sibling, other have not. They love the experiences." (Mum)

### Increased family/sibling bonding

Families reported that siblings were able to spend fun time together. K reported that the Disney party was "more special for E," the older sister, and has enabled her to bond even closer with her sister. Additionally, the Disney theme centred on Frozen, a story of two sisters. As such the event was extra special for both the sister and her mother.

> "The party was more special for E. She got to spend lovely time with her sister. It was lovely them sharing things like that. You don't get opportunities for them to do a lot together. It was really sweet."-(Mum)
>
> "Frozen is one of her favourite movies. She was singing all the songs…it was 'me and my sister thing' you know and whenever I see it I start crying…it was lovely because they don't get many opportunities for them to do things together." (Mum)

### Experiencing hospices as a positive space

Some of the families reported that their children associated the hospice with a positive space. K found it difficult to speak about Disney events in isolation. She reported on all the events and activities the hospice provided them as a family in which the Disney event was one of many. K reported that both her children took part in 'sibling activities' organised by the hospice, and had "good feelings about going to [the hospice]". She also reported that her children started experiencing hospices as a positive space "from the start". The hospice had always had fun things for them such as video games; as such they had always associated it with fun activities. The Disney events "add to those nice things".

> "[E] Remembers [the hospice] as a happy place, [a] special time. This adds to the joy, adds to the memories and nice feelings….when we take [S to hospice] [the siblings] have good feelings about it. They don't refuse to come. They like to come. They feel a part of the place."(Mum)
>
> [Siblings] just saw [the hospice] as a fun place. They had video games. It cemented the party as happy place." (Mum)
>
> "They have the sibling activities. Tomorrow they are going to scout camp. They go [on] a trip once a year with all the group." (Mum)

H reported that she had only experienced the hospice as a positive space since she got involved after her brother had passed away. As a result, she reported having an "open mind" and a better understanding of what hospices do.

> We got on a lot with the staff. They were very friendly with us. We interacted [with them] a lot, one to one if we needed to. At the age of 7 or 8 we had never experienced the hospice, only the hospitals we had been to, so we had no idea. At that age you just think hospices are places where the elderly go and that's where they die, but when we first went, we had a tour and they showed us all the things we could do,

> the different events they had coming up. As a family we did a lot of stuff together, and it gave us more of an open mind about hospices and what they are like."(Sibling)

**Resilience/coping mechanism**

Coping was understood to have been achieved in different ways depending on the context. Some families reported that the family's stress level/mental health would have worsened if these events were unavailable. One family reported, they were able to cope better as a result of having had the opportunity to open up about their loss with others who would understand due to going through similar situations. Another family reported coping as a result of increasing their understanding of disability when spending time with others in the hospice.

One mother reported that her son is able to cope better because the event gives him and his sibling with a life-limiting condition the opportunity to have a break from the constant focus on the medical aspect of their lives and "just be kids".

> "If [events were not available], the impact on children's wellbeing would worsen. It helps with the whole family's mental health. It is holistic. It encompasses what you need and takes away the focus from medicalisation. They are kids; they are not patients." (Mum)

**Coping with grief**

For those families who have lost a loved one, resilience has been understood as better coping with the loss during bereavement. Families who were bereaved reported that the events they attended supported them in their bereavement. One sibling reported being better able to cope with her feelings as a result of taking part in the hospice events and parties. She was better able to cope with the loss through spending time with other children with similar experiences. This allowed her to open up more, thus making it "easier to deal" with her loss.

> "[The parties] were important because you were meeting other people and you [got] to chat to people with experiences like [yours]. You could chat to other children who understood, while back at the home the people who mainly understood were obviously Mum and Dad. So it [the parties] was something like enabling us to do stuff whilst chatting to the specialists that came in, the other people that worked at the hospice as well as the other children. It was a lot easier to deal with what we had been through having both people [specialists and other children] to chat to." (Sibling)

> "[There was] a lot to talk about. We went quite regularly. It gave you your own coping mechanism to comprehend what was going on in your own way. We were quite young. We were not experienced [in] many feelings, and it as quite useful to understand them…we grew up a lot in that time. It gave us a better understanding of the reasons. The fact that we saw all these children meant we were not the only ones, because at primary school, everyone…their grandparents die but they are not necessarily like immediate family. We went to a very small primary school, so we

> don’t come into contact with people like that. It gave us an opportunity to interact with people that we wouldn’t come into contact with necessarily. It was [a] comfortable environment. It was a chance to catch up and see how they [the other children] are doing and how their siblings are if they were still in hospital.” (Sibling)

> “They went through what was a traumatic event and being supported by [the hospice] helped their ability to deal with that. [It helped them understand} they were not the only people going through [it and that] they were OK feeling about what went on and what they happened with D.” (Dad)

**Positive memories leading to positive feelings and social interactions**

One of the driving forces of attending these events for most families is to make as many good memories of their loved one before they pass away. The photos and gifts they receive at these parties are often used to recall positive memories and as an engagement method to keep close relationships with one another.

One mother reported the importance of making memories and taking as many pictures as possible of their daughter as they live their lives moment to moment. Parties like this have also enabled E to make “nice memories” of her sister. One sibling reported that the hospice events heavily focused on nurturing positive memories of their sibling to help them cope both in the immediate term, but also later on in life through creating memory boxes of their brother. Memory boxes are a collection of personally meaningful items which act as tools for opening up different conversations about the past and fond memories.

> “The girls got dressed up in lovely costumes. There were [Frozen] characters and [both sisters] got their pictures taken with them. S cannot do a lot, so we sat her up, well [held] her up to take photos. It was really sweet. When they grow up they [the siblings] can say they included [their sister] all the time.” (Mum)

One mother reported that both her daughters received presents at the end of the party – toys and books. K reported that E still uses the book [two years later] she had received at the party to interact with her sister at home by reading to her.

Similarly, another mother reported recalling positive memories from the events of their late son with her other son on a regular basis which brings them closer together. This leads to them both feeling happy. It is one way to spend quality time with one another and helps her to maintain a positive relationship with her son.

> “[Memory boxes] gave you something to talk about. [We made] a jar full of memory sand with different colours and each colour was allocated to memory… we have stuff so it triggers the thought [memory] all the time…quite often we will dig out say at the anniversary of his birthday the things we had created. Me and [my other brother] have a memory box each [with] photos. That [memory box] is where we keep most of the stuff. It is quite [a] useful tool to go back at and think about because obviously we were quite young, so it is a good tool to reinstate the good things that

> did happen. So one of the things I did was the poster with stickers and stuff and that is on the wall. It is a good tool to talk about it when people come over, including with people who did not know us at the time."- (Sibling)

H reported that she is able to think back about her brother regularly thanks to the memory boxes and other things they had created at the hospice. Furthermore, the memory boxes have also been very useful for H's youngest sisters who never knew their brother as they were born after he passed away. H reported that the memory boxes trigger conversations about their late brother with her two sisters regularly.

> "I have two young sisters now that didn't know D. Through showing them what sort of stuff we did…this brings me and my sisters together." (Sibling)

## Outcomes for the parents/guardians

**Feelings of normality and positive feelings**

A number of the families reported that the parties provided opportunities for the family to experience a semblance of normality. They also provided some escapism from the treatments and illness.

> "I could watch them [both sons]. We had our own normal. Things like that [events] meant we could do it. We probably would not be sane if it had not been for that. [It was] like there was light at the end of tunnel, one that did not involve epilepsy, invasive procedures. [They were] just being a kid, because [he had] become a medicalised patient, so seeing him being a kid and smile and relax is huge. You cannot buy it. That is why it is so special" (Mum)

One mother reported that she appreciated events like the Disney parties because they provide opportunities for her daughters to have quality time together: "I love watching my kids interact, E holding S."

**Increased bonding with family**

The families reported that hospice events and parties provided a distraction from treatments and illnesses and an opportunity to spend quality time with their loved ones.

One mother reported that she appreciated the Disney parties as they gave her an opportunity to bond with her daughter. Usually she was extremely busy with medical appointments and looking after three children, and she did not get to spend quality time with her daughter. Another mother reported that now the children had grown up, they had started doing their own things, and these events provided an opportunity for the family to have a nice time together as a family again. Another mother reported that the hospice parties provided opportunities for the family to spend quality time together. They would not have been able to experience such experiences together otherwise.

> “On days like that [Disney parties] the focus is on your child. I can sit there and hold her. [I] don’t have to do anything else [just] put her on my lap. I got no excuses. [I] get to cuddle them. I don’t sit at home cuddling her all the time, I haven’t got the time. I just run, run, run do this, do that… you are extra busy when you got a disabled child [with] all the appointments [and] looking after the other kids…[Disney parties] stop the other business of life and create lovely memories.” (Mum)

> “Now they are 13 and 15….it is a day out for the family. [At] the weekend E is going to her gymnastic class, J is going to the gym. Before S we would go [out] even when she was little, but we don’t do that so much now. We split, conquer and divide. To have those things where we all do something together is nice…she [has] Make a Wish coming up as well. For us it is a nice thing to be all together.” (Mum)

**Positive memories**

Some families reported the importance of making nice memories with their children and that the events and parties are crucial for enabling those moments. Without them the family usually does not have opportunity to have quality time together.

> “We don’t know how long S is going to live. I take loads of photos of her…I mean she could live till [she's] 30, I don’t know. She could get a seizure, [her condition has] sudden death in epilepsy and other things could happen with her health…and we might not be able to do all the things we can do now. Even though we can’t do a lot, it is important to do them well while we can.” (Mum)

Families also recalled those memories to interact and facilitate conversations with their children.

> “Sometimes I will take out the stuffed toys [she has received from events and parties] and go 'oh remember at [the hospice], look at this' and she responds in her little way.” (Mum)

One parent reported that though he had been attending the hospice parties and events after his son had passed away in 2010, the memories he had created back then are still useful for him.

> “[The parties were] useful. The impact [they] had almost 10 years on, both in terms of having certain things that happened on holiday, you forget them. Sometimes years later, you go ‘the one thing that stuck in my mind was so and so’.” (Dad)

Another parent reported that the events had helped in supporting him to reflect on his son through the activities he had taken part in such as building a memory garden of his son. He reported that he regularly reflects and recalls these memories on his own. However, he also reported that these memories centred on his son D rather than the parties or the events. This could be because the events took place after his son had passed away and focused on how to cope with loss rather than on positive memories of his son.

> “We helped to build a memory garden. Actually by helping to build the memory garden other people benefit too. We reflect on D [not the hospice events/memories] more than anything specifically.” (Dad)

**Better relationship with staff and increased sense of belonging**

The parents had also an opportunity to socialise with staff; this was important as parents reported either knowing them really well and enjoying spending the time with them or not getting to know them properly outside medical circumstances. One father reported the importance of interacting with people who know exactly what they were going through and how this makes them feel understood and accepted.

Another parent improved her relationship with the care staff by being able to socialise with them; she valued socialising with people who knew very well what she was going through and as such took account of her difficulties when suggesting things to do together.

> “For me- it was a chance to relax. They [care staff] might look at me and say let’s go do this. It meant I could kick back a little bit. The care staff they knew about the condition." (Mum)
>
> “They knew me inside out. It meant I could trust them and relax more and that is the whole point.” (Mum)
>
> “They affected the trust, the trust increased.”(Parent)
>
> "[The Disney party] helped me to get to know the nurses better. The nurses dressed up…I am only [at the hospice] 14 nights a year, so [I am] not staying around to get to know everybody, so it was nice…having a cup of tea and cakes with other staff.” (Mum)

One mother reported how the hospice provided the family with a sense of relief as it is familiar space where they feel like they belong

> "When go somewhere new, it can be overwhelming. [It] is good because you know where can get into the building, know the facilities, [and] staff are on standby. [You] feel at ease.” (Mum)

**Respite leads to social interactions, which may improve coping**

Respite, which leads to a distraction from the daily struggles, can lead in a reduction in stress. One mother reported that the parties give her an opportunity to meet other parents, as she does not have much opportunity to socialise. The events and parties enabled her to have a “chat and cup of tea” with them and “get a break from the grind”. Furthermore, she reported that usually she took the kids to these parties which gave her husband a break and some time on his own. She reported that this has led to a reduction in stress. Similarly, others reported that the events provided them opportunities to interact with others who may be going through the same experiences

> “It took a load off for a while, not necessarily for a long time, but enough for you to feel refreshed. It gave us a little break. [Life] is a merry-go-round, one time you are up and then down…then you go and have a party and forget for a little while and can be just a Mum and they the kids. That does not happen in the day to day when you have a sick child.”(Mum)

The events supported the families to be feel less alone when grieving and meet with people who could relate and understand their experiences. This enabled them to open up more and talk about their feelings rather than further isolate themselves.

> “We felt very supported by them. Bear in mind, when a child is alive, you are very much focused on your child. You are cared for by a wide range of organisations, and after the child died, we were appreciative that we were picked up by [the hospice] and blown away by the level of care. It was valuable for the family to share our story with other people who went through the same circumstances.” (Dad)

> “Coming together with other families, also a time for your own family to get together and reflect on D's life, it is a personal and collective thing.” (Dad)

**Coping mechanism: memory leads to a better grieving process**

Both families whose children had passed away reported how recalling positive memories from the hospice parties helped them with the grieving process. One mother reported recalling positive memories of her son from the hospice parties “every day”, leading her to feel happy, both on her own but also when she recalls these memories with her other son. She reported that recalling positive memories of her son was a way of spending quality time and maintaining a close relationship with her other son.

As a result, she reported that she is now better able to cope in relation to her health and feelings.

> “Instead of focusing on constant pain, watching your child unwell, it meant I got lots of memories when he was well and smiling. It meant he had a better quality of life. That is comforting from [my] point of view. It means there was an element when he was not suffering.” (Mum)

> “I am able to have more positive feelings, when I look back. [It] helps with grieving.” (Mum)

Similarly, one father reported that the events supported the family to dedicate time to reflect on their loss with others present.

> “[Events let you] dedicate time to grieve and reflect on how to grieve, nurturing the memories of your child and that was a good experience. “(Dad)

One parent reported that the events helped them cope better with the loss and how he dealt with the grieving process.

> "[Events] helped me cope better in relation to the grieving process. The whole environment was pleasant. The memory it produced, and the sense of wellbeing was beneficial. They are good memories." (Dad)

**Attribution**

On average families attributed 65% of the changes to the events and parties hosted by the hospice. One mother attributed only 10% of the changes to the Disney party; she explained that it was an event that lasted a few hours, but it was still "a special thing and worthwhile". She also reported that due to the day-to-day business of her life, she did not take part in the events as much as she would have liked, as such the impact therefore may be limited.
J fully attributed (100%) the changes experienced to the hospice events and parties; she added: "They went all out every time; everything was thought of and taken care of."

One father and his daughter largely attributed (75%) the changes to the hospice events and parties; both of them also mentioned other support networks such as friends and families, and the play therapist that contributed to supporting him and his family during those difficult times

> "They had a very big impact on us. They gave us so much aftercare continually. We were involved for a good 4-5 years. We did go quite a lot. [Recently] we were invited to place a memory stone they created [in a] huge garden. My sisters have both been down with them. It gave them a place to [put to] the name so they knew what they were talking about." (Sibling)

**Counterfactual**

Most families reported that their lives would have worsened had these parties, including the Disney-themed ones, and events never existed. They reported that their relationship with their children as well as with their spouse, their mental health, and their feelings would have worsened either slightly or significantly.

# Appendix 1: Example interview guide

## MediCinema children interview guide

### Background

1. How old are you?

2. Tell me a little bit about yourself, what you like to do, what you don't like to do?

### About your MediCinema experience:

3. When did you first go to MediCinema?
   a) What films have you seen, what do you remember?
   b) How frequently did you go? What was your experience?
   c) Did you get to meet any Disney characters?

### Increased positive feelings

1. How did [insert from above activities] make you feel?

2. Here is a picture of some faces. The two smiling faces, 5, is if you are really happy with life (including school, friends and at home). The two sad faces, 1, is if you are really not very happy with life. Circle the number that best fits how you feel **at the moment.**

3. Here is a picture of some faces. The two smiling faces, 5, is if you are really happy with life (including school, friends and at home). The two sad faces, 1, is if you are really not very happy with life. Circle the number that best fits how you felt **before ever going to MediCinema.**

### Increased opportunity to spend quality time with family (parents/guardians and siblings), strengthen bonds and form new friendships

1. Who were you with when watching films at MediCinema?

2. What did you (and your family) enjoy most about the experience? Did you do anything as a family after?

a) What did you and your sibling enjoy most about the experience? Did you do anything as brothers/sisters after?

3. Who else did you meet? How did they make you feel?

4. Thinking about a typical week in your life **now**, how often in a week do you experience the following?

| | Never | On one day | On a few days | Most days | Every day |
|---|---|---|---|---|---|
| **I get on with my friends and family** | | | | | |
| **I have someone to play with** | | | | | |
| **I feel like I fit in at school and in other activities** | | | | | |
| **I have fun and enjoy myself** | | | | | |

5. Thinking about a typical week in your life **before** your MediCinema experience how often in a week do you experience the following.

| | Never | On one day | On a few days | Most days | Every day |
|---|---|---|---|---|---|
| **I got on with my friends and family** | | | | | |
| **I had someone to play with** | | | | | |
| **I felt like I fit in at school and in other activities** | | | | | |
| **I had fun and enjoyed myself** | | | | | |

6. Thinking about the last week. Have you felt lonely?

| Never | Not often | Quite often | Very often | always |
|---|---|---|---|---|
| | | | | |

7. Thinking about before ever going to MediCinema. Have you felt lonely?

| Never | Not often | Quite often | Very often | always |
|---|---|---|---|---|
| | | | | |

8. How strongly do you feel you belong and feel valued by your family and friends?

| Very strongly | Fairly strongly | Not very strongly | Not at all strongly | Don’t know |
|---|---|---|---|---|
| | | | | |

## Create positive memories

**1.** When you think back about your time at MediCinema, what is your strongest memory?

**2.** How does that memory make you feel?

3. How often do you think back about your strongest MediCinema memory?

| | Never | On one day | On a few days | Most days | Every day |
|---|---|---|---|---|---|
| **On my own** | | | | | |
| **I talk about it with my parents/guardians** | | | | | |
| **I talk about it with my siblings** | | | | | |
| **I talk about it with my friends** | | | | | |

## Better health engagement, choice, and control

1. Did MediCinema help you to get to know the nurses better? How did it help you get to know them better?

2. How do you feel now when you get medical treatments? Did anything change? Why?

3. Thinking about a typical week in your life **now**, how happy are you with

| | **Very unhappy** | | | | | | | | | **Very happy** |
|---|---|---|---|---|---|---|---|---|---|---|
| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How much choice you have in life?** | | | | | | | | | | | |
| **The way that you use your time?** | | | | | | | | | | | |

4. Thinking about a typical week in your life **before** ever going to MediCinema how happy were you with

| | Very unhappy | | | | | | | | | | Very happy |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How much choice you have in life?** | | | | | | | | | | | |
| **The way that you use your time?** | | | | | | | | | | | |

## Increased resilience

1. Can you tell me a story/draw me something that you are proud of in your life?

2. Can you tell me a bit about/draw something about the times you feel strongest?
   a. What makes you want to be strong?
   b. What/ who helps you when you feel weak?

3. Do you agree with the following statement: As a result of going to MediCinema I am better able to cope with

| | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|---|---|---|---|---|---|
| **My health** | | | | | |
| **My feelings** | | | | | |

## Increased confidence

1. What changes, if any, have you noticed in your behaviour, since going to MediCinema?
   a. Have you started acting differently? Why?
   b. Since going to MediCinema, have you felt more confident about taking part in different activities? How? Why?

2. Thinking about a typical week in your life now, how confident do you feel in the following:

| | Not at all confident | Slightly confident | Moderately confident | Very confident | Extremely confident |
|---|---|---|---|---|---|
| **You future goals** | | | | | |
| **Social interactions/friendships** | | | | | |
| **Work/school** | | | | | |

3. Thinking about a typical week before ever going to MediCinema, how confident do you feel in the following:

| | Not at all confident | Slightly confident | Moderately confident | Very confident | Extremely confident |
|---|---|---|---|---|---|
| **You future goals** | | | | | |
| **Social interactions/friendships** | | | | | |
| **Work/school** | | | | | |

## Attribution

1. Is there anyone else in your life who also helps you achieve *[interviewer to insert a few examples of outcomes discussed above]?*

2. To what extent do you think any of the changes we've talked about *[summarise those listed]* are because of going to MediCinema?

| Not at all (0%) | A little (25%) | Some (50%) | Quite a lot (75%) | A great deal (100%) |
|---|---|---|---|---|
| | | | | |

## Counterfactual

1. Imagine what things would have been like in your life if you couldn't go to MediCinema. Would things have improved, worsened, or stayed the same for you? How would the following things have changed? Why?

| | Worsened significantly | Slightly worsened | No change | Slightly improved | Significantly improved |
|---|---|---|---|---|---|
| How you feel | | | | | |
| Your relationship with your sibling(s) | | | | | |
| Your relationship with your parents/guardians | | | | | |
| Your relationship with friends | | | | | |
| Your confidence/ | | | | | |

## Finally

4. Is there anything else you want to say about your MediCinema experience?

**Thank you**

## Endnotes

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[1] Thompson, S. & Marks, N. (2008). *Measuring well-being in policy: issues and applications*. Report commissioned by the Foresight Project on Mental Capital and Well-being, Government Office for Science. Retrieved from https://b.3cdn.net/nefoundation/575659b4f333001669_ohm6iiogp.pdf

[2] Tugade, M. & Fredrickson, B. (2004). Resilient individuals use positive emotions to bounce back from negative emotional experiences. *Journal of Personality and Social Psychololgy, 86(2), 320–333*.

[3] Heath, G. et al. (2019*).* Understanding the impact of Make-A-Wish UK wishes on children with life-threatening conditions and their families. *Archives of Disease in Childhood, 104, A246.*

[4] Tugade, M.M., Fredrickson, B.L. & Feldman Barrett, L. (2004). Psychological resilience and positive emotional granularity: examining the benefits of positive emotions on coping and health. *Journal of Personality, 72, 1161-1190.*

[55] Bryon, M. & Greenwood, J. (2015). *Play Service.* Great Ormond Street Hospital.