Exploring the Potential Contribution of a Therapeutic Recreation-Based Bereavement Programme for Families who have Lost a Child to Serious Illness

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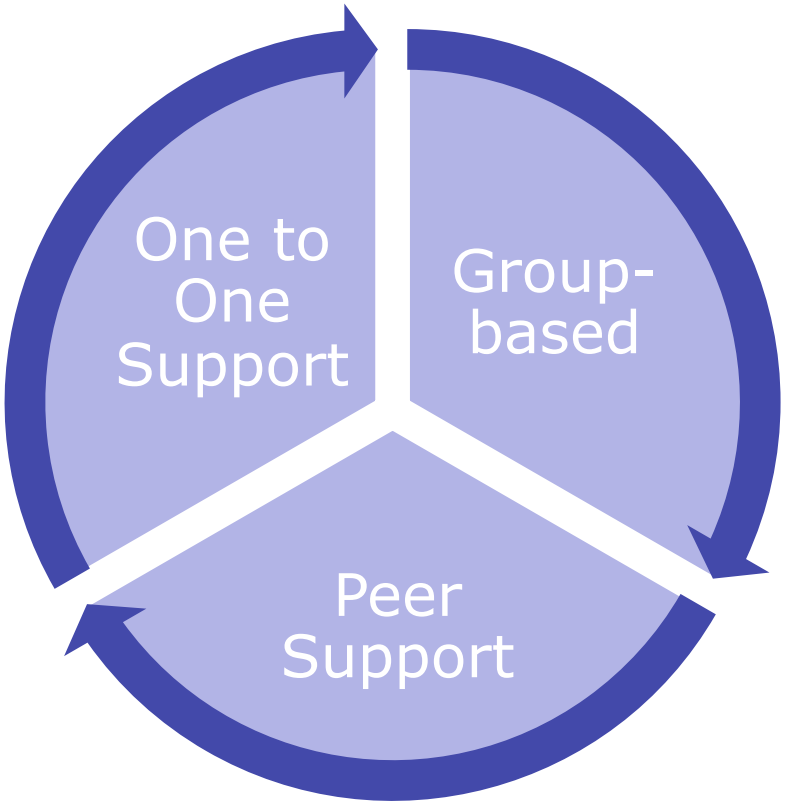
Perspectives on Family Grief

- De Spelder & Strickland (2005 p. 238) *"our conventional views of bereavement, grief and mourning are being revised."*
- Gilbert (1996): as well as being an experience for each family member, a child's death impacts on the family as a unit

- Available Interventions



Barretstown Bereavement Programme

- Barretstown in Co. Kildare, Ireland
- Member of Serious Fun Children's Network
- Bereavement programme has evolved over time
  - 3 camp cycle over one year
  - 3 night residential camp
  - Reunion camp (new development)
  - Includes parent volunteers with experience of bereavement

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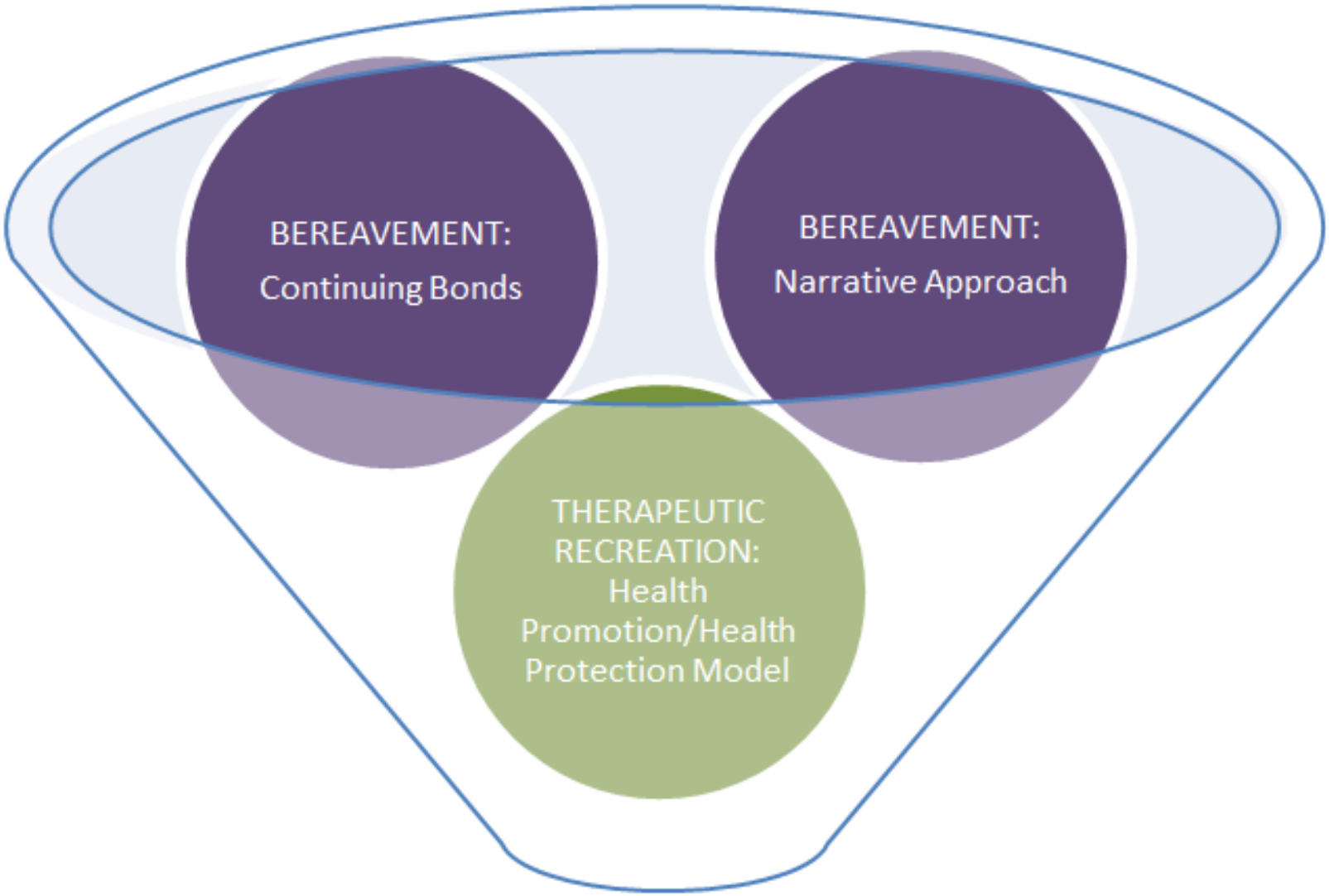
BARRETSTOWN

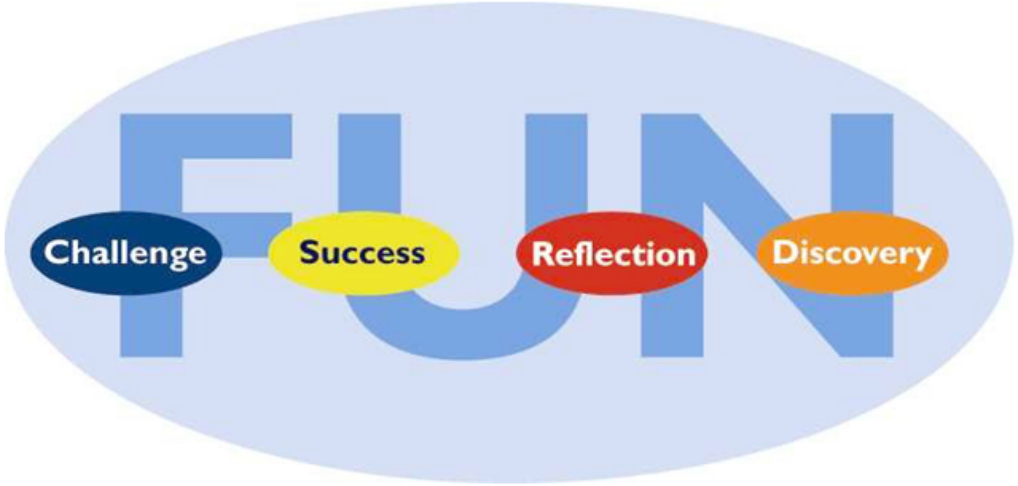
a seriousfun camp

Models Used in the Programme



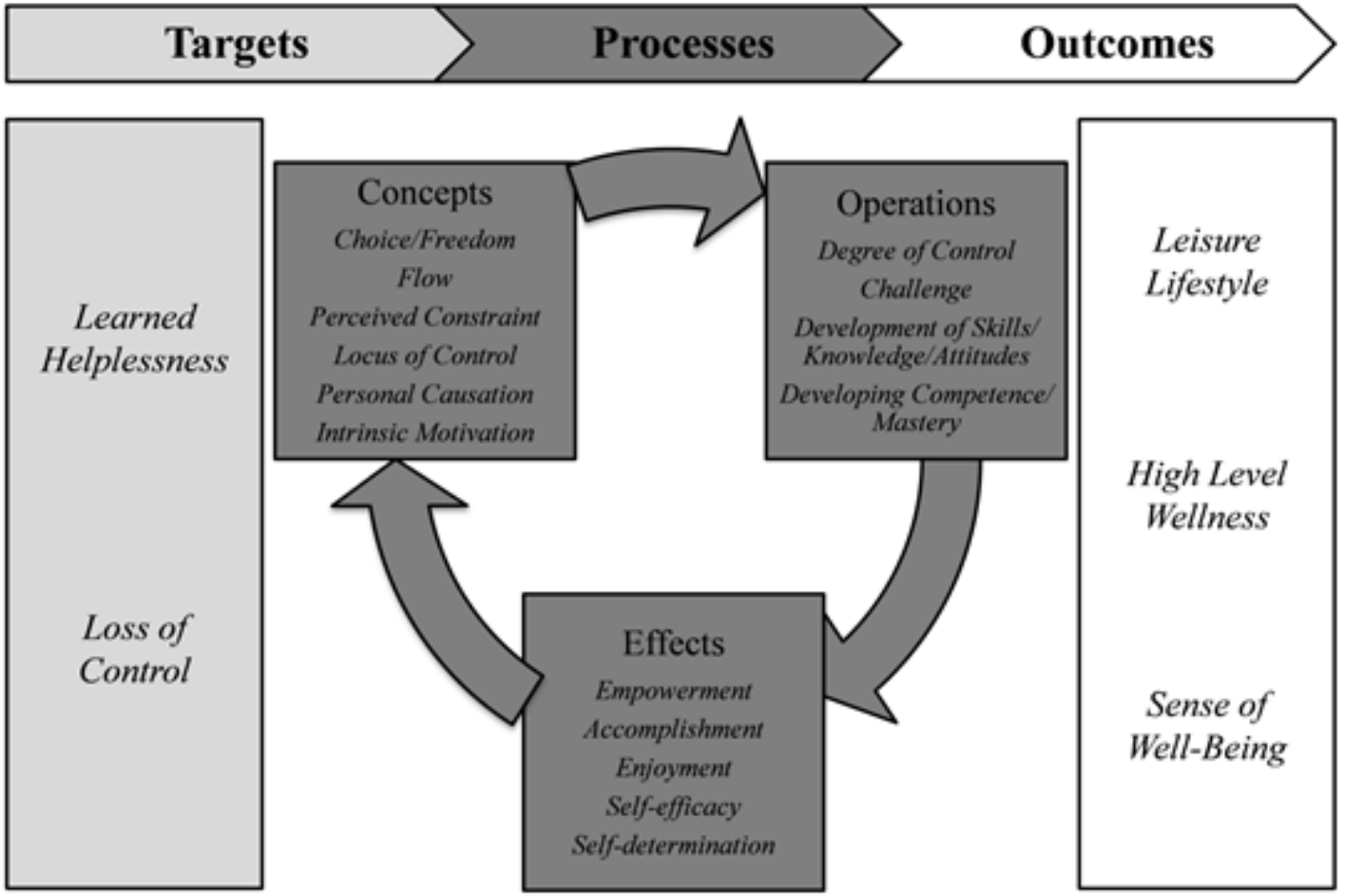
Therapeutic Recreation (TR)

- Purpose of TR *"the provision of treatment services and the provision of recreation services to persons with illnesses or disabling conditions"* and to *"restore, remediate or rehabilitate"* those who participate (Association of Therapeutic Recreation of America, 1997, Definition statement, para. 1).



Barretstown TR model as reported by Kiernan et al. (2004).

Elements of TR (Jennings & Guerin, 2014)



Visual Representation of Key elements of TR Models (Jennings & Guerin 2014)

Bereavement Components on Camp

- Approximately 5 – 6 hours each weekend
- Movies that address issues of loss
  - Camp 1 – The Lion King
  - Camp 2 – My Girl
  - Camp 3 – The Bridge to Terabithia
- Reflections – Focus on remembering family members
  - Music
  - Spoken word
  - Photographs
  - Candles
- Bereavement group sessions

Celebration of Life

- More elaborate setting
- Candle heart
- Photographs (individual, family)
- Flowers
- Gift (3rd camp)
- Focus on remembering & celebrating

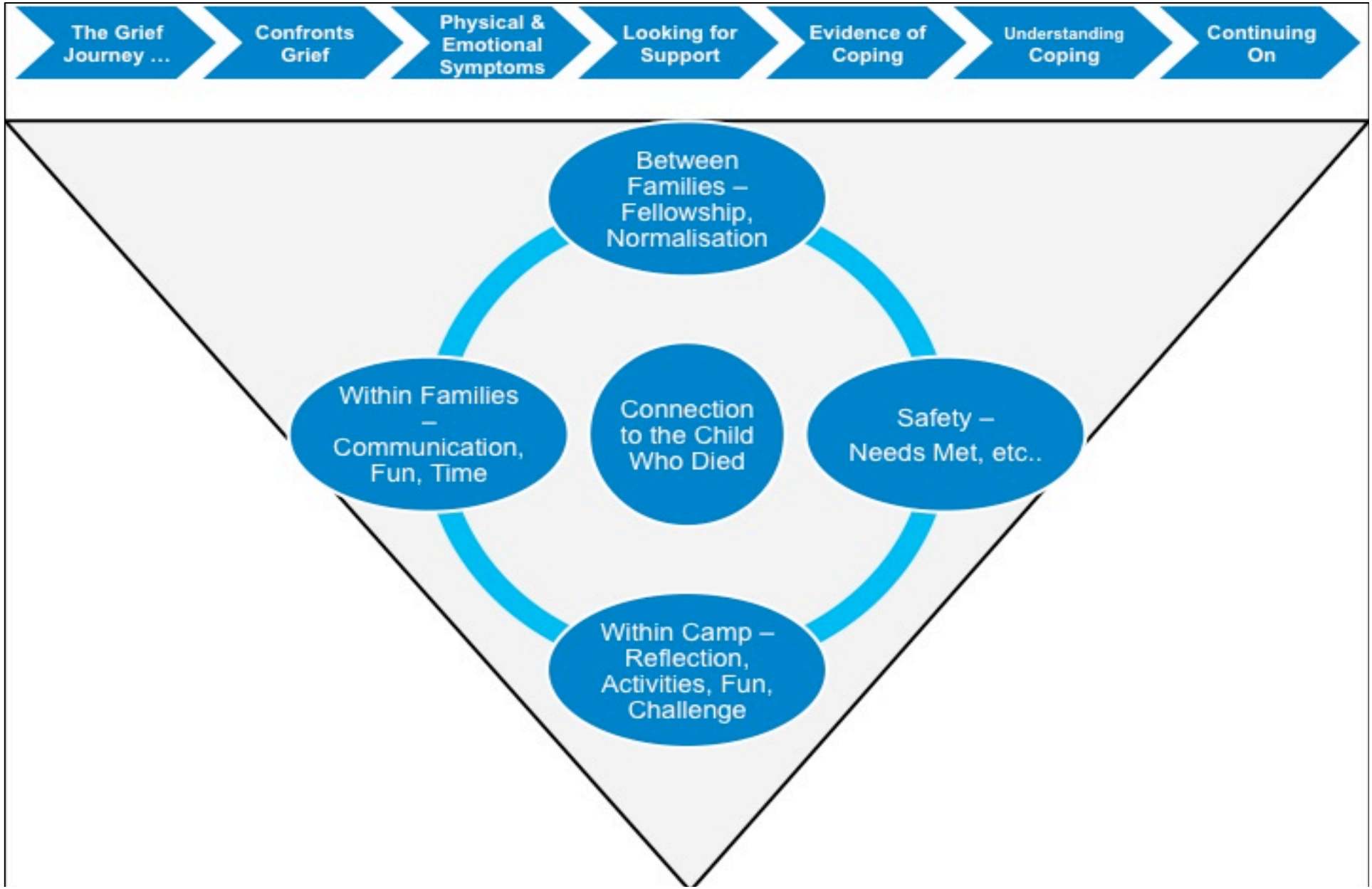
The Present Study

- Objectives:
  - describe the nature of a bereavement programme delivered within the context of a therapeutic recreation programme, for families who have lost a child to serious childhood illness;
  - **to explore staff and parent perspectives on the potential contribution of the TR-based bereavement programme on families who participate.**

Methodology

- Informed by Medical Research Council Framework (Campbell et al, 2000)
- Mixed methods action research study
- Key components
  - Documentary analysis & researcher reflections
  - Mixed methods longitudinal study of parents taking part in a 3-camp cycle
    - Surveys (9 families, n = 13) & case studies (3 families, n = 6)
  - Qualitative study of parents taking part in reunion camp (n = 6)
  - Qualitative study of staff perspectives (n = 6)

Integrated Findings from Parents



The Grief Journey

- **Feelings** vary - from *"doing well and coping"* to *the depths of depression every time I think of her"*.
- **Confronted** by how the loss has impacted upon them **physically** or **emotionally**.
- Parents **search** for supportive intervention but are hesitant. Feared camp might *"make us worse".*
- **Coping:** Families report they are *"doing well"* and *"initial difficulties and grief, the highs and low seem to have smoothened or lessened".*
- Desire to **continue on** with the business of living, but maintain the connection to their child - *"she is with us".*

Contribution of the Programme

Within Families

- **Communication**: *"we speak about him regularly and can now enjoy and laugh at some of the memories".*
- **Relationship** concerns *"I have no enthusiasm to join in with/feel isolated from my partner".*
- Opportunity to **have fun - "***you realised that you were having a bit of fun".*

Between Families

- Desire "***to meet others*** *who have experienced similar losses and find folk to talk with"*
- **Fellowship** of parents - *"wonderful sense of being special among other special families"*
- **Normalising** their experience

Contribution of the Programme (Contd)

Within Camp

- Offers **time away** from outside world
- **Fun activities** as a counterbalance
- ***Bereavement sessions*** *"beautifully difficult".*
- **Challenge** but *"completely invaluable experience, teaching us so much about ourselves"*

Safety

- Camp was *"safe at every level".*
- Allowing children to do more *"adventurous things".*
- Among other parents who *"get it".*
- Camp can *"wrap me up and mind me, keep me safe until Sunday".*

Connections

- **Ongoing connection to the child who died:**
  - Connection to the child is ever present *"felt close to him before Barretstown and this has not changed to any greater or lesser extent"*.
  - Connection as courage - *if I hadn't had gone through what I had [child's death] I wouldn't have done [the high ropes course]"*
  - Comments on reflections and celebrations of life - allowed parents to *"hear their names said out loud, only usually heard at anniversary mass"*
  - *"Barretstown is a place where you meet people and can talk openly about your child".*

Potential Impact

- Perceptions of positive impact on coping with bereavement, access to support and implications for family functioning.
- Staff stressed the opportunity to be yourself and not feel judged
- Meeting others, not feeling judged, having fun, while still remembering the child who died appears to be important elements of this contribution.
- Bereavement components made parents aware of their own and other family members' grief.
- Parents would *recommend* the programme to other bereaved parents.

What does it do?

- Fellowship and shared experience addresses isolation and offers a non-judgmental place to share stories, discuss difficulties, come together as a family, and create a support network
- Children can be remembered and celebrated, but surviving family members can also reinvest in themselves and each other, and have fun again.
- The safety of the environment allows families to reconnect with their child and siblings
- Residential nature create a safe space

Reflections on the Study

- Action research design conducted in one setting => may reflect a possibly unique context.
- Study included multiple stakeholders' views and multiple methods of data collection. A dynamic set of data was collected.
  - BUT not views directly from children!
- Longitudinal element allow for examination of patterns over time
- Rigorous approach to the analysis of data
- Need for further research to systematically test the model for impact on families

Potential Contribution of the Model

- Findings suggest the programme, which combines TR with a bereavement component, may be a valuable one in the support of families who have had a child die from serious illness.
- Potential for this model to be applied in other TR camps (Serious Fun Network)
- Closing the holistic loop - ensuring the availability of support through all areas and periods of a children's illness and subsequent death

Thanks for your attention

Any questions?

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