Developing the evidence

How research impacts programme development at Barretstown
Seriousfunnetwork.org
Our camps

A choice of seven/eight day and weekend camps throughout Spring, Summer and Autumn

- Family Camp
- Summer Children’s Camp
- Summer Teen Camp
- Summer Sibling Camp
- Brothers and Sisters Camp
- Bereavement Camp
- Camp and Friend Day

Illness Groups

- Childhood cancer, haematology related disease, Immunodeficiency related disease
- *Ireland only*: Nephrology, Rheumatology, Dermatology, Gastroenterology, Neurology, Endocrinology
### Research at Barretstown

#### Evaluation
- **Outcomes Evaluation Study**
  - Yale Child Study Center and SFCN (2010 to date)

#### Exploring the process
- **A qualitative Exploration of Children’s Experiences of a Therapeutic Recreation Camp for Children affected by Chronic Illness.**
  - (Jennings, 2013)

#### Small scale (feedback)
- **Parent**
- **Camper**
- **Professionals**

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**Barretstown**

*a serious fun camp*
More Than Just SeriousFun: The Impact of Camp on Resilience for Campers with Serious Illness

Kelsey Graber, Shauna Tominey, Steven Southwick, and Linda Mayes
Yale Child Study Center
### Past Studies: Participants and Methods

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Method</th>
<th># Camps</th>
<th># Campers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploratory (1 time point)</td>
<td>2010-2011</td>
<td>Surveys &amp; phone interviews</td>
<td>3</td>
<td>Post-camp: 172</td>
</tr>
<tr>
<td>Exploratory (1 time point)</td>
<td>2011-2012</td>
<td>Surveys &amp; phone interviews</td>
<td>6</td>
<td>Post-camp: 141</td>
</tr>
<tr>
<td>Scaling (3 time points)</td>
<td>2012-2013</td>
<td>Surveys</td>
<td>14</td>
<td>Pre camp: 919/764 Post camp 1:262/188 Post camp 6: 152/104</td>
</tr>
</tbody>
</table>
Current Study: Participants and Methods

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Method</th>
<th># Camps</th>
<th># Campers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing generalizability</td>
<td>2014-2015</td>
<td>Phone surveys</td>
<td>5</td>
<td>Pre-Camp: 645</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Post-Camp 1: 481</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Post-Camp 6: TBD</td>
</tr>
</tbody>
</table>

Response Rates

- 2013-2014: 18% (pre), 5% (one month post), 3% (6 months post)
- 2014-2015: 76% (pre), 57% (one month post)
## Methods and Participants

<table>
<thead>
<tr>
<th>Participant Stats</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Attended camp before</td>
</tr>
<tr>
<td>Diagnoses included</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
Research Questions

• What changes do parents notice in children following camp?
• Does social support play a role in supporting camper resilience?
Phone surveys – Pre Camp Questions

How would you rate your child’s level of...

- Self-acceptance
- Acceptance of his/her illness
- Feeling understood
- Openness to try new things
- Feeling a sense of belonging

How often does your child typically:

- Talk to friend(s) about what to do
- Talks to family about what to do
- Asks someone for help
- Internalizes or feels sad/depressed
- Gets angry/upset
- Has difficulties dealing with challenges
- Takes time to figure out challenging/difficult situations on his/her own
- Deals with challenging/difficult situations
- Ignores or avoids challenging/difficult situations
Phone surveys – Post Camp Questions

Please circle the number that best describes how much of a problem each one has been for your child since returning from camp.

• Feeling afraid or scared
• Feeling sad or blue
• Worrying about what will happen to him/her
• Getting along with other children
• Other kids not wanting to be his or her friend
• Getting teased by other children
• Unable to do things other children his/her age can do
• Keeping up when playing with other children
• Missing school because of not feeling well
• Missing school to go to the doctor or hospital
What changes did parents notice in campers following camp

<table>
<thead>
<tr>
<th>Changes</th>
<th>Lot less</th>
<th>Little less</th>
<th>No change</th>
<th>A little more</th>
<th>A lot more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidence</td>
<td>29%</td>
<td>50%</td>
<td>21%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>27%</td>
<td>50%</td>
<td>23%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Interest in social activities</td>
<td>26%</td>
<td>40%</td>
<td>32%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Sense of belonging</td>
<td>30%</td>
<td>34%</td>
<td>34%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Feeling understood</td>
<td>19%</td>
<td>37%</td>
<td>42%</td>
<td>10%</td>
<td>0%</td>
</tr>
<tr>
<td>Acceptance of illness</td>
<td>19%</td>
<td>35%</td>
<td>46%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Camp, Social Support, and Resilience

According to parents and caregivers...

- 66% of campers reported increased interest in social activities
- 79% reported increased confidence
- 77% reported increased self-esteem
- 64% reported increased sense of belonging

Campers also experienced:

- Significant decreases in psychosocial problems
- Significant increases in relationship skills and the ability to make friends
Implications for camp programmes

Consider ways to connect with campers during the year recommended as important direction for programme expansion

- Intentionally target camper relationship skills
- Help campers connect with one another throughout the year
- Help promote lasting change in positive outcomes relating to attending camp
Barretstown response to research

- Hospital Outreach
- Growing Camp Connections
- Camp on the Move
- Camper & Friend Day
- Brothers and Sisters Camp
- Camp in Schools

Yale School of Medicine
SeriousFun
Barretstown
Hospital Outreach Programme

- “The treatment has become a distraction from the activities these days!”

Camp on the Move

- “Really great to see Barretstown during the year and helps save on travelling with work time and commitments.

Camp in Schools (teachers)

- “They have sometimes looked on her (the camper) as being a little different but now view her as part of a very special club!”

Camper & Friend Day

- “The day solidified their friendship but it also brought it back to a more reciprocal level”
- “I felt it was invaluable in helping bridge the two worlds”

Brothers and Sisters Camp

- Discussion on impact of serious illness of sibling relationship
- Increase in requests for siblings to attend a camp together that is just for them
### Brothers and Sisters Camp 2012

Examining the possible role of the programme

<table>
<thead>
<tr>
<th>Interviews with professionals, parents and children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methodology and research</td>
</tr>
<tr>
<td>Professionals (n = 8) parents/carers (n=7)</td>
</tr>
<tr>
<td>Children (n = 9)</td>
</tr>
</tbody>
</table>
### Professionals
- Perceived responsibility
- Integration
- Share in the fun together and bring it home
- Structure and scheduling of the session

### Parents
- Jealousy in relationship, going together will help
- Spend time together and have fun
- Hoping to rebuild a bit of their relationship as been getting colder with each other
<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breakfast</td>
<td>Breakfast</td>
<td>Activity Block</td>
<td>Departures</td>
</tr>
<tr>
<td><strong>Sibling Challenge</strong></td>
<td>Activity Block</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Lunch</td>
</tr>
<tr>
<td>Cottage Time</td>
<td>Cottage Time</td>
<td>Cottage Time</td>
<td>staff debrief</td>
</tr>
<tr>
<td><strong>Free Choice Activities</strong></td>
<td>Activity Block</td>
<td>Free Choice Sign Up</td>
<td></td>
</tr>
<tr>
<td><strong>Free Choice Activities</strong></td>
<td>Activity Block</td>
<td>Wrap Up and Pack Up</td>
<td></td>
</tr>
<tr>
<td>Dinner</td>
<td>Dinner</td>
<td>Dinner</td>
<td></td>
</tr>
<tr>
<td><strong>Evening Programme</strong></td>
<td>Evening Programme</td>
<td>Evening Programme</td>
<td></td>
</tr>
<tr>
<td>All in Cottages</td>
<td>All in Cottages</td>
<td>All in Cottages</td>
<td></td>
</tr>
<tr>
<td>Lights Out</td>
<td>Lights Out</td>
<td>Lights Out</td>
<td></td>
</tr>
</tbody>
</table>
Parents views on the camp
Perceptions/impact of the programme

“[healthy sibling could] actually stand out and do her own thing and stand on her own two feet ... you know she wasn’t in the shadow of her sister”

“.... they wouldn't have went separately, I think if they would have went separately they would have probably came home after the first night”

“it was more that they’d had fun wasn’t it”
(to other interviewee)
What the kids had to say

“You get to spend more time with your brother and sister instead of rushing around town with your friends”

Playing games together after camp!

Mischief for two participants (brother and sister) both recounted similar tales

Two siblings from the same family talked about the development of trust during a game where one was blindfolded and the other had to lead
Continuing development

Objectives
- Fun, challenge, confidence building, independence, friendship

Improvements
- Outcomes and reflective components

Research
- Family based psychosocial interventions
- Impact of camp on siblings
Conclusion

Yale and Serious Fun
Children’s Network

Growing Camp
Connections

Brothers and Sisters
Camp
Acknowledgements

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• Dee Ahearn, CEO, Barretstown

• Camp Directors, staff, and volunteers across all SeriousFun Camps

Campers and their families
Thank you