

Rebuilding Lives Affected By Childhood Cancer

BARRETSTOWN

a seriousfun camp



Developing the evidence

How research impacts programme
development at Barretstown



BARRETSTOWN
a serious fun camp



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



Seriousfunnetwork.org

BARRETSTOWN
a seriousfun camp

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

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*



Yale SCHOOL OF MEDICINE

seriousfunSM
founded by paul newman

BARRETSTOWN
a seriousfun camp

Past Studies: Participants and Methods

| Study | Year | Method | # Camps | # Campers |
|-------------------------------|-----------|----------------------------------|---------|---|
| Exploratory (1 time point) | 2010-2011 | Surveys & phone interviews | 3 | Post-camp: 172 |
| Exploratory (1 time point) | 2011-2012 | Surveys & phone interviews | 6 | Post-camp: 141 |
| Scaling (3 time points) | 2012-2013 | Surveys | 14 | Pre camp: 919/764 Post camp 1: 262/188 Post camp 6: 152/104 |

Current Study: Participants and Methods

| Study | Year | Method | # Camps | # Campers |
|-----------------------------|-----------|---------------|---------|---|
| Increasing generalizability | 2014-2015 | Phone surveys | 5 | Pre-Camp: 645 Post-Camp 1: 481 Post-Camp 6: TBD |

Response Rates

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

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

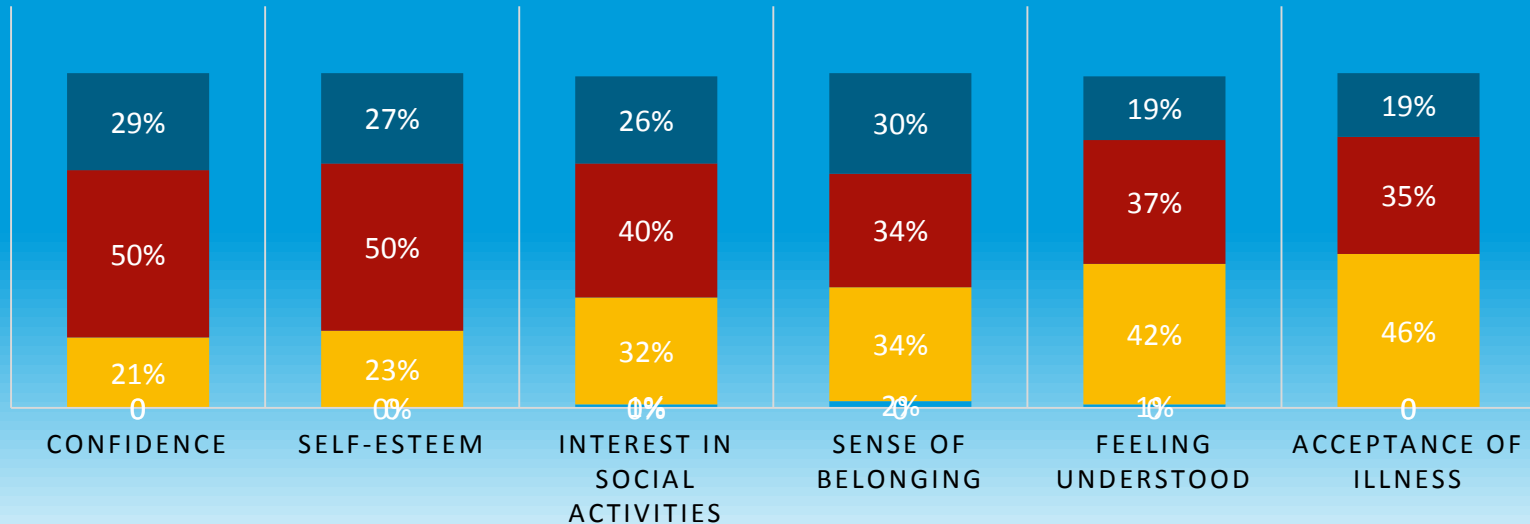
Please circle the number that best describes how much of a problem each one has been for your child since returning from camp.

- 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

CHANGES

Lot less Little less No change A little more A lot more



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 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



Examine the
possible role of
the programme

Interviews with
professionals,
parents and
children

Methodology
and research

professionals (n = 8)
parents/carers(n=7)
children (n = 9)

Professional and Parent Interviews

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

| Monday | Tuesday | Wednesday | Thursday |
|------------------------|-------------------|---------------------|---------------|
| | Breakfast | Breakfast | Breakfast |
| | Sibling Challenge | Activity Block | Departures |
| | | Activity Block | |
| Lunch | Lunch | Lunch | Lunch |
| Cottage Time | Cottage Time | Cottage Time | staff debrief |
| Free Choice Activities | Activity Block | Free Choice Sign Up | |
| Free Choice Activities | Activity Block | Wrap Up and Pack Up | |
| Dinner | Dinner | Dinner | |
| Evening Programme | Evening Programme | Evening Programme | |
| All in Cottages | All in Cottages | All in Cottages | |
| Lights Out | Lights Out | Lights Out | |

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 to 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

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

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

Continuing development

Objectives

- Fun, challenge, confidence building, independence, friendship

Improvements

- Outcomes and reflective components

Research

- Family based psychosocial interventions

Conclusion

A group of children are participating in an activity on a red carpet. In the center, a young boy in a purple t-shirt and white pants is smiling and reaching out. To his right, a girl in a white and blue costume with a green hat and yellow skirt is also reaching out. Other children in various costumes, including a girl in a blue and white dress, are visible in the background. The scene is outdoors with trees and a building in the distance.

Yale and Serious Fun
Children's Network

Growing Camp
Connections

Brothers and Sisters
Camp

Acknowledgements

- **Many thanks to:**
 - **Shauna Tominey, Steven Southwick, and Linda Mayes at the Yale Child Study Center**
 - **Steve Nagler, Laura Marrocco, Patrick King at SeriousFun Children's Network**
 - **Dr Suzanne Guerin, Ciaran Jennings at School of Psychology, UCD**
 - **Dee Ahearn, CEO, Barretstown**
 - **Camp Directors, staff, and volunteers across all SeriousFun Camps**

Campers and their families





Thank you

