The role of research in understanding the psychosocial needs of families affected by serious illness and innovative programme responses

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For the past 20 years Barretstown in Co. Kildare, Ireland has been developing and delivering a suite of therapeutic recreation programmes to children and families from across Europe and the USA who have been affected by serious illness.

A key element of Barretstowns development has been an ongoing programme of research into the nature and impact of therapeutic recreation as a support for families.

This research has allowed the organisation to systematically gather research data on the lives of children and families affected by serious illness, highlighting the varied nature of reactions and responses to illness.

a seriousfun camp
BARRETSTOWN
Celebrating 20 Years

RESEARCH 1

Assessment of outcomes for children with serious illness associated with participation on therapeutic recreation programmes. Includes research on Barretstown's programmes (Kiernan, Kinsella, Walker) and partnering on International research with Serious Fun Children's Network (Yale).

PROGRAMMES

- Residential Summer & family weekend camps
- Camper & Friends
- Camp on the Move
- Camp in Schools

RESEARCH 2

Qualitative studies of professionals`, parents and children`s views of joint programmes for children with serious illness and their siblings.

PROGRAMMES

- Brothers and Sisters Camp

RESEARCH 3

Action research documenting the development and potential contribution of the Barretstown bereavement programme for families who have lost a child to serious illness.

PROGRAMMES

- Bereavement Camps

RESEARCH 4

Future opportunities to examine new programmes, with research informing the development of new initiatives.

PROGRAMMES

- Hospital Outreach
- Camper and Friends Days
- Camp in Schools
- Camp on the Move

> "Two great moments of my life were my 10 days at Barretstown and when my treatment finished."
> – Camper, aged 7 Ireland

> "An environment is created where they [brothers and sisters] feel safe and comfortable trying new things and moving out of the comfort zones that they would have had."
> – Professional, Ireland

> "I look back at Barretstown, [and] remembered there [was] huge joy, we connected with bereaved families there, and that gave us hope to keep going."
> – Mother, Ireland

> "Everything I have done today has been brand new. I have learned so many new things."
> – Child, aged 11, Hospital Outreach

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Conclusion

Importance of research in helping us to respond to the child and the family as a whole through individual and joint programming

- The value in running separate programmes for the sibling unit
- The need to support the child remain connected to friends made at camp
- The need to support children reintegrate back into school and with their peers

Barretstown has contributed to the international knowledge base regarding families affected by serious illness and the role of TR programmes in this