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

Caroline Stott
Executive Camp Director, Barretstown

Suzanne Guerin, PhD.
Senior Lecturer, School of Psychology
University College Dublin

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 Barretstown’s 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.

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).

RESEARCH 2
Qualitative studies of professionals’, parents and children’s views of joint programmes for children with serious illness and their siblings.

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.

RESEARCH 4
Future opportunities to examine new programmes, with research informing the development of new initiatives.

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 Barretstown’s 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.

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

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

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

Acknowledgements:
We are very grateful to all of the children, parents and professionals who have contributed to research at Barretstown and to the researchers and academics who have worked with us to conduct these studies. In particular we would like to thank Peter Hanlon, Eimear Guthrie, Ciaran Jennings and Emma Meyler whose work is included in this presentation.

www.barretstown.org

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