

Imagining different futures with disabled young people

November 5 2018, by Hannah Postles



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The ambitions and future goals of disabled young people with life-limiting and life-threatening impairments are being documented for the first time in an innovative study by the University of Sheffield.

Initial findings suggest that this group of disabled young people feel

frustration that society treats them as 'tragedy cases' because they could die young. This discrimination can be a barrier to enjoying full lives as other teenagers and young people do, according to the research.

Attending parties, achieving work and career aspirations and even indulging in rebellious behaviour are among the experiences often denied to them.

The Economic and Social Research Council (ESRC) funded Living Life to the Fullest project, led by Dr. Kirsty Liddiard, Professor Dan Goodley and Professor Katherine Runswick-Cole at the University of Sheffield, will be the focus of an event as part of the annual ESRC Festival of Social Science.

Dr. Liddiard, from the School of Education at the University of Sheffield, said: "Young disabled people with life-limiting and life-threatening impairments want to plan their futures and have the space to be normal.

"But our initial research suggests they feel their futures are often shut down because they're seen as having short lives. People respond emotionally so they're often stuck with labels like 'brave' or 'inspiring.'

"This can make developing a sense of identity and self-hood difficult. It's therefore vital that the views of these young people and those of their families are heard."

Life-limiting or life-threatening impairments are those with no reasonable hope of a cure and can result in early death. Until now, this group has been excluded from disability research.

Dr. Liddiard and her colleagues have set out to listen to people's stories to increase understanding about their experiences. They have recruited

six people aged from 18 to 30 called the Co-Researcher Collective to co-lead the project, including carrying out data collection through peer-to-peer interviews.

These have been conducted via Skype, FaceTime and Facebook Messenger, which is a departure from the traditional method of travelling to meet interviewees face-to-face.

"This group of disabled young people is often seen as hard to reach and that engaging with them takes time and resources," said Dr. Liddiard.

"The co-researchers' advice on asking these marginalised young people sensitive and ethical questions has been invaluable. We're not solely focusing on issues such as end-of-life, being at-risk or illness. The aim is to explore what disabled young people with shorter lives want to achieve."

A website set up by the research team includes blogs from young people such as on the joys of fulfilling 'bucket list' dreams. Lead co-researcher and health and disability activist Lucy Watts MBE writes about her experience camping at a festival and feeling 'so free' when treated the same as others at the event.

The next step is to carry out in-depth interviews with around 20 parents. Getting their views is important, Dr. Liddiard says, because disabled young people with such conditions often spend more time within families because they often do not go off to university.

This is predominantly because of the considerable barriers they face within education. Dr. Liddiard says: "It's extremely difficult for a parent knowing they might outlive their child. But these parents are fighting for their children's futures."

Living Life to the Fullest is also developing arts projects such as a poetry workshop to capture people's experiences. This is in collaboration with organisations including Purple Patch Arts and the Attenborough Arts Centre.

Dr. Liddiard said: "The notion of a dying child is inherently emotive in our culture. But we should be focusing not on pity but on the injustice young people face and how to live life to the fullest."

Dr. Liddiard and the Co-Researcher Collective will be sharing their findings as part of an event in Sheffield titled The Co-Researcher Collective: Living Life to the Fullest on 6 November 2018 for the general public, academics, practitioners, disability activists and organisations, and students.

The event, from 2pm-4pm at St Mary's Church, Bramall Lane, Sheffield, is part of the ESRC's flagship annual Festival of Social Science.

Professor Jennifer Rubin, ESRC Executive Chair, said: "The Festival of Social Science is one of the largest co-ordinated endeavours undertaken by a science community and demonstrates ESRC's commitment to public engagement.

"We know social scientists and economists value the opportunity to talk with the public to make an impact with their work. These events should inspire [young people](#) to pursue a career in social sciences and raise awareness about the impact made to wider society."

Provided by University of Sheffield

Citation: Imagining different futures with disabled young people (2018, November 5) retrieved 3

May 2024 from <https://medicalxpress.com/news/2018-11-futures-disabled-young-people.html>

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