

# Welcome to the Living Life to the Fullest Project...

## Research Findings



The  
University  
Of  
Sheffield.

**iHuman**

Disruptive research into  
what it means to be human.

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ECONOMIC  
& SOCIAL  
RESEARCH  
COUNCIL

**We are coming to the end of a funded research project exploring the lives, hopes, desires and contributions of disabled young people living with life limiting and life threatening impairments (LL/LTIs)...**





**Find out more at  
[livinglifetothefullest.org](http://livinglifetothefullest.org)**



# Key Finding 1

Young disabled people routinely carried out multiple forms of work across the many spaces of their lives.

This involved things like self-advocacy, managing others' emotions, & fighting for their rights.

Frustratingly, young people said that the adults around them seldom recognised or acknowledged their efforts.



# Key Finding 2

**For disabled young people, illness or progression of disability are often only considered as threat and jeopardy, which had a number of impacts.**



**While disabled young people told us that illness was hard for them, it brought an intimate knowledge of their bodies and experiences.**



**But often, doctors do not appreciate this knowledge, or realise that disabled young people are experts of their own experience. Young people want to be listened to more in medical contexts.**



# **Key Finding 3**

**Disabled young people living with life limiting and life threatening impairments (LL/LTIs) routinely identified themselves as striving and thriving!**

**Young people told us they have strong desires to live full lives in the present and the future, regardless of how much time they have to live.**



# Key Finding 4

**Disabled young people told us that they experienced barriers when finding love, sex and relationships.**

**This included a number of issues, such as difficulties with care; online dating and disclosing disability; a lack of relevant sex education; dealing with others' attitudes; and worries about having their own families in the future.**





# Key Finding 5

Disabled young people told us that they needed good quality care and support to live and achieve their goals.

However, managing care and support took a lot of time and effort. It could also mean a lack of privacy and, for some, feeling like they lacked control of their own lives.

Many also said that care and support could be emotional experiences - often young people built relationships with carers/personal assistants, only for them to leave suddenly for reasons beyond their control.







# Key Finding 6

Understandably, disabled young people had complicated feelings about future, death, dying and legacy.

We found that young people had both pragmatism and a desire to live life to the fullest, despite shortened life expectancies.

Importantly, legacy – being remembered by friends, family and community and leaving something of value to the world – was most important for young people.



**Please see our website to  
find out more...**



**[livinglifetothefullest.org](http://livinglifetothefullest.org)**

**If you want to learn more about ways of doing research with disabled young people, check out the Living Life to the Fullest Co-Production Toolkit**

**[livinglifetothefullesttoolkit.com](http://livinglifetothefullesttoolkit.com)**



**Thank you  
for  
watching!**



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