Making connections to support disabled young people to live their lives

SCOPE = Equality for disabled people

iHuman

The University Of Sheffield.

Background

Scope wanted to better understand disabled young people's lives and what's important to them. We wanted to do this to help us decide what we do next to support disabled young people. We wanted to develop something that we could share to help us and others co-produce services with disabled young people.

So Scope asked researchers and disabled young people from iHuman at the University of Sheffield to find out what support disabled young people need to live their lives in ways that meet their hopes and aspirations.

We started with a literature review and data analysis. We wanted to understand the resources and relationships that support disabled young people.

We then spoke to 39 disabled young people, aged 18 to 36, in online interviews and focus groups. They told us what they thought they have needed while growing up to live a full life.

Disabled young people are experts by experience. We worked with them to create a model of what's important to them. A model is a thinking tool that allowed us to explain what disabled young people need to meet their hopes, dreams and aspirations. Working with disabled young people in partnership is called co-production.

The Connections Model

Disabled young people worked with the research team
to create the model which has two connected parts:

Component elements
Key resources and relationships

Expressive elements
Desires, expectations and aspirations

Component elements

Finances – money, benefits and funding.

Technology – from low to high technology, from wheelchairs to smart homes.

Environment – welfare, care, access and inclusion.

Digital – platforms, software and online communities.

Human – families, friends, professionals and carers.

Animal – assistance animals and pets.

Disabled young people told us that these components are important, in their own right, but they can also interact with and have a huge impact on expressive elements.

Expressive elements

Emotions and identities – the emotional lives of disabled young people and the impact on identity.

Mental health – a broad sense of psychological well-being.

Educational expectations – the importance and expectations around education.

Work aspirations – ambitions and experiences of paid and unpaid employment and training.

Belonging and mobility – feeling a part of and accessing the community.

Making connections

The research team worked with disabled young people to create a model that captured relationships between component and expressive elements. We experimented with lots of different designs and images before settling on a merry-go-round; a traditional ride you would find at a fairground.

A merry-go-round is a large circular turning platform on which there are horses for people to sit on. Underneath the platform, and hidden from view, there are cogs that keep the merry-go-round turning.

The hidden cogs represent the **component elements**. They are not always visible but are important resources and relationships in a disabled young person's life. They are money, technology, environments, digital, animals and other human beings. The cogs can all move on their own but they must connect to keep the horses on the top of the platform moving.

The horses are the **expressive elements**; emotions and identities, mental health, education, work aspirations, belonging and mobility. These represent the desires, expectations and aspirations of disabled young people. Each horse is a separate element but connects with other horses as the merry-go-round moves around.

The merry-go-round will not turn unless each of the elements and components are working with and for one another.

Disabled young people need others to recognise the importance of those connections. This image reflects the connections between the different elements in disabled young people's lives.
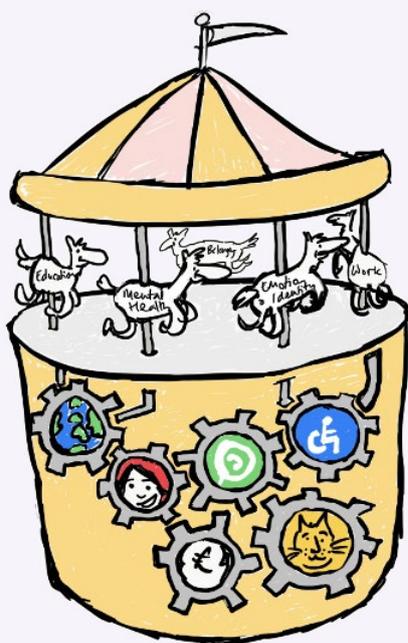
This image allows us to:

- Understand how disabled young people can best live in the world.

- Explore disabled young people's resources and relationships.

- Understand the whole of a disabled young person's life in an interconnected way.

- Recognise that disabled young people's lives continuously evolve, change and move.

- Highlight those resources and relationships that might have been ignored in the past.

"A lot goes on behind the scenes... working together to achieve a successful end result".

What is most important to disabled young people?

We have identified a number of priorities in the accounts of disabled young people.

Promoting inclusive environments

Inclusive spaces help give disabled young people a sense of belonging, enhance their mental health and well-being, and raise aspirations around employment and education.

But many places, spaces and communities remain out of reach for disabled young people. The pandemic has made this situation worse.

"I worked in an environment where my autism was denied".

"I prefer less crowded, quieter peaceful sort of places, I prefer smaller rooms, if I'm struggling, but it's funny people saying [the pandemic] must be paradise right now, but it is a bit different when you are forced to".

And while the impact of the pandemic has been devastating for many disabled people, one disabled young person described how a changing environment had increased her sense of belonging:

"I felt that I was missing out on things, but with COVID happening, now I can join in and be more social, like team meetings at work I would have missed and performances online, concerts and theatre, things I wouldn't have been able to see and now I can. And parties online with friends. It has made me feel a lot more accepted by society... now everyone has the same barrier as I had before, it has made me feel more included in work life and with friends".

Recommendations

We need to remove barriers to inclusive environments. We must design environments that are always accessible to disabled young people. We must challenge what people think, too. We must create inclusive environments by working with disabled young people to anticipate and meet their needs. For example:

"When I was at my university, the leader of my course said, basically, 'Tell us what you need, and we'll put it in place'. And that was in direct contrast to my previous university".

Enhancing digital lives

Many disabled young people remain digitally excluded and still find it hard to access digital content and communities.

An accessible digital world can have a big impact on disabled young people's lives.

"The move to online learning is an opportunity for inclusion".

"[Digital technology] has enabled me to connect with a world that I am otherwise secluded from most of the time".

"When the whole world is invalidating my feelings, symptoms... allies like my family are there to say, 'I see you. I hear you. I believe you'. The media often talks about the perils of modern technology and social media but often neglects to talk about the abundance of benefits of technology, especially for disabled people".

"I always felt different like an outsider, but since COVID I've felt more included and I'm not judged as much. I walk with crutches and a stick sometimes, and that is the first thing people see but now they just see me and that has broken down the barriers a bit".

Recommendations

There is an urgent need for digital content and platform providers to work closely with disabled young people to ensure not only inclusion but also accessibility.

Providers must recognise that disabled young people are digital users too and reach out to them.

A digital campaign could raise awareness of the concerns of disabled young people as digital users and designers.
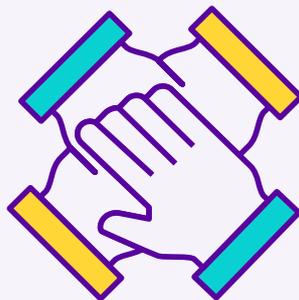
Developing inclusive technology

Technology is crucial to disabled young people and ranges from low to high technology. Technology includes a wide range of items. For example, artificial intelligence (AI) and voice-operated systems (in smart homes) through to adapted cars, wheelchairs and prosthetic devices.

Disabled young people associate technology with the promotion of freedom, independence and mobility.

"Having the right tech is very important. It allows you to do the things you want to do without any help. That has a big impact on my mental health. This wheelchair lets me unload the dishwasher. I know other people might not want to do that, but it was important to me, and I felt better about myself and more useful. I could start going outside again with friends".

"Long cane gives me more independence - lets the public know I'm deafblind. Voiceover/zoom help me access technology + several different magnifiers + tinted glasses help me read labels on stuff. Definitely wouldn't be able to do PhD without assistive technologies".

"I've been able to drive all around the country thanks to my adapted car. If it wasn't for the motability scheme I wouldn't have the independence I have".

"When I went to uni, DSA [Disabled Students' Allowance] provided quite a lot of useful tech, so I could study in bed I had a laptop holder and a chair so I was in less pain and Dragon software – speech to text software – so I didn't have to type so much".

Recommendation

There is an urgent need to promote inclusive technological design by putting disabled young people at the centre of research, design and innovation.
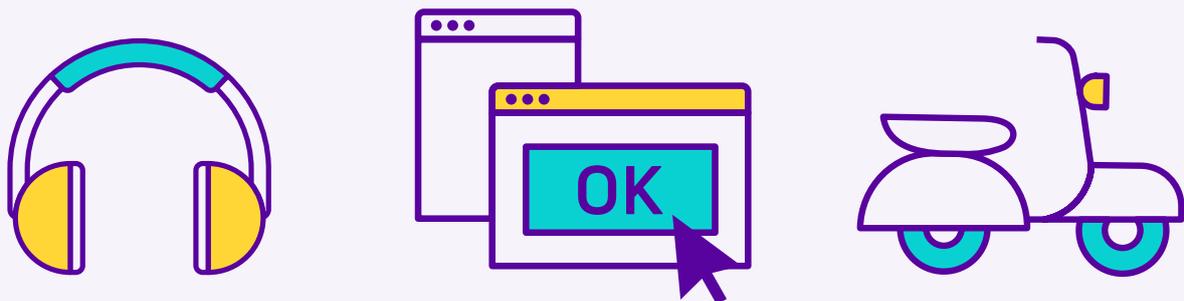
Next steps

We see this research as the start of a journey. We have started developing a new way of understanding how to support disabled young people's lives. Here's what we're going to do next:

Scope will use the research findings to help us decide what we'll do to support disabled young people to live their lives in ways that meet their hopes and aspirations.

Scope will use what we have learned about co-production, apply it to other parts of our work and share it with others.

Scope will work collaboratively with the iHuman team at the University of Sheffield to think about how we can build on this model and explore it further in collaboration with disabled young people.

If you are a disabled young person and would like to take part in possible future research, please contact: **research@scope.org.uk** and/or **ihuman@sheffield.ac.uk**

If you work at an organisation that supports disabled young people and are interested to discuss our research, please contact: **research@scope.org.uk**

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