

With thanks to the thirty disabled Christians who trusted me with their stories, and many more who let me into their lives and worship for this project.

The Upside-Down Kingdom Of God:

Stories of Disabled and Neurodivergent Christians in Churches



A SUMMARY OF A RESEARCH PROJECT

by Dr Naomi Lawson Jacobs

The Research



Introduction

“Disabled Christians have their own stories to tell.”

- Rhona

The most important message that arose from my research into the stories of 30 disabled Christians was this.

Disabled people can be a force for change in churches. Rather than just doing things “the way we’ve always done them,” new ways of doing church can make churches more inclusive of everyone - including, but not only, disabled people.

John Hull called this a radical and prophetic ministry.

The Research: A Summary

For the research, I interviewed **30 disabled Christians**.

What is a disabled person?

In my research, I have used the term disabled for my research participants. The people I interviewed have different impairments - some have mobility needs, some have sensory impairments (are blind or D/deaf), some have learning difficulties, some have mental health problems, and others are neurodivergent (including autistic people). But all their bodies or minds differ from socially accepted expectations, and they all talked about their experiences of exclusion from churches related to those differences.

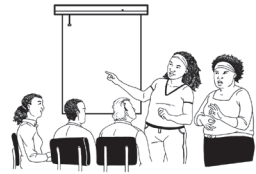
We have stories to tell, and our stories can change the church.

What experiences have these disabled Christians had? (In simple English)

They had different stories to share...
...but they had many experiences in common.

They were asking churches:

- for **better facilities** and **access**, so they could take part
- to be **supported** to do church in the way they wanted to
- to help them be an active part of the church **community**
- to **let them lead**, not just be looked after
- to help them share their **own unique gifts** with their churches
- to **listen to them** so they could **tell their own stories**
- not to treat them as examples, lessons or **objects**
- to **accept them** as they are.



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The ideal worshipper

In my research, I found that these disabled and neurodivergent people did not fit well into churches' idea of a 'normal' or 'ideal' worshipper.

The ideal worshipper can climb steps to church doors. They can open church doors themselves. They can choose where they want to sit in church, and they can hear what is said from the front. They can go the front for communion, and go up steps to the altar. They understand what is happening during the service. They can follow a sermon. They can take part in coffee after church, can attend home groups in the evenings, and can socialise with other members of the church community.

Many of the research participants could not achieve this ideal image of a 'normal' worshipper. When these people's bodies or minds differed from the norm that churches expected, the churches found it hard to change and make space for them.

Churches are designed for ideal worshippers.

Of course, not all non-disabled Christians fit perfectly into all these 'ideals' in churches. They may struggle with one or two of these things, some of the time.

But when disabled Christians do not fit this ideal, it can be particularly difficult for them to fit into churches.

They may not be able to get into their church, because it has steps, heavy doors or poor lighting. They may not be able to hear the sermon, or they may not be able to understand it. They may need to take communion differently from everyone else, but not be given that option. They may find it hard to socialise, or to be involved in busy activities in loud church halls. They may be too tired to attend home groups in the evenings, or they may find it hard to get up in time for Sunday morning services, and so miss out on church services altogether.



The Stories



Disabled Christians Need Full Access to Churches, So They Can Be Full Members

When a church is built around for an ‘ideal worshipper,’ it can be difficult for people with different bodies and minds to take part in that church. The attitudes of church staff can make this even harder. The disabled people I interviewed often felt excluded and wanted to be able to go to accessible churches where they were fully included. But for many, finding an accessible church was not easy.

“I haven’t been to church regularly for some years now. I never feel at all comfortable during a service.”

- Anthony

Many people’s churches were not providing good disability access or facilities...

Anthony, who is on the autistic spectrum, could not find a church where they would let him take part in the service in ways that worked for him.

Victor and Hazel, a married couple who are blind, could not learn new songs because their church put the words up on a screen.

When Brianna, a wheelchair user, arrived at her cathedral church, she was told where to sit, and separated from her husband. She felt she was not being listened to about all kinds of access difficulties she was facing at her church.

“They could email the songs. They could pick up the phone and speak to us. But at no time do they.”

- Victor

“They watch me struggle... I have cried bucket loads over it, because I do feel completely invisible and violated by it.”

- Brianna

Church Buildings and How They Are Used

While church buildings could be inaccessible, choices about *how these buildings were used* could make access harder.

When Miranda went forward for communion in her wheelchair, she was made to wait until it was convenient for the servers to make space for her.

Shona, who is deaf, was often told where to sit, even if it was not the best place for her to hear from.

Brianna had to attend a different church at Easter and Christmas, because the high altar was used for these services and it was not wheelchair accessible.

Disability access can mean different things to different disabled people

In some churches, it was the *culture* of the church that excluded disabled Christians.

Lucy, who is autistic and dyslexic, found it hard to follow long sermons preached from the front. She would have preferred short talks with discussion.

Andrew, who is Deaf, asked his church to if they could subtitle the sermon. They could not afford this - but they were also not willing to share speakers' notes with him.

...But some churches were working with disabled members to make access better.

"I often haven't got a clue what they talked about in the sermon because I just can't keep track."

- Lucy

"The sermon, I've never seen that subtitled. I asked my church but I think they were quoted like £300. And they said we can't afford that for one person."

- Andrew

"But when [the new vicar] came, there was a guy in a wheelchair already, so he reordered it so there's a slope going up to the altar area in the church, which is amazing. So we can all get onto the sanctuary area."

- Sheila

Disabled people are the experts on their own needs

Decisions about uses of buildings were usually made by non-disabled leaders. Disabled people were not often asked what they needed. But they had many suggestions about what could make access better for them - often at very little cost.

When Brianna asked for changes for disabled people at her cathedral, she was not listened to.

Lucy was not asked what she needed at her church, but had ideas that would help her and other autistic members.

As Victor explained it, listening to the expertise of disabled people, instead of assuming their needs, could encourage more disabled people to come to church.

“Christ often asks: What would you like me to do for you? Does the Church ask us what we’d like the Church to do? Not so much.”

- Charlotte

“How could the church encourage more people with disabilities into the church? And what things are holding people back? It’s not just the simple things.”

- Victor





Disabled Christians Can Tell Their Own Stories

The disabled people I interviewed wanted to be more than just objects of care and charity in churches. They wanted to be full, active members of churches. They wanted to be encouraged in their own ministries, service and leadership in churches.

Disabled people want to be able to lead, not just to follow

Many of the people I interviewed wanted to take a more active role in their churches and Christian communities. Often, they were not encouraged in this, although sometimes churches were able to think differently about how to include them in active ministries.

We become our own expert, don't we? And that's the biggest message in terms of access. How about asking people in your church how you can help them?

- Zoe

Some **used their experience of being disabled people** to help others in churches.

Miranda helped to put information for her lay order into Braille.

Faith ran an online group for Christians who could not leave their houses.

Mary supported other young people with mental health problems in churches.

But **not everyone's disability experience was welcome in their churches**. Some people were not encouraged to share their expertise.

Deirdre wanted to have a prayer ministry from her bed. Her church could not find a way to include her in church prayer ministry.

Other people wanted to have wider roles in churches. This was not always easy - attitudes about disability sometimes got in the way of their ministries and gifts.

Talitha was a welcomer in her church. When they saw her welcoming from her wheelchair, people often assumed she needed help.

Victor wanted to help run Alpha groups. His church leaders were concerned about a blind person leading, because he would not be able to serve food.

Serving Others, Not Just Being Served

For many of the people I interviewed, churches were places where they became objects of care and charity. Churches I encountered during the research often talked about serving disabled people, but they did not often talk about **enabling people in their own gifts and ministries**. Instead, many disabled people were underestimated when they tried to use their gifts and ministries in churches.

But, as we will now see, disabled people have unique stories to tell and unique roles to play in churches, that can help to transform churches.

What Stories do Disabled People Tell?

Transformative Disability Theologies

Not everyone I interviewed thought they were capable of doing theology, or thought of their ideas as theological. But they all shared transformative ideas about God, churches and disabled people, from the perspective of their lived experiences.

Disabled people in my research told many different kinds of stories...

...Stories about disability and the Bible

Some people I interviewed wanted to know what the Bible had to say to *them*, as disabled people. Some disliked the way that churches sometimes use disabled characters from the Bible as spiritual metaphors. They identified with characters in the Bible who could be considered disabled, or thought in new ways about God.

...Stories about heaven and healing

Although everyone I interviewed had very different views on healing and disability in heaven, they all thought about it from the perspective of their own stories and lived experiences, as disabled Christians.

“The sermon this week was about Jesus healing a blind man. The minister said, “You’ve got to remember this man was blind and what trust he had. He threw down his cloak. He was never going to find it again.” I laughed and said, ‘Well, you’d be surprised.’”

- Hazel

“Yes, I would be autistic in heaven. It’s a key part of who I am. If you were able to amputate the autism, it would change my entire experience of life and what has made me who I am. God would accept me just as I am.”

- George





...Stories about the Upside-Down Kingdom of God

Some of the people I interviewed were very interested in the idea of a society organised according to God's values. They said churches should not treat disabled people as society treats them, but in line with God's values for disabled people, instead. Participant Zoe coined the term "the upside-down Kingdom of God" for this concept.

In some people's experience, churches are not treating disabled people any better than the rest of society.

But this was not the end of the story, for many of the people I interviewed.

"In heaven I don't know whether I will be physically healed or not but I don't think it really matters. I will be whatever is my complete self in God."

- Charlotte

The church should be better at understanding people who aren't in positions of privilege. Quite often the Church follows what the privileged society wants. I think if Jesus was here he would be interested in people who are on the margins of society?

- Andrew



Even if the churches were failing disabled people, there was hope - in the form of Jesus.

Some people identified with Jesus, as broken or disabled himself. They thought about Jesus as a man with a body. And, despite having that body broken, he was still God in human form.

Many of the people I interviewed talked about the way Jesus inspired them to ask churches to include disabled people better. Andrew talked about the need for the churches to meet disabled people where they are, on the margins of society, instead of aiming for church growth and traditional signs of success. Rhona said that churches need to look at whether their theologies match the values of the Beatitudes, and who they are a blessing to. Charlotte said that Jesus asked people what they wanted, and that the churches need to ask disabled people the same question.

“The revelation of God—I think we forget—it was a person, and somebody with hideous wounds. It was a broken person with the revelation of God.”

- Zoe

Listening to disabled people - following Jesus's example

Most of the disabled people I was interviewing found it hard to find teaching that spoke to them.

Many of them felt that churches were talking about disabled people, but not listening to them.

Several of the people I interviewed said that, by asking disabled people about their lived experience - their stories - the churches would be following Jesus's example.

“If Jesus was living here in this age, he would be with the people that don’t have anything to eat, with the people being sanctioned from benefits, with the people who aren’t able to work, and with the people that are lonely and need somewhere to go. So, as a church, those are the people that we should be honouring and ministering to.”

- Susanna







Find Out More

You can follow me on twitter [@naomi_jacobs](https://twitter.com/naomi_jacobs). As I write more about my research, it will be shared on the research blog at naomijacobs.wordpress.com.

A note on research ethics

This research study aimed to be participatory, and for disabled Christians to set the agenda for the research. This is particularly important when disabled Christians are not widely asked about their views, theologies and stories. There was a Research Advisory Group made up of disabled Christians who advised throughout the research process. As well as the interviews, I spent several months taking part in three church groups led by or with disabled Christians.

What's been left out?

This is a very short summary of some of the stories that disabled people shared in interviews for my research, intended to be written in accessible language. There is much that is not covered, as a result, including:

- Questions around who is considered disabled in our society
- Whether the Bible represents disability at all
- Theologies of disability
- The secular disabled people's movement, disability studies and the responses of these to Christianity (and vice versa)
- The ideal worshipper and the ideal minister
- Healing and eschatology
- The idea of 'welcome', and whether it is an empowering concept for disabled people
- Liberation theologies, and the role of theologians in enabling disabled Christians to tell their own stories.

Future research summaries will discuss many of these issues. In the meantime, you can read my thesis online to see my complete research. Search for *Naomi Lawson Jacobs* at the British Library online thesis repository, or email me at naomilawsonjacobs@gmail.com to request a copy.

I took part in Naomi's research because I felt that there is a part of the body of Christ that is unseen and if we can make our voices heard then we might get our needs met by our fellow brothers and sisters in Christ. We may not be physically able but I believe we still have gifts to share with the rest of the church if they could only accommodate us!

- Faith, post-interview correspondence on research message board

Disability—it's just part, for me, of the whole theology of the Church. That Jesus came to turn values upside down with the Beatitudes.

- Rhona, focus group 1

