

Fiona MacMillan - Calling from the Edge - Friday 9 February 2018

Calling from the Edge* celebrates five years of conferences on disability & church, a partnership between St Martin in the Fields and Inclusive Church. The booklet shares something of our stories and ideas, our learning and experience. And what we hope to do today is bring this booklet to life, giving you a sense of the work we've been doing together – as disabled people calling to the church. In a moment, Emily will outline her role as a digital prophet, Tim will challenge the church on baptism promises, and Ann will explain something of autism and intersectionality. But first I'll begin with a bit of background, say something of where the conference story started, and what we'd like the church to understand about **"Opening the Roof: *opening a conversation on disability, society, church and God*"**.

It's a painful thing to come back to a community and find you can no longer take part. It's hard to realise that the people around you can't see the barriers which hold you back, and don't understand your difficulties. Finding yourself on the outside and feeling you no longer belong is particularly hard to bear when that community is the church. The church is "supposed to" be with us in our vulnerable times, to accept, encourage and enable. But the church is made up of people with finite time, resources and experience.

Disabled people are often isolated by experience and that indeed was my own. Like most disabled people I've acquired conditions and had to learn to adjust. I haven't done so quickly or quietly. The key for me has been finding others who understand, who share something of my experience of disability and exclusion, and working together. I was also lucky that my particular community was St Martin in the Fields, who were willing to listen when they didn't understand and to learn alongside and from us. Over the last 6 years we've done some good things together, using our painful experiences to try to make something better.

Historically the church has been prophetic in its care for those on the edge. For hundreds of years the church challenged and changed society through its valuing of people who are powerless. It practised faith in action by feeding, housing and caring for those who otherwise would have suffered or died through poverty or disease. Many great institutions, hospitals and charities have their origins in people living out their faith, particularly in the 19th century.

Since the 1960s the disability rights movement has campaigned for greater autonomy, but the Church has been slower than society in responding to what is a significant sector of the population. In the UK today there are around 13 million people living with a disabling physical, sensory, cognitive or mental health condition, a neurodiversity or a learning disability. Of these 13 million, about 80% were born healthy and have had to learn to adjust¹. We all spend our lives somewhere on a spectrum between the super-fit athlete and the profoundly disabled person in need of 24-hour support; we move and change as a result of accident, illness or ageing. Disability will affect us all, and disabled people can be

1 *Family Resources Survey* (2015/16)

an uncomfortable presence in a society lauding youth and strength. But in a Church which professes the Gospel paradox of strength in weakness, we're often objects for pastoral attention rather than agents of change.

The Church of the 21st century frequently fails disabled people, bringing echoes of an understanding that links sickness with sinfulness, mental health issues with possession, and disability as brokenness in need of cure – often conflated with ideas of healing. Pounded on by street pastors, spoken about rather than listened to, regarded as difficult or demanding, costly or time-consuming, it's not surprising that many disabled people are put off going to church – even if we can get in. And access is often focused on getting in rather than joining in – on ramps and lifts, hearing loops and loos. We are more likely to be known by our needs than celebrated for our gifts.

Disabled people face significant barriers to access and participation and are particularly vulnerable to the impact of austerity cuts in wider society and the church. Thus in 2011, St Martin's began to explore the experience of disability, part of an ongoing commitment to working with groups who are excluded from full participation.

Within St Martin's this work is led by the Disability Advisory Group, which brings together people with experience of physical, sensory, cognitive or mental health conditions, from their own lives or from a caring or work role. Open meetings once a term explore issues and ideas - both barriers to belonging and the insights that grow from living vulnerably. We share our resources and learning with the wider community and congregation in a variety of ways – suggesting solutions to practical problems, raising awareness and increasing understanding through workshops, partnerships, creative community projects and in writing liturgy.

St Martin's works in partnership with Inclusive Church to hold an annual conference on disability and church, offering a place and space for disabled people to learn alongside and from each other. Centred on lived experience, underpinned by theology and modelling belonging, disabled people gather to resource each other and the Church.

Back in 2012 we opened our conversation by ***Opening the Roof***, a conversation about disability, society, church and God". We had no idea what we'd find or who, if anyone, would come. We heard a story of vocation, of disability theology as a liberation theology, and the changing context of wider society amidst cuts and Paralympics. In 2013 ***Places of Belonging*** explored disability, mental health, God and inclusion - because mental health issues are generally not recognised as being part of disability. We heard stories of outsiders and Otherness, the importance of church communities and that "to belong means you are missed".²

In 2014 ***Transforming our Vision*** was led by the wonderful John Hull, a beloved, blind theologian, as we explored the importance of language in naming, understanding and transforming our experience, and considered vision as sight, insight and hope. 2015's

2 John Swinton in *Mental Health: The Inclusive Church Resource* (DLT 2014)

Living on the Edge discussed disability, church and exclusion, and living where we are without waiting to be included. We heard stories from individuals and groups from around the country, using their painful experiences of exclusion positively and creatively to call to the church. In 2016's ***Prophets & Seers*** we considered if disabled people have a distinct prophetic ministry to the church. We heard stories from people who call from the edge with courage and clarity, and encouraged each other to find our voice and speak our own truth. Finally, last year in ***Just As I Am*** we asked what it means to be disabled, and what that might tell us about God? Are we living theology?

Over these six years we've drawn more than 300 delegates from across the country to explore gifts and share ideas of presence, paradox and prophetic ministry. People who come and find community are often an only in their church – the only wheelchair user, the only voice-hearer, the only cancer survivor or the only autistic person.

In our gathering we know what it is to live with our own vulnerability, to know our weakness, to depend on others and to feel our Otherness, and perhaps that gives us a particular wisdom, a prophetic voice to call out to those at the heart of the Church. We are canaries in the modern mine and it might be wise to listen.

So what would we like to say? Looking back to the beginning, these are my headlines:

When we began in 2012, two things in particular had changed our understanding of disability in the UK, and they're still competing narratives. The Paralympics had brought a sudden increased awareness of disability, making it OK to be a person in a wheelchair or to have one leg, even if you couldn't win medals with it. Disability was almost cool. But according to a recent SCOPE survey, 67% of the public hesitate even to talk to a disabled person³. *67% of people hesitate even to talk to a disabled person*. That's worth remembering next time we're talking about unconscious bias.

At the same time we had the Welfare Reform Bill, then the Bedroom Tax, followed by a host of cuts to support and services⁴. Cumulatively catastrophic, they have damaged disabled people's ability to live independently and take part in society - the social model of disability in action⁵. Narratives abound that "benefits are a lifestyle choice" and "work is always good for your health". Newspaper stories of benefit scroungers led to exaggerated ideas of widespread fraud and an unprecedented rise in disability hate crime⁶. Otherness always trumps understanding. Yet while disabled people are increasingly excluded, church resources are largely focused on buildings and adaptations.

In some parts of popular culture, disability and superpower are impossible to separate. Superman is known for his strength and speed rather than his Kryptonite allergy, and Spiderman for his balance and ability to hear people in peril from miles away. He's not

3 *Current Attitudes towards Disabled People* (Scope, 2014)

4 *Counting the Cuts* (Centre for Welfare Reform, 2015)

5 <https://www.theguardian.com/business/2016/nov/07/uk-austerity-policies-amount-to-violations-of-disabled-peoples-rights>

6 <https://www.disabilityrightsuk.org/news/2016/september/ehrc-publishes-disability-hate-crime-report>

diagnosed with hyperacusis or blamed for being too sensitive. It is our perception which creates our understanding of what is strength or weakness, what is need or gift.

But we are all a combination of needs and gifts, and when our needs are met, our gifts can flourish. Some of us may have needs which are more obvious, or gifts which are more hidden, but we are all a combination of needs and gifts. This is at the heart of my understanding of disability theology.

The disability rights movement of the 1960s coined the phrase “Nothing about us without us”. Sadly within the church today most of the talking about disability is still done by non-disabled people. Talking about is not yet listening to; “being for” is not “being with”⁷.

This conference work has been blessed by design, with a majority of disabled people in the planning team, as speakers and as delegates. We welcome all who are interested in the issues, but disabled people are the primary audience. Each year we invite new people to join us at the heart – drawing a speaker from the previous year's delegates, or a liturgy-writer from among the previous year's speakers, and inviting them to join the planning team. We are refreshed and renewed by this growing network of energy and ideas, resourced by a community where our needs are understood and our gifts are celebrated and put to work: calling from the edge.

Fiona MacMillan is a Trustee of Inclusive Church and Chair of the Disability Advisory Group at St Martin in the Fields. The above talk was given to a fringe event alongside General Synod, Central Hall Westminster, 9 February 2018.

*Available to download from: <https://tinyurl.com/y8cdlzvg>
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