

Calling from the Edge



I worked in a community for several years where one of the leaders once said to me, 'You know, we're a bunch of misfits who somehow fit together.' What he was recognising was that, rather than rebelling against feelings of rejection, we'd found if we worked constructively with them we could become something rather beautiful. People sometimes use the word inclusion but inclusion isn't really the right word. It isn't the right word because it suggests there are a bunch of people in the centre whose lives are normal and sorted and privileged, and they should jolly well open the doors and welcome people in and be a bit more thoughtful and kind and generous. The problem with this is that it's such a patronising and paternalistic model. When the community leader said, 'We're a bunch of misfits who somehow fit together,' he wasn't regarding himself as normal and secure and somehow above it all: he was one of the misfits too. He was reframing the whole idea that there was a centre and a periphery, where the centre gave kindly hospitality to the periphery, because the cost of that idea is that the periphery feels humiliated and the centre feels smug.

The churches in England are down in the dumps because they think they need to be full of big and strong and powerful people. But Jesus was the stone the builders rejected; and in his ministry he surrounded himself with stones that the builders had rejected. Jesus didn't found the church on the so-called centre – the sorted, the normal, the benevolent and condescending. Jesus assumed the church would always need the work of the Holy Spirit – the work or miracle, of subversion, of turning the world upside-down. Nothing has changed – except for a lot of the intervening years the church has forgotten who Jesus was and whose company he kept.

I'm not talking about a bland and affirming insight that a lot of people who've been overlooked in life turn out to have some important things to contribute.

This booklet celebrates five years of conferences on disability and church: a partnership between St Martin-in-the-Fields and Inclusive Church



The stone that the builders rejected didn't find a place in the wall somewhere by being thoughtfully included like a last-minute addition to a family photo. The rejected stone became the cornerstone, the keystone - the stone that held up all the others, the crucial link, the vital connection. That's what ministry's all about - not condescendingly making welcome alienated strangers, but seeking out the rejected precisely because they are the energy and the life-force that will transform everyone. Every pastor, every missionary, every evangelist, every disciple should have these words over their desk, their windscreen, on their screensaver, in the photo section of their wallet, wherever they see it all the time - the stone the builders rejected has become the cornerstone. If you're looking for where the future church is coming from, look at what the church and society has so blithely rejected. The life of the church is about constantly recognising the sin of how much we have rejected, and celebrating the grace that God gives us back what we once rejected to become the cornerstone of our lives. That's what prophetic ministry means.

Revd Dr Sam Wells, Vicar, St Martin-in-the-Fields

The following pages come from these conferences; the text above the line is from speakers, below are comments from delegates. These are our calls to the church.





Opening the Roof • 2012

We opened our conversation about "disability, society, church and God" without much idea of 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.



Fiona MacMillan is chair of the Disability Advisory Group at St Martin-in-the-Fields and a trustee of Inclusive Church. She leads the conference planning team.

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 vulnerability; to accept, encourage and enable. But the church is made up of people with finite time, resources and understanding.

Disabled people are often isolated by experience, and that indeed was my own. Like 80% of 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 lucky that my particular community was St Martin's, who were willing to listen when they didn't understand, and to learn alongside and from us.

Over the last six years we've done some good things together, using our painful experiences to try to make something better. Within St Martin's, the Disability Advisory Group leads this work, identifying issues and sharing the insights that grow from living vulnerably. We work with Inclusive Church to bring these conferences to life, giving spaces and places for others to come and share their stories and ideas, refreshed in the knowledge that they are not alone. Centred on lived experience, underpinned by robust theology, we gather to resource each other and the church. We're all a combination of needs and gifts, and when our needs are met our gifts can flourish.





The Revd Rachel Wilson was ordained in 2012 and currently serves as Vicar of St Thomas, Southborough in Kent. She has cerebral palsy.

Disability is not something to be "allowed for" or excused but something to be truly embraced. I say this because each person who crosses the threshold of the church, disabled or not, is made in the image of God and is to be regarded as precious for that reason.

It is the role of the church, first and foremost, to welcome people by virtue of their unique humanity, whoever they are, not because you might believe that as a disabled person I especially need to be "looked after". However unwittingly, if we are not careful, such all-encompassing kindness can become oppressive.

We must allow disabled people to grow within the church, to become the people God has intended them to be; that includes allowing them the room to question, to make mistakes, to be angry, to be dismissive, in common with their brothers and sisters.

I believe that if disabled people were allowed to truly flourish in the service of the church, in whatever capacity, then the effect would be transformative.

from Disability: The Inclusive Church Resource © 2014 Inclusive Church



It is really important to have a chance to tell our stories, hear them underpinned by theology and find out how they can – or should – influence wider public policy."





The Revd Dr Clare Herbert is Tutor in Practical Theology and Pastoral Care at St Augustine's College of Theology in Kent. She was previously on the staff at St Martin-in-the-Fields and a trustee of Inclusive Church.

My task as Lecturer in Inclusive Theology at St Martin-in-the-Fields was to draw into the light groups of people who receive a warm welcome at St Martin's but who consequently remain in the shadows, unlikely to find a voice in organisational leadership, policy making, or the performance of liturgy.

When I began this work I was outraged that my disabled colleagues vented such wrath around St Martin's. Now I understand... a little. When I add up what has happened to them most weeks in terms of benefit cuts, rudeness, means assessment, disablement from positions of empowerment, and frustrations in travel and communications I wonder how they have made it to Church at all.

Then, if the door is locked, or face unfriendly, or lift not working again, the effects of the frustrations endured in the past week may be cumulative.

from Disability: The Inclusive Church Resource © 2014 Inclusive Church



We need to move on from welcoming disabled people as an act of grace and see them as whole people with as much right to be there as anyone else."



Places of Belonging • 2013

We focused on "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 "to belong means you are missed".





Professor John Swinton was keynote speaker in 2013. He is Chair of Divinity and Religious Studies at the University of Aberdeen and an ordained minister of the Church of Scotland.

Stigma occurs when we name things wrongly. The world of stigma is ugly. It destroys and caricatures people and leaves them lonely, isolated and lost. This is why the apparently small gesture of giving someone back their name is profoundly powerful. It is a way of making people who have been deemed to be ugly beautiful again.

To name things properly is to act humanly and to bring "non-persons" back into the community of humanness. The task of the church as it meets with people experiencing mental illness is to model Jesus renaming of the disciples: I no longer call you mentally ill, a schizophrenic, bipolar or any other destructive name. Now I call you friends.

from Mental Health: The Inclusive Church Resource © 2014 Inclusive Church





Miriam Hodson was diagnosed with bipolar affective disorder in 1996 at the age of 29. As well as being a speaker, Mims has been a member of the conference planning team since 2014.

When I am manic I talk incredibly fast and sometimes don't make sense. Please try to listen to me and don't just walk away. Sometimes there is a lot of sense in what I am saying if you take the time to listen and even if there isn't you can normally tell what emotions I am feeling and feedback to me, how I seem.

Sometimes when I am psychotic I may tell you completely mad things, like some of the stories I have talked about above. Again you can listen and try to put yourself in the situation of understanding what it feels like to be in the world I am experiencing. If you bluntly tell me you don't believe what I am saying rather than understanding it is my reality you will upset me or make me angry.

One of the most hurtful things that can happen when I am manic, is that people walk away because they don't know what to say or do. I believe that one of the biggest causes of exclusion is fear. People are scared they will make things worse. It is ok to say you don't know what to say or do. We are all individuals and have different needs, so just ask how you can help.

from Mental Health: The Inclusive Church Resource © 2014 Inclusive Church



I never knew there were so many people who thought the same as me, experienced the same as me. It's easy to feel very alone, especially when church is hard to access and people want to fix me all the time. I wish we could do it more often."





The Revd Eva McIntyre is a storyteller and actor as well as an author and priest. She was a speaker when also national coordinator of Mental Health Matters.

The statistics tell us that one in four people will experience mental illness in their lifetime. This figure is based on those who go to their GP and receive a diagnosis; the real figure is likely to be much higher.

Mental illness is no respecter of age, gender, race, class or education. None of us is immune; at the drop of a hat, our lives can change and bring us to a point of crisis and then we are one of those 'statistics', whether we go to the GP for help or suffer in silence, afraid of the stigma that will attach to us if we acknowledge what is happening.

When I first spoke out about my past experience of depression and anxiety, I wasn't sure what the response would be. As I stood at the Church door, one after another, people confided in me, 'I'm one of four, too!' and so we were no longer alone.

It's as simple as that to begin the journey towards mutual support and trust.

Extract from Mental Heath: The Inclusive Church Resource © 2014 Inclusive Church



The church's role is to heal, not cure – including mental health problems like depression. Holy joy does not equal the absence of depression."



Transforming our Vision • 2014

We explored the importance of language in naming, understanding and transforming our experience. We considered vision as sight, insight and hope, and heard stories of awareness, acceptance and transformation.



Professor John Hull was an outstanding speaker at the first conference and returned in 2015 as keynote speaker. His experience of blindness and deep understanding of disability theology gave him an unparalleled insight which he was delighted to share.

Until his death in 2015, John was Honorary Professor of Practical Theology in the Queen's Foundation for Ecumenical Theological Education, and Emeritus Professor of Religious Education at the University of Birmingham.

Disabled people have a distinct ministry in the church. Disabled people are not so much a pastoral problem as a prophetic potential. We need to ask not how the church can care for disabled people but to ask what is the prophetic message of the church in our culture and how disabled people can make a unique contribution to that renewal.

This is not to value disabled people because of what we are supposed to be able to learn from them, such as their alleged courage, patience and cheerfulness. That would be to make instrumental use of disabled people. My question is not what we have to learn from disabled people but how the whole church can respond to its evangelical calling and how disabled people can not only participate in this but can become witnesses to and leaders of it.

In order for the church to be the church, people with disabilities should accept the church and try to change it from within. There is not so much a question of including disabled people in the church; it is rather a matter of the normal church learning how to welcome those who appear to be different, and in that welcome which embraces difference to rediscover the prophetic calling.

from Disability: The Inclusive Church Resource © 2014 Inclusive Church





Ben Allison is a priest in the Church of England and an award-winning performance poet who is dyspraxic and autistic. He was a speaker in 2014.

My disability is stealthy, I have no chair, or stick, or missing limb to mark me out. Indeed for the first 18 years of my life the thing I now call "disability" was invisible even to me.

There was always a certain "oddness" about me; words and phrases like "scatterbrained", "eccentric," "nutty professor", "distracted", and sometimes just plain "lazy", have followed me throughout my life.

But when the label, "dyspraxic", and later, "autistic", were applied to me, I finally felt that here were words that my "oddness could truly inhabit. I finally felt like I had found words for what I could not see or understand in myself.

from Disability: The Inclusive Church Resource © 2014 Inclusive Church



I survived all kinds of things in the church – coming out as gay, being a woman... I didn't survive disability in the church – I lost my faith. The church needs to examine itself on disability issues, or more and more people will leave."







Revd June Boyce-Tillman MBE is Professor of Applied Music at the University of Winchester. A celebrated hymn writer, composer and priest, June has a particular interest in the relationship between theology, spirituality, healing and the arts. She has been part of three conferences.

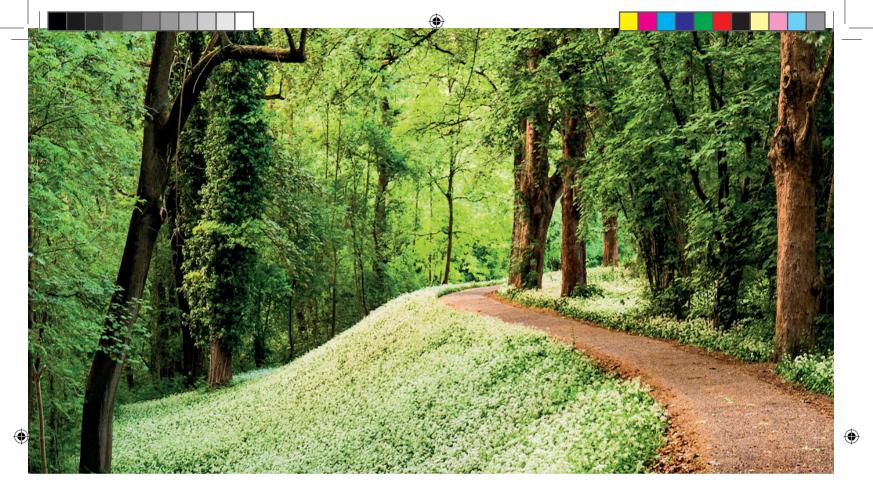
Disabled clergy celebrating and preaching confronted me with my own assumptions. I shared leading the conference communion service with a priest who had difficulties with his hands. I watched the care with which he broke the bread - the energy and the concentration.

There was immense power in the body of a vulnerable priest at the heart of the Eucharist. It enabled me to come to terms with my own walking difficulties, to be more honest about my own disabilities and to see them as a strength rather than a weakness.



Our disabilities don't necessarily detract from how whole we are, please don't presume we need to be healed or that we have nothing to contribute – everyone has gifts to give."





Living on the Edge • 2015

We discussed disability, church and exclusion, and living where we are without waiting to be included. We heard stories of individuals and groups from around the country who are using their painful experiences of exclusion positively and creatively to call to the Church.



Susan Marina Wolfe is an American social historian living in London. Following an encephalitis, a brain tumour, surgery and epilepsy, she suffered a stroke affecting her vision, hearing and balance.

Like the War Poet, Edward Thomas, "I don't so much believe in God, but I do believe in the landscape."

I was feeding pigeons organic popcorn in a little park one day when a solitary starling, looking for a nosh, strolled into the group. Starlings can't eat popcorn. They're carnivores. I love a starling. Who doesn't? But I hadn't thought to bring the mealworms he could eat.

The starling looked at the popcorn. Organic or not, he couldn't eat it. He gave a sad and starling sort of shrug and flew away.

Every day for weeks now, I've brought mealworms with the popcorn but he's never come back. Prepared for him now, but too late, I've never seen him again. I'm happy to feed the pigeons. I talk to them, they talk to me, but the bird who needed something else has not returned. I hadn't brought what he could eat. I'd only thought of pigeons because they're all I'd seen there.

"Inclusive" must anticipate. Our October conferences anticipate even when our individual churches have sometimes failed to do so. We come together at each conference and we talk - together. Our own differences don't matter as much as what we have to learn from them and from each other.

Some of us eat mealworms and some of us eat popcorn but, year on year, aren't we together, the most wonderful, powerful flock in all creation? Damn straight we are and more so all the time!

Ann Memmott is autistic, disabled, and the author of the guidelines for autism for the Church of England. She is also a national speaker on autistic access, and on the intersection of autism, disability and LGBTQ lives.

What do these annual disability conferences mean, to me? I chose this photograph that I took. It was taken from the Lightwell at St Martin-in-the-Fields, looking up towards the church spire. There is the symbol of the cross visible at the top, against a patch of light blue sky. A bird is flying past. In the lightwell, it seems dark.

Life as a disabled person can seem dark at times. The barriers in society are so great. It can feel like having to climb an unclimbable wall. Never seeing the sunlight. The journey I had with cancer has been one such experience. So has the journey with arthritis that has been very bad at times.

The conferences have brought me into contact with such good people. People who know this journey. People who have brought the light back into my faith life. People who have shown me anew what it is, to be a disabled autistic Christian. People who have realised that my brain takes in too much information, rendering me blinded and deafened... and exhausted. Pacing myself has been so important, but so difficult in life.

At the conference, I felt as free as a bird. Free to be myself. Free to express my faith and my love, in ways that are meaningful for me. Free to communicate in ways I can manage.

It is a true blessing, and I am so very thankful to be a small part of this great venture.



I found myself at the conference almost by accident. I have been moved and shaken into myself. For the last year I have been really struggling to keep going. I've had no idea how to get by. Now I know what I'm doing. I know how to live going forwards. Thank you, thank you, thank you. Whatever the cost, you are doing the right thing."









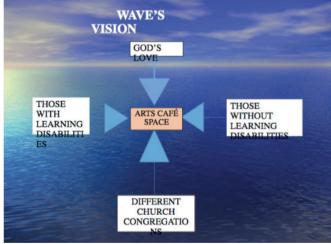
It's amazing to find that there are other disabled church leaders; I always thought I was the only one."



WAVE (We're All Valued Equally) is based at St James Muswell Hill in London. WAVE creates communities where individuals with and without learning disabilities can comfortably mix, learn together and encourage each other while growing in confidence and friendship.











I've never heard people talk about disability as being a positive thing. Now I feel special."





Naomi Lawson Jacobs is a PhD candidate at SOAS, University of London, carrying out research with disabled Christians.

There is much discussion about disabled people in churches and theology today. but the conversation is not being led by disabled Christians. Instead, non-disabled ministers and theologians are writing most theology of disability. We have almost no research about disabled Christians, so we know very little about their experiences.

In my research with disabled Christians, I have found that their stories and opinions are varied – of course. However, many of the participants feel shut out of churches. Sometimes they are literally shut out, by inaccessible church buildings. Sometimes they are excluded through church cultures, and the inflexible attitude of 'we've always done it this way'.

For many, being accepted as they are is important, but they feel 'spotlighted' for healing in church. Some want to lead in churches, but instead have only had opportunities to be looked after.

Research likes this shows that disabled Christians have their own stories to tell. Stories about being disabled in society and churches today. Stories about faith, Christianity and God.

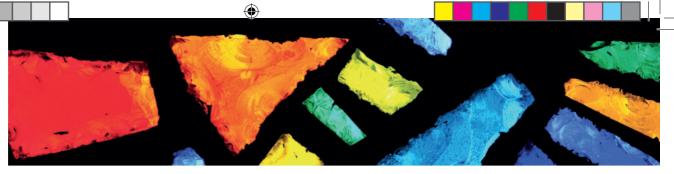


Disabled people are amongst the most marginalised and overlooked people in today's church, and the church needs to acknowledge its contribution to our general social oppression."



Prophets & Seers • 2016

We responded to the challenge from our late friend Professor John Hull, considering whether 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.



Donald Eadie lives with a serious spinal condition which forced him to retire early as Chairman of the Birmingham District of the Methodist Church. He is a much-consulted Methodist minister, leading retreats and writing about spirituality. He was our first virtual speaker, contributing via video.

Physical limitation, perhaps even divine calling, brings some of us to a marginalised place. It becomes a conversion experience. There is a connection between our experience of our body and the body of Christ. We are discovering theological and spiritual meaning within the experience of our bodies.

We are learning that theology must not be left to the fit and strong. Theology must also be wrestled for through pain and disability; these are the raw materials of our encounters with a mysterious, silent, hidden and powerless God. It is our experience that the church finds it difficult to receive the gifts of God through those who live with impairments. We are an uncomfortable presence.

We bring our experience of darkness as the context of hidden growing and transformation. We bring our calling to go into the fearful places without being imprisoned by fear. We bring our experience of fragility, of physical weakness, of what it means to trust, and of the mystery of strengthening within our continuing reality.

We bring our experience of restoration through touch, embrace and holding, and of an inner healing which is deeper than physical healing. We bring our experience of our bodies, a source of wonder, pleasure and pain; the dwelling place of God, where we meet God in the here and now of our actual humanity.

We bring our experience of waiting, waiting into the unknown. We bring our experience of anger. We bring faith journeys which sometimes include the experience of dereliction, of God-forsakenness, of being apparently without faith in order to grow in faith.

We bring these gifts and many others, not as victims but as liberators.





Emily Richardson tweets for no less than three churches and is passionate about communication on digital media. She is involved in the Moot Community, a contemplative community in the City of London, as well as her home church All Saints Fulham.

I attended my first disability conference in its fourth year and found it hugely inspiring. I was a quiet delegate in the audience. The next year I was somehow sharing my story from the front!

This pushed me way beyond my comfort zone since I have always found it hard to speak in public. But something about the conference's strong emphasis on seeking the voices from the edge compelled me to be brave and share my story.

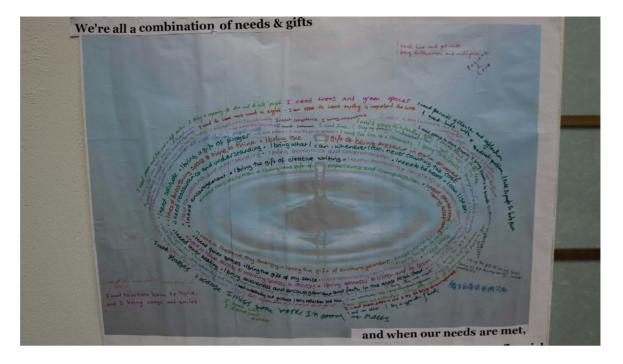
Knowing that I was in an environment of my peers gave me the courage to stand up in a room full of people and do the unthinkable: make my voice heard.



I have to remember to book months ahead because so many of us are competing for that one wheelchair space on the early train from the North"







Katie Tupling, Bill Braviner and David Lucas (accompanied by guide dog Jarvis) make up Disability & Jesus, a user-led group who campaign on a wide range of disability issues. They are building their large Twitter following into a lively virtual community.

We were in a room full of people who were talking not just about disability, but from within disability.

The hallmark of these conferences is that disabled people are not just part of what is happening, but are the driving force in planning, hosting, delivering, reviewing, and participating.

To encounter such real inclusivity, to see what incredible depth there is in the experience when real inclusion happens, is a wonderful thing.



My weakness and my weariness can be something like a gift."





I thought that I had this 'inclusive' thing sorted. After all, I worked for Inclusive Church and had been Vicar of an inclusive church. Ticking the disability box was easy – get the ramp out, switch on the hearing loop and make sure the loo is ready. Job done!

What changed for me was meeting disabled people at the conferences. Having listened to people with first-hand experience, I have a better understanding of the physical and emotional energy needed to do things that many of us take for granted. I am more aware of the complex hidden disabling conditions that many live with where no sticks or wheelchairs are in sight.

Many people are excluded from church simply because church is entirely geared for (and run by) the well. Our failure to recognise that disabled people are present in our congregations means that we fail them. We fail to make provisions and many drift away.

The conferences on which St Martin-in-the-Fields and Inclusive Church have collaborated over five years have drawn together people with lived experience of disability, each of whom has a story. It was listening to these stories that changed me. I hope you will allow these 'voices from the edge' to speak to and change you.

Bob Callaghan, National Coordinator, Inclusive Church



Our thanks

These conferences have been made possible because of the generous support of too many people for us to name individually.

We are particularly grateful for the conference planners, contributors, speakers, facilitators, delegates, stewards and staff, who have shaped, shared and supported our work together. Except where indicated, copyright is retained by the authors.

We are grateful for the support of the clergy, congregation, committees and staff of St Martin-in-the-Fields, who have generously shared resources, expertise and encouragement.

We are grateful for the support of the trustees of Inclusive Church, who have enabled our voices to be heard.

This booklet would not have been possible without the generous support of Westhill Trust.



Resources

Material from the conferences, suggestions for further reading, and a downloadable version of this booklet, are available from:

www.inclusive-church.org/disability • www.smitf.org

The Inclusive Church Resource Book series - particularly *Disability and Mental Health* - were initiated through the conferences. Details can be found at

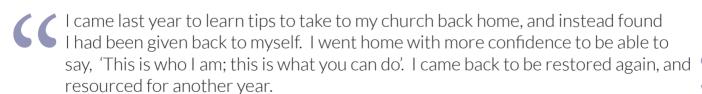
www.inclusive-church.org/resources/inclusive-church-books

Enquiries to disability@smitf.org









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