

# THE ENABLED LIFE

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# THE ENABLED LIFE

*Christianity in a disabling world*



Roy McCloughry

**SPCK**

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*For my mother  
Enid McCloughry  
(1917–2013)  
whose gentle Christian presence in my life  
has been an inspiration*



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# *Acknowledgements*

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I still regard it as a privilege to be asked to put down some thoughts on paper with the assumption that others might want to read them. As someone involved in publishing I am aware of how many people are working industriously on books that will never see the light of day. What can be the justification for adding another book to groaning bookshelves everywhere?

I think there are subjects of such importance and urgency that it is an obligation to contribute something if one can. In my case this small book comes out of my own personal experiences and theological reflection on them. Although there are some ideas and passages that readers may find challenging, it is a book aimed at disabled people, their friends and colleagues as well as church and community leaders, and is written from a faith perspective. Those who want a more academic approach to the subject will find that authors such as Brian Brock, Deborah Creamer, Nancy Eiesland, Stanley Hauerwas, Hans Reinders, John Swinton, Amos Yong and Frances Young have written books that are illuminating and strategic in their approach to the subject. I have included a short guide to further reading at the end of this book.

I am grateful to the many people with whom I have had conversations over the years, including Brenda Darke, Christina Gangemi, Tim Hull, Lars Johansson, Jon Kuhrt, Nick Ladd, Alice Lawhead, Else Månsson, Helen McCloughry, Lizzie McCloughry, Joanna McCloughry, Lauren McCloughry, John Naudé, Ian Paul, Karin Ramachandra, Vinoth Ramachandra, Hans Reinders, Elisabeth Sandlund, Haydon Spenceley, John Swinton, Michele Taylor, Gordon Temple, Christopher Ward, Harriet Ward and

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I am also grateful to successive years of students who have taken my lectures on personal and social ethics at St John's College, Nottingham and who have become interested in this subject. Most of them are, or will be, ministers in the Church of England and it is my hope that something of our time together will have affected their ministry for the good.

I am also grateful to Jean Vanier for being willing to see me at his home in Trosly-Breuil outside Paris in June 2012. Jean is now in his 80s and his kitchen table was piled high with books, manuscripts and tapes. He was very gracious in receiving Helen and myself when he was very busy. Seated opposite me and with eyes fixed on me as our conversation progressed, I was aware of a quality of listening that is rare. On occasions when talking of the gospel his face lit up with joy. Several times I was so moved that I found it difficult to carry on with the interview. Jean's life has been lived with people with profound intellectual impairments and he speaks as one who 'walks the talk'.

I would also like to thank those many people who have entrusted me with their stories, whether it was coming to see me following a talk in a church or a Christian festival such as Greenbelt, or more personally because they wanted to be heard by someone willing to listen to what had happened to them. In particular I would like to thank those who shared their stories with me on trips to Asia, Africa and Central America; they often seemed to be living in very challenging, or impossible, circumstances.

I am grateful to my friend, Alison Barr from SPCK, who edited an earlier book I wrote with Wayne Morris. She has been the epitome of patience and graciousness as the book refused to 'drop into her inbox'. Thank you, Alison. The trustees of the Kingdom Trust have been supportive of my work for many

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years and I am grateful to them as well. My thanks go to Martyn Eden, Peter Ellis, Richard Farnell, Jon Holt and Wendy Sayers.

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My mother, who from my ninth year brought me up as a widowed single parent, enabled me to flourish by possessing that loving liberalism that appears to give a child freedom while maintaining invisible barriers around them. This book is dedicated to her, not just for that, but also for the fact that she has been an inspiration to me in my Christian life. Sadly for me but gloriously for her, she passed away while this book was in its last stages, at the age of 95. As I stood by her bedside in her last moments I signed her with the sign of the cross and read from 1 Corinthians 15.54–55: ‘Death is swallowed up in victory. O death, where is your sting? O grave, where is your victory?’ For me, that is an illustration of one of the themes of this book. What the world sees as weakness and defeat, the Christian sees as power and opportunity.

Finally, my thanks go to my wife Helen, who being lovely as she is could have got a better deal in a husband, but chose to bestow her love on this one. No man could wish for more.

*Roy McCloughry*  
*West Bridgford*

## A preliminary note

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It is important to say something about language. Throughout the book I have used the term ‘disabled people’, which refers not only to people because they live with an impairment but also to the fact that they are disabled by social attitudes and other barriers. Often the word ‘disabled’ is seen as just applying to the body, for which I use the word ‘impairment’. The question is, what complementary term should be used to describe people who do not have an impairment? Often the term ‘able-bodied’ is used, but this is not the complementary term to ‘disabled’ when it is used in this sense, as it refers only to the body and not to social attitudes and barriers. At other times the word ‘non-disabled’ is used, but this term defines people by a double negative which is not helpful. If we want to emphasize that disability is as much about inappropriate social attitudes and prejudices as it is about physical impairment, then the word to use is ‘abled’ rather than ‘able-bodied’. What we need to show is how much of the identity of people who do not have an impairment is socially constructed. Some are *disabled* by society while others are *abled* by it. I want to highlight the extent to which those who do not have an impairment are privileged by the society that also disables those with an impairment.

However, I am as aware now as I have been over the last 15 years that you cannot win when it comes to the use of language, as it is so inextricably intertwined with ideology. I was grateful to commentators at the 2012 London Paralympics such as Dame Tanni Grey-Thompson, who went a long way to defusing this by drawing attention to the fact that the most important consideration is not wishing to cause offence rather than knowing the acceptable political language of the day.

I was not brought up to think of myself as a disabled person. Some would say that epilepsy is a ‘disabling condition’, making that a distinction. Epilepsy is one of those conditions where people affected can spend much of their time appearing to be healthy and functioning well, only to then experience a time when they are seriously debilitated by having a seizure. One can live in two worlds, and I discuss this in the book. For this reason readers will find that I sometimes include myself as a disabled person and at other times refer to disabled people more generally.

There is perhaps one other thing to say. In the West we are blessed with good medical care and a recently improved situation with respect to rights for disabled people although many disabled people live in poverty in this country. Many have also experienced heartache and injustice because of the current UK government’s campaign to ‘reassess’ the suitability of disabled people to return to work. This seems to be based on the extraordinary idea that many disabled people are ‘scroungers’ and ‘benefit cheats’. Although it has to be acknowledged that state benefits have to be adjusted from time to time, it has to be said that a nation should be judged by how it treats those who are poor and marginalized rather than how many ‘freedoms’ it creates for its wealthy. History may not judge this episode kindly.

However, while keeping this in mind I am also thinking of those in other parts of the world who are among the 650 million people who live with an impairment, or those who live with someone with an impairment. To walk the streets of Asia or Africa, or have the privilege of visiting people in their homes, is to become aware of the powerlessness and abject poverty in which many disabled people live in other parts of the world. They are frequently to be found among the poorest of the poor. I would ask readers of this book to have them in mind too – not just those of us who live in Western society.

# 1

## *Two worlds*

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A woman who is a wheelchair user is accustomed to others treating her as if she is only half there. People often talk over her head to the person pushing her wheelchair. Then one day she breaks her leg. She is still in her wheelchair but now has her leg very visibly in plaster. Everything changes. People now assume that she is a ‘normal’ person who has broken her leg and will be walking again soon. They treat her entirely differently. She is one of ‘us’. They talk to her and treat her as a ‘real’ person. After a few weeks the plaster cast comes off and within days she returns to her previous experience of being overlooked. She is one of ‘them’.

We live between two worlds. We see competition, ambition and autonomy as characteristic of the world of success. On the other hand we see disability, poverty and powerlessness as signs of a world haunted by endemic failure. We assume that the world of success has nothing to learn from the world of failure. It is best not to have anything to do with it. Of course, the media presents us with harrowing pictures of the ‘other world’, but we are well-practised voyeurs who do not engage easily. We are like tourists who have paid ‘good money’ to go on a guided tour of a shantytown but who are more concerned with taking photographs of people than relating to them. We may be money-rich but we are time-poor – we do not have the time to slow down and listen. We move on.

In a fast-moving world, ‘making time’ for someone is to give them significance in one’s life. But there is a pressure in our culture to make time only for those things that benefit us.

In a competitive and ambitious world, we may see ‘networking’ as something that is beneficial but see ourselves as having too little time to spend on making friends. After all, true friendship is an end in itself, not a means to an end. To say of someone, ‘I’ve got no time for her’, is an act of judgement so complete that there is no comeback from its total rejection.

People who live in a world of success would like to seal it hermetically and deny that any other world exists. Yet from time to time they experience an irrational sense of fear. They know that there is just a thin veil separating being successful from being destitute, between successful relationships and being rejected, between being autonomous and being disabled. Elderly relatives may succumb to dementia, friends may be made redundant, people they love may die of cancer; and they are reminded that at any point they might find themselves living in a world they know little about and for which they are totally unprepared. They realize that they are only *temporarily* abled.

These two worlds, far from running in parallel, are closely intertwined. To befriend people who have experienced brokenness is to realize that although at that point their story may differ from ours, they are no different from us. We become more human as we learn from one another, and to do so is to make time for one another. It is time rather than money that ends up bestowing the greater affirmation upon another person. In a universe of two worlds where one is characterized by success and the other by apparent failure, all cross-cultural relationships are asymmetric. Friendship is impossible because the world of success cannot admit that it can learn from the world of failure, and the world of failure can find no place in the world of success.

If I believe that who I am depends on what I have achieved, I am unlikely to value the life of someone with an intellectual impairment. I can live my life without that person. To break this deadlock takes courage. It can only be done by realizing

that there is no ‘us’ and ‘them’ – there has only ever been ‘us’. We are not doing things ‘to’ other people, nor are we doing things ‘for’ other people. We can only do things ‘with’ other people. People like us.

It takes a revolution in thinking for a person rushing through the day aided by the accoutrements of time-saving tablet PCs, computers and mobile phones to realize that the wheelchair user they have just ignored, who they pass every day, might be the one who can rescue them from the dehumanizing fate that is rapidly approaching. To be successful in a world so distorted that it drives people to prefer the material to the spiritual and status to friendship is to trade one’s soul for the ephemeral. The fact is that in order to change a society in which disabled people are excluded, I have to change *my* life. This is the task of theological reflection, discussed later in this book. It is not something that is addressed by the disability rights literature, which, like politics in general, talks the language of justice but not the language of love.

We are most ourselves when we are present with one another. Being able to do this requires a degree of stillness and a willingness to see being with another person as worthwhile, when previously we might have viewed it as wasting time. Nor are we most human when we are receiving something worthwhile from another person. Love does not require reciprocity. A friend does not have to speak or be coherent. Listening conveys love. True friendship is based not on what I receive from other people but on loving them for their own sake. Jean Vanier talks about this in the conversation at the end of this book.

But in a world where some are too busy to be attentive to other people, and where in turn others have been led to believe that they are unworthy of those attentions, love is rarely to be found. Of course, decent people can act in a friendly way towards another person, but to involve oneself in friendship is quite another matter.

When we reflect on the world of disability and the challenges and opportunities it represents, the question we face is, 'How can we bring these two worlds together so that we can learn together what it means to be human?' It is impossible to develop any kind of Christian perspective on disability without the two worlds coming together. The problem is that there are major hazards in both worlds that prevent us closing the gap. These may be invisible to us: often our most powerful beliefs are the ones we are least aware of. Those of us who are prejudiced against disabled people may well protest the loudest when we are accused. Self-delusion is everywhere and we have the capacity to pull the wool over our own eyes. When we befriend someone who is very different from us, they may begin to tell us that they see us differently from the way we see ourselves. In complete contrast, spending time in the company of people who have identical views and backgrounds to ourselves means that we are rarely challenged and will never learn to see the world differently. It is when we open up to those who are different from ourselves that we begin to grow as human beings.

The problem that arises between abled and disabled people is one of power. People who are abled and hold positions of power make many of the decisions that affect disabled people. Politicians and policymakers rarely see the world through the eyes of disabled people, even when they are appointed to committees to advise them. Disabled people have to live in a world made by and for abled people. The onus is on disabled people to raise awareness that they have additional needs that have not been taken into account or perspectives that have not been appreciated. It is true that legislation in recent years has attempted to bring about equality in this area, but in every part of life there are still huge barriers to be overcome. It is ironic that it is those who may feel most powerless who constantly have to take the initiative to remind society of their presence. The invisibility of disabled people in the community and in public debate leads to their additional needs being overlooked.

Such invisibility can lead to disabled people being stereotyped only as consumers of community resources rather than also being contributors to its culture.

The fact that power belongs to abled people means that a friendship between abled and disabled people has to start by disabled people becoming visible. In societies where disabled people are hidden (sometimes literally) from the community, no such friendship can occur. As one writer has put it, 'to belong I need to be missed'.<sup>1</sup>

There has been much talk recently about the idea of 'inclusion' in the disability context. An inclusive community is one where abled and disabled people are present on equal terms. They have the possibility of interacting and forming relationships. Yet there are two issues here that need to be confronted. First, it is often the case that in order for disabled people to be in a position to access such a community there needs to be positive discrimination. Just in terms of attending a meeting: they may need the provision of transport in order to find their way there, or a venue that provides the facilities they need during the evening. Second, being an inclusive community is still based on abled people 'including' disabled people. It is abled people who do the including, not disabled people. They are the objects of inclusion. Under inclusion, power can still belong to the abled person. There are a thousand reasons why abled people may not wish to belong to such an inclusive community, because they do not see forming a relationship with a disabled person as being worth the effort.

Despite this, inclusion is vital if disabled people are to exercise power. This will never happen unless they are enabled to participate in such a community. Participation is an active word, not a passive one. The virtue of inclusion is, however, that it highlights the barriers that prevent disabled people participating in the community. The Paralympics in 2012 were a success because the concept and practice of inclusion was central to all that went on. But the most visible aspect of the games was that they

were about participation. The sporting venues were packed with spectators who wanted to support disabled athletes' participation in their chosen sport, and who wanted them to excel at it. Inclusion is the foundation on which participation is built.

Of course, the use of the word 'inclusive' has developed as we have discovered how 'exclusive' contemporary society is of disabled people. The kind of community we want to see is helped rather than hindered by such an insight. But the politics of inclusion must be egalitarian, active and participatory. If people are disabled by the barriers others place in front of them, they will never be able to celebrate their potential.

## 2

### *A story and a meditation*

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Recent books on disability and Christianity have often included descriptions of the author's own experience of disability (although hopefully we are past the days when an author on the subject had no credibility without a personal experience of disability). We now recognize that many people whose lives are touched by disability have important insights to share even though they do not live with an impairment themselves. Nevertheless, I am aware that personal experience fundamentally affects the way a person sees the world. It also affects the way in which they are perceived by the world.

My own story is about living with epilepsy. About 50 million people in the world live with some kind of epilepsy; 80 per cent of them are in developing regions of the world.<sup>1</sup> About 75 per cent of people with the condition in these regions do not get the treatment they need (epilepsy responds to treatment in about 70 per cent of cases). In Africa around nine out of ten people with epilepsy go untreated. Death rates are two to three times higher in people with epilepsy than in the general population. Risk of sudden death is 24 times greater.

Even in the UK there is a real shortage of doctors, nurses and therapists who specialize in epilepsy, despite the fact that around 600,000 people have epilepsy. Only 52 per cent of people with epilepsy in the UK are seizure-free, although it is estimated that the figure could rise to 70 per cent if they had the right treatment.<sup>2</sup> Despite the Equalities Act 2010 and other legislation requiring that people with epilepsy have equal access to employment, education and other necessary resources,

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