

A Discussion Paper from Barnardo's CANDL Project

This is one of a series of discussion papers dealing with current and controversial questions for the church in modern society, and primarily distributed with our quarterly newsletter. Our aim in these papers is to provoke debate and action. As such, the views and questions expressed herein are sometimes quite deliberately blunt and to the point, but do not necessarily represent the policy of Barnardo's.

Disability and the urban church

There is an interesting blog written by an American Christian Jeff McNair about disability and Christianity. He makes the statement that 'disabled people don't go to church'. I mentioned this to a cousin of mine who has ME and she gave it her immediate assent -- 'Yes, you just have to look at who goes!' This problem that disabled people have with church is reinforced by another American Christian -- Mel Dugosh in a moving paper about his experiences

In 1995 I attended a conference sponsored by C.A.M.P., Children's Association for Maximum Potential, and moderated by the editor of Exceptional Parents Magazine. The conference objective was to improve relationships between parents of children with significant disabilities and medical and educational professionals. After ten years of parenting one child, I admit that I had become very cynical that those relationships could do anything but worsen.

The workshop was dry and predictable with the professionals extolling their expertise and the parents participating little. Suddenly a male parent stood and said, "Hey, lets talk about what's really bothering me ... we can't even go to church as a family anymore ... our child isn't welcome there. When we find a church that wants all of us ... this is where we are going to go."

The meeting went haywire, with the parents all speaking at once ... out loud and amongst themselves, each of them sharing a story of exclusion at the hands of a church. I said nothing; this hardened parent had dissolved in tears, silently grieving the church I had lost. The church that had asked us to stand in the lobby during a song because our son was disruptive. The church that was not able to provide child care in the nursery because of his special needs. The church I took my son to for healing, and they "cast the devil out of him." This huge famous church that showcased its deaf ministry and occasionally proudly handed over its pulpit to an evangelist with cerebral palsy, had no room for our tiny lovable son, Chris, who was born with blindness and deafness but sees and feels what most of us cannot. Our son Chris, who without hands somehow manages to touch us with warmth each day.

This story sums up many of the issues that face disabled people: the problems in relating to medical authority, the difficulty in getting their real voice heard, the exclusion from participation in mainstream society and the abuse they suffer from people who want to 'heal' them. The additional vulnerability of children makes them even more at risk of these kind of experiences. I want to explore some of the challenges that disabled children might bring to the urban church. I bring my own experiences as a disabled person but also an awareness that the voice of disabled children is little heard and that every disabled person has a different experience and carries the burden of different issues.

Safe spaces

My cousin, previously mentioned, stayed with my parents recently and calls their home a safe space. She suffers from Multiple Chemical Sensitivities and can quickly be made unwell by perfumes and furniture polishes and the like. It is the kind of condition people make jokes about but it is very isolating when you suffer from it. But her use of the concept safe space rang bells with me. A safe space is very important for disabled people -- it is a space which is physically accessible but also where you are welcomed in a non-judgemental and non-patronising way.

We would all like to think that our churches are safe and welcoming spaces. Every church calls itself friendly! But this is often not the case for disabled people and disabled children. The issues, however, can

be complicated. Let's examine the issue of incense. I used to have no problem with incense, I was brought up as a Baptist and incense seemed very exotic and quite exciting. In recent years, however, I have found that incense aggravates my sinus problems and leaves me feeling very uncomfortably blocked up. I am therefore very reluctant to attend services where incense is used. I have heard similar stories from parents whose children suffer from asthma. Incense does not make things impossible for me but it does turn a church into an unwelcoming and hostile place. I've heard one Roman Catholic priest say that the asthma issue has caused his parish to give up the use of incense altogether. Yet alongside these perspectives we also need to hear this voice

Kathy Lisner Grant, an adult with autism, articulates the importance of finding a spiritual home in the Orthodox Church: '... as a person with autism, the Liturgy appealed to all my senses. For my eyes, there were icons of the saints, the Theotokos, and Jesus. For my nose, there was the incense that the priest used. For my ears, there was the music, because the entire service is sung. (Quoted in MT Burke et al)

But the issue has some more subtle undertones. Within the Anglican church it is a key point of tension between the high church and low church. Opposition to incense is a theological battleground where the experiences of disabled children can be used by the different parties for their own interests rather than in the interests of disabled children.

The wheelchair syndrome

Disability is often associated with the use of a wheelchair. The wheelchair is the symbol of disability in our society -- think of all those irritating disabled parking bays which use up the best parking spaces in a supermarket car park! Facilitating wheelchair access is also a headache for many churches. But my particular disability gives me a somewhat different perspective. I welcome the disabled parking bays (if there are any free) but, generally speaking, places that are good for wheelchair access are less good for me as I have painful feet which have no problem with stairs but I do find long corridors with gently sloping ramps less helpful.

This alerts us to the different experiences that people with disabilities have, as the discussion of incense has already demonstrated. People who are born deaf often become part of the deaf community - the community has its own language, its own culture and its own churches. It is a very different experience from someone who starts to suffer from ME in their 30s. Many people don't accept ME as a real disease, so it is often difficult to be accepted as a person with a real disability. Some people join ME pressure groups and build a new identity around their condition, but this is often criticised by psychologists, doctors and other therapists for creating a sickness identity based on an unreliable diagnosis. So whilst we use words like disability to describe a particular condition, people labelled as disabled may actually have very little in common. Perhaps what they have in common more than anything else is their marginalisation by the wider community! This has encouraged the development of what people call the social model of disability. This is contrasted with the medical model. The medical model sees a person's disabilities as residing in their own impaired body, their main need is for medical interventions which can help them overcome their bodies' inadequacies. The social model, on the other hand, recognises that people have physical impairments but believes that the disability -- the lack of ability to do things -- is created by society not by their body. So a wheelchair is only disabling when you have to climb stairs to get into a building. We would not call someone disabled if they were unable to climb a rope to get into a tree house, just that the treehouse was inaccessible. The social model has been an important component of the political campaign for disabled people's rights, it can be rightly criticised for, at times, failing to pay enough attention to disabled people's actual embodied experiences but it is a helpful tool for enabling us to look at things from a different perspective.

ADHD and worship

When I was the pastor of the Church in south London we had a young toddler who was very lively. In fact he was pretty uncontrollable and would have preferred to run about unhindered for the whole service. He was thoroughly disapproved of by a number of our more conservative members but his mother was our only musician so he pretty much came with the territory! Some years later they moved to Germany and he now has a diagnosis of ADHD and attends a special school. ADHD (attention deficit and hyperactivity

disorder) is a controversial issue and no one seems very sure where ADHD stops and autism begins. They provide a challenge for those people who want to see disabled children included in school and other activities. I know of a school in East London who did their best to include an autistic boy but had to give up when other pupils were cowering under their desks in fear of his violence. It is, also, a modern challenge for many churches to know how to include small children, now that we don't find it culturally acceptable to force them to sit still and completely quiet. Some churches specifically advertise 'noisy services' so that parents can feel comfortable about bringing young children to church, but what about those children who seem particularly disruptive? Do they need to be labelled as autistic or suffering from ADHD and drugged up with Ritalin? Or is there some better way in which we can express the all-inclusive love of Christ -- which is, after all, what we are meant to be about?

I am sure we would all like to think that we are inclusive but how much are we prepared to change, for this to become a reality for disabled kids - and would including disabled kids mean that people looking for peace and quiet are excluded? No easy answers I think. Jeff McNair argues that the main church service should embrace noise and disruption and not expect people to be quiet and solemn. Quiet and stillness could be provided for in the secondary services.

Miraculous healing

Healing is a controversial issue. Some believe that miraculous healings are a necessary part of the mission of the Church, others believe that they were a temporary phenomenon of the early Church and no longer occur. I don't want to get involved in this argument but I want to explore briefly why healing can be an uncomfortable issue for disabled people. The following quote by Samuel Kabue, a blind African theologian illustrates this well

On Sunday afternoon I crossed the town with two friends, David and Bernard, Bernard had substantial residual vision, so he acted as a sighted guide for David and me, as both of us were totally blind. We met a woman preaching at the market gate. We had no intention of listening to her, but some people intercepted us and pleaded with us to have the woman pray for us to recover our sight. We were prevailed upon and we found ourselves kneeling before the woman. After the prayer, the woman declared that we had received our sight back. Everybody rushed around us, and for a time I thought my friends might have received their sight and that I was the only one left blind. People started placing all sorts of items such as potatoes, pineapples, bananas and sugarcane in front of us and asking us what they were. My friend Bernard kept shouting what these were, yet since they were being brought rather close to our eyes and David like me was not responding, I knew that he could still not see and Bernard was just using the little sight we all three knew he had. Every time he responded, there was pandemonium -- shouts and ecstasy made the crowd continue to swell. Although Bernard may have been under the delusion that he could see better than before, I must say I was personally very irritated at his response because the more he named objects, the louder the shouts of excitement became. The crowd was getting bigger, with nearly the whole market coming to witness the healing, making it impossible for us to move. (Fritzson and Kabue p34)

In this instance the desire for a miracle has overridden the ability of the crowd to actually listen to the disabled boys. This is very different from Jesus in the Gospels who never pushes healing on people but first enters into a conversation with them and asks them what they want. Another problem that disabled people have with contemporary healing is when the failure to heal is attributed to the sins of the disabled person. It is difficult to overemphasise how offensive this is to disabled people, nothing is more likely to turn them away from the church, and, I would suggest, nothing is more likely to besmirch the good name of the Church. This issue is explored at a website www.whereisgod.net where a helpful booklet is also available that gives a good introduction to the experiences of Christians with 'invisible disabilities'.

Listening and including

Most of the problems with healing in the Church are created by people with an overenthusiastic desire to see miracles happen, who don't spend the time to listen to disabled people and find out what they really want. Disabled people simply become the subject of other people's desires. It is this which is so frustrating for disabled people. Their experience is by and large one of marginalisation by mainstream society, they

are disempowered not so much by their own impairments but by people's attitude to them and the inability of our society to include them with dignity and respect. It is a shame when the Church fails to offer a different example and a disgrace when it marginalises disabled people even further.

It is my belief that disabled people and disabled children actually have much to teach the Church. The theology of the blind theologian John Hull is one example, as is the amazing witness of the L'Arche communities where people with learning difficulties are included in a remarkable way. But perhaps more important are the small lessons that can be learned in our own churches as we try to find ways of including disabled people in our congregational life. It is a beautiful thing to see marginalised people finding a place where they are truly loved and accepted. A place where they can make their own contribution to human flourishing. Anyone feel like giving it a go?

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References and contacts

Anne Fritzson and Samuel Kobia *Interpreting Disability* WCC 2004

Jeff McNair <http://disabledchristianity.blogspot.com/> Discussion of issues related to Christianity/theology and persons with disability

John Hull <http://www.johnmhull.biz/OnBlindness.htm> a number of interesting resources

John Swinton *Building a Church for Strangers* and many other resources at

<http://www.abdn.ac.uk/cshad/resources.shtml> (Centre for Spirituality, Health and Disability)

L'Arche <http://www.larche.org.uk/> an international federation of communities for people with learning disabilities and assistants.

Mel Dugosh *Inclusion in Church Communities* <http://www.tsbvi.edu/Outreach/seehear/fall97/church.htm>

MT Burke, JC Chauvin, JG Mirati. *Religious and Spiritual Issues in Counselling Application across Diverse Populations*. Psychology Press 2004 ISBN 15839137 26

Roy McCloughry *Making a World of Difference* SPCK 2002

Through the Roof www.throughtheroof.org a Christian disability organisation working to change attitudes in churches and wider society towards disabled people and disability.

Wayne and Cherie Connell *Have a Little Faith – a guide to administering to believers living with chronic illness and pain* www.whereisGod.net

You can download a pdf file of this paper from our website.
If you want to respond to any of the above points, or follow-up any of the ideas,
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*It is better to
light one candle
than to curse
the darkness*

