Health on the Margins: Minimising the Trauma of Health Essentialism

By Patrick Johnson

Some authors have pointed out that the acceptance of people with disabilities depends on "the discourse present within the Christian faith community." One of the prevailing discourses within the Seventh-day Adventist church is that of health, so it is no surprise that the church is known perhaps foremost for the benefits our members derive from our emphasis on health. We attribute this somewhat unique insight to the writings of one of our pioneers, Ellen White (1827-1915). For example, here is one of her quintessential purpose statements on health reform,

'In teaching health principles, keep before the mind the great object of reform—that its purpose is to secure the highest development of body and mind and soul. Show that the laws of nature, being the laws of God, are designed for our good; that obedience to them promotes happiness in this life, and aids in the preparation for the life to come.'

From this we can see that Mrs White believed that health reform was theocentric, based on a wholistic anthropology and meant to promote the wellbeing of all. Briefly probing the significance of the latter two beliefs will illustrate how the Seventh-day Adventist concept of health can have a traumatic impact on people with disabilities.

¹ Nicole Tillotson and others, 'Faith Matters: From a Disability Lens', *Journal of Disability & Religion*, 21.3 (2017), 319–37 (p. 328) https://doi.org/10.1080/23312521.2017.1348924.

² Dan Buettner, *The Blue Zones: 9 Lessons for Living Longer from the People Who've Lived the Longest* (Washington D.C.: National Geographic Partners, LLC, 2012), pp. 121–65.

³ Ellen Gould Harmon White, *The Ministry of Healing* (Nampa, Idaho: Pacific Press, 2003), p. 146.

Adventist health and wholeness

In mentioning the development of 'body and mind and soul' Ellen White illustrates the type of wholistic anthropological thinking that is typical within Adventism. Ginger Hanks-Harwood summarises the significance of the idea of wholeness in the following way:

In sum, the doctrine of wholeness has had a significant impact on the Adventist church. Its presence can be demonstrated in our theology, anthropology, ecclesiology, and ethics. It has provided the church with a central part of its identity and sense of mission. It would be hard to envision the history of the church without the doctrine of wholeness, since this theme is woven into almost every recurrent theme and doctrine of the church.⁴

The main ethic coming from wholeness is that 'the medium is indeed the message'.
In other words, the gospel is to be embodied by those who proclaim it. Ellen White seemed to underline this in order to stress the importance of health reform. However, the potential disadvantage of this is that one could infer that a certain norm or standard of health is expected to accompany the proclamation of the gospel. This could leave the subconscious impression that the healthier a person is, the more they are seen as representative of the message that God wants to give to the world. In other words, wholeness can lead to a form of health essentialism.

Such an attitude could potentially become problematic for people with disabilities, for it raises the question of whether they are seen as enjoying the same level of health as everyone else. Are people with disabilities viewed as being in some way below the normal

⁴ Remnant and Republic: Adventist Themes for Personal and Social Ethics, ed. by Charles William Teel (Loma Linda, CA: Loma Linda University, 1995), p. 133.

⁵ Teel, p. 131. This is based of course on the popularly quoted phrase of the media theorist, Marshall McLuhan, 'the medium is the message.'

⁶ Essentialism is understood as the belief that objects have a set of attributes that are necessary to their identity. Thus resulting in the view that different categories of people, such as women and men, members of ethnic groups, or abled and disabled people, have intrinsically different and characteristic natures or dispositions.

standard of health, however that may be defined, and thus seen as less useful in the mission of the church? How does Adventism's innate drive towards wholeness react, for example, to the presence of a person with a chronic incurable condition?

Adventist health and individual responsibility

Another way in which the Adventist focus on health can potentially be disadvantageous for people with disabilities is in emphasising individual responsibility for health. Naturally, health is a personal commodity and the onus to live according to recommended principles of health lies with the individual. At the same time, whenever health reform is sought in a community of people there is also the risk of generating a kind of elitism where it is possible to single out groups who do not seem to comply with the expected norm.⁷

This is very reminiscent of the medical approach to disability, which sees disability as residing with the individual who needs assistance from the medical profession to fix their problem. Similarly, if disability is viewed solely as a problem of the individual member, then those members can easily be seen as needing help from others. Could this be said to give rise to attitudes of pity, offers of unsolicited intercessory prayer, comments implying lack of faith on the part of people with disabilities bringing lack of healing, and a general lack of empathy for a person with a chronic condition? In other words, could it be said that patronising attitudes are a natural consequence of Seventh-day Adventism's underlying individual health emphasis?

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⁷ For example, in UK debates about the 'sugar tax' and the various manifestations of 'fat taxes', such levies are seen by some as an unfair targeting of people who struggle with obesity.

Thus, the issue for the SDA church is that our wholistic anthropology, when combined with an emphasis on individual responsibility for health, can result in a form of health essentialism that discriminates against people with disabilities. That is to say, there is the theoretical danger of the Adventist health message having a trauma inducing effect on people with disabilities due to it producing ableist attitudes.

The challenge of ableism

Ableism is discrimination in favour of non-disabled people. It assumes that being non-disabled is the default, and anything outside of this is abnormal and undesirable. In other words, it is the idea that people with disabilities are not the same as "normal" people, and their lives are intrinsically less valuable than those who are non-disabled. Ableism can also be distinguished from disablism which emphasises discrimination directly against disabled people.

Since the World Health Organisation's first attempt in 1980 at a universal definition of disability, society has become more aware of how prevalent ableism is. As a result, most countries have some form of legislation outlining the political, social and economic rights of people with disabilities. This legislation has ensured that public buildings and institutions now have physical access for people with disabilities.

But there is a downside to this. Wheelchair accessible ramps in a building can signal that a church is disability friendly, whilst masking a deficiency of deep communality in the congregation in general and a lack of acceptance of people with disabilities in particular.

⁸ International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease, ed. by World Health Organization (Geneva: World Health Organization, 1980).

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Some have captured this in the idea that 'Narrow doorways are more easily rectified than narrow mindsets.' Are ableist attitudes a problem in the SDA church?

My research into the lived experience of people with disabilities involved in-depth interviews with Seventh-day Adventist church members with physical disabilities. Their responses showed a wide spectrum of experiences that can be illustrated in the following diagram.

The Continuum of Disability Experiences		
Negative	Mixed	Positive
Insignificance Discrimination Stereotyping	Ministry ex/inclusion Occasional insensitivity	Ministry inclusion Proactive adaptability Involvement space Belonging

As you can see, the negative and mixed experiences illustrate that ableist attitudes are quite prevalent in the church.

Insignificance

Insignificance is used to describe the experience of feeling that as an individual you're not regarded as an important member in the life of the church. You feel you are of so little value to the community that if you are not present you will not be missed. It is being left with the impression that you are undervalued and seen as a liability rather than an

⁹ Jill Harshaw, *God beyond Words: Christian Theology and the Spiritual Experiences of People with Profound Intellectual Disabilities* (London: Jessica Kingsley Publishers, 2016), p. 34.

asset. Robert¹⁰ expressed this when he concluded, "Whether intentional or not, you feel you're burdensome. And I think some of that was made to feel intentional."

Discrimination

Discrimination describes the experience of being treated unfairly or prejudicially because of one's disability. Arthur described his disappointment of being met with continual resistance to his suggestions of changes or adaptations that could be made in order to meet his needs as a wheelchair user.

"I have to say, the amount of discrimination I have found at church is probably greater than any discrimination I've found anywhere else. I'm talking specifically about my church. My experience was not always a comfortable one, and I felt the way in which I was spoken to at times, it was not the way in which a 58-year-old able bodied person would be spoken to or treated."

His disappointment was compounded by the fact that he thought church members would have understood what it is like to be discriminated against for being a minority.

Stereotyping

This is where disability is viewed as something negative and treated as a problem of the individual without any communal responsibility. Melissa had developed a chronic debilitating condition which left her needing to use crutches. She described how disappointed she was to be intentionally excluded from a particular programme at her church.

"People were invited to tell their stories, telling about their challenges etc. Then you would talk about your progress, or your healing or whatever is keeping you and bringing you comfort. One of my 'adopted' daughters in church went to enquire why I wasn't invited to take part in the programme. And she was told, 'Well we didn't ask her because she's disabled, she can't walk, so we didn't ask her to sing.' You know, I

¹⁰ All names of research participants are pseudonyms.

don't use my feet to sing. I don't use my hands to sing. As a matter of fact, the strongest part of my body is my mouth, and that's the only thing I've got! The funny thing about that too is that for the first eight years before I got sick I used to sing almost every Sabbath in that church."

Ministry ex/inclusion

The power of including people with disabilities in church ministries should not be underestimated. This is how Richard described his experience.

"At one time I wasn't included at all. I don't think there was anything nasty about it. I suppose perhaps people didn't consider me because I'm blind. But we've all got talents, we've all got different skills. I used to come to church then go home again, and you can feel out of things. But since I've become a deacon it's brilliant! I'm glad because I feel I'm involved, I feel like I'm offering something."

It should be obvious that total member involvement also includes people with disabilities, but sometimes inclusion only comes as the result of persistence on the part of the person with disabilities. Joanna, who is blind, initially got involved in her local church as a result of her own tenacity rather than the church seeing her as a resourceful person.

"When I was baptised, there was a big baptism of, I think, about nineteen of us. Afterwards, they started to organise people into the various departments, you know, to get us settled in. But I wasn't put anywhere. So I went to the elder and said, 'Hold on, everybody's been put somewhere, what about me?' That was ignored so I went to the pastor. I said, 'I need to be settled into a ministry also.' They never really did put me anywhere. So when they started to announce different things, like prison ministry, then I put my name forward. (I can go out there and talk for England, so I know that I'd be effective in the prison ministry). I'd follow up by phoning the person in charge, and asking what I need to do to go into the prison ministry. You have to follow things up. Then eventually people realised, 'Oh she can do something.' And then from there I've been asked to be more involved."

Insensitivity

Joanna's experience as a blind person has been somewhat bitter-sweet, however, because of insensitivity. Once, while sitting in church, she heard a lady sitting a couple of rows behind her commenting on her blindness and being a mother. "How did she manage to find a husband and have children and I can't even find one?" Joanna's evaluation shows her hurt,

"Those are the things that can really destroy you if you're not a strong person. Over the last five years, I've been so discouraged that I said I wasn't coming back. But then again I know God called me, and I have to remind myself that I'm not here for them, and so I keep going. The disability in itself is easy to cope with compared to how people see you. Sometimes when people open their mouths it leaves me questioning myself, 'Do they think that you don't have feelings?'"

Becoming a church for everyone

To counteract ableism and become more welcoming to people with disabilities, the SDA church needs to do at least two things: be conscious of the language it uses, and be intentional in using the Bible to inspire positive attitudes.

Ableist language primarily starts with definitions, and disability definitions can be organised into three models: medical, social, intersectional. The medical model of defining disability has been useful in providing society with the vocabulary for describing disabilities in the form of labels and classifications. This has resulted in increased expertise and specialisation in many different conditions. However, medical classifications have an underlying notion of normal functioning against which disability is measured, thus they invariably portray disability using negative language. This ableist attitude results in a power imbalance where the disabled person becomes a passive recipient of treatment by an all-powerful medical profession. Furthermore, relying only on medical definitions accentuates a

person's pathology, thus we end up associating people with their condition rather than seeing them as unique individuals.

The social model of disability emphasises a minority rights idea of disability. It makes a distinction between impairment and disability and thus disability can be seen as a social construct, a category that is imposed on an individual by society. Hence it is possible to speak of impairment being located in a person's physiology, disability being the social result of the impairment, and handicap being the disadvantage that comes from the impairment or disability. As a result, the term "disabled people" has become the label of choice, particularly by activist groups. In other words, being "abled" or "disabled" is primarily a result of social structures. This makes disability the responsibility of society and not the individual. Thus, the attitude of ableism is the cause of the problem of disability, not physical impairment.

The social model of defining disability has led to law-based equality for people with disabilities. However, because of its focus on ableism, one of the main challenges with the social model is that it can be in danger of downplaying the very real physical and emotional impact of impairments. If taken to the extreme, the social model could lead to the opposition of all attempts to cure or rehabilitate medical conditions. Hence, for example, the debate around cochlear implants for deaf children.

Even though the medical and social models have long provided the dominant discourse for understanding and theorising disability, postmodern reasoning has now moved the discussion beyond this binary. Instead, disability is being understood as the sum of complex interrelations between a person and their surroundings. Intersectional definitions attempt to take into consideration a more comprehensive understanding of the

complexity of human identity. So, they consider how things such as race and gender impact on the experience of disability.

Given that acceptable terminology for disability is ever evolving, and what might be considered politically correct today might be unacceptable tomorrow, the safest way for the church to avoid ableist language would be to learn to use "people first" terminology. For example, referring to someone as a person with a seizure disorder rather than an epileptic. Disability does not define a person, so our first aim is to get to know the individual.

Regarding using the Bible to inspire positive attitudes, it is important to recognise that God's attitude of favour towards all people, including those with disabilities, is repeatedly featured in the OT. For example, when Moses attempted to use his speech impediment as an excuse not to answer the divine call to leadership, he was reassured that a person's disability was no hindrance for God (Exod 4:10-12). In Isa 56:1-8 marginalised people are promised that they will no longer be side-lined or forgotten, but that they belong in God's "house of prayer for all nations." Similarly, in Jer 31:8-10 people with disabilities are specifically mentioned among the people who will return from exile and have God as their shepherd.

In the NT we find an example of an ableist attitude expressed in the question of the disciples in John 9:2, "Rabbi, who sinned, this man or his parents, that he was born blind?" They were voicing the common belief in the link between sin and disability.

In contrast, Jesus clearly denied any connection between sin and the man's disability. Instead, he gave the following reason in John 9:3, "this happened so that the work of God might be displayed in his life." At first sight it may seem that the "work of God" that was displayed was his physical healing. However, as Jesus had made plain earlier in John 6:29,

"The work of God is this: to believe in the one he has sent." This was clearly revealed by the man himself testifying "He is a prophet" (John 9:17); "If this man were not from God, he could do nothing" (John 9:33); and more specifically his direct confession and worship of Jesus (John 9:38).

Thus, we can say that it was not so much the healing of disability but rather the man's faith in Jesus that was revealed in the story. In other words, Jesus's healing ministry was illustrative of God's continued attitude of favour towards humans and how he takes the initiative to restore trust to the relationship (Luke 4:16–21). Hence, when Jesus healed a crippled woman on the Sabbath, he illustrated the dignified way he viewed her by referring to her as "a daughter of Abraham" (Luke 13:10-16).

Conclusion

The SDA church has been blessed with a health message. One direction in which this needs to be developed is to emphasise the importance of communal health. Devan Stahl offers a corrective that is worthwhile reflecting on,

Our current Christian communities must become less concerned with individual health and instead recover a Christian conception of communal health. This is not to say that individual disease or disability should be overlooked; rather, caring for those with disability or disease must be understood as a political and inherently eschatological act. Our current understanding of "health," which is a wholly individualized commodity, has obscured Christ's vision of God's Kingdom.¹¹

If we were to expand our health emphasis beyond individual duty and focus more on communal responsibility, the cultural shift needed to create an inclusive environment for

¹¹ Devan Joy Stahl, 'A Christian Ontology of Genetic Disease and Disorder', *Journal of Disability & Religion*, 19.2 (2015), 119–45 (p. 140) https://doi.org/10.1080/23312521.2015.1020186>.

people with disabilities would become possible. We would no longer be blinded by ableist attitudes that focus on what a person is unable to do or view people with disabilities as simply needing our benevolent support. Rather, we would be concerned with exemplifying the multifaceted nature of the Kingdom of God by recognising the possibilities that all members embody. By upholding the dignity of everyone as individuals created in the image of God, we will be more reflective of the church described in 1 Cor 12:24-25, "God has combined the members of the body and has given greater honour to the parts that lacked it, so that there should be no division in the body, but that its parts should have equal concern for each other."