

DISABILITY NEWS

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 **UnitingCare**
South Australia

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from the Editor....

Greetings!

In this issue we touch on the hidden or invisible nature of disability.

Being invisible can mean someone in a wheelchair being “talked over” by someone who talks about you to your able-bodied friend who stands next to you.— That is, you don’t count.

Being invisible can mean being treated solely as a client requiring disability services. — That is, you’re simply a person in need requiring services, not a person in your own right.

And being invisible can mean *looking normal* and having to work hard to convince others that your disability requires daily struggles. — And this means that whether it’s Chronic Fatigue Syndrome or Autism (both mentioned in this issue) an allergy, a visual impairment, ADHD, deafness or one of countless other disabilities, “looking normal” can present significant social challenges.

That is to say, *You don’t look disabled!*

Feel free to share this newsletter with your friends.

If you don’t already, let me know if you would prefer to receive this electronically.

Email me (address above) with the names of anyone who would like to be added to the mailing list.

Your feedback is always welcome.
Enjoy the read.

Rev Trevor Whitney

Disabilities Ministry Chaplain
UCA, Presbytery & Synod of SA
UnitingCare Commission

Chronic Fatigue Syndrome Marianne’s Story

I never expected, at the age of 28, to lie down on the couch and not be able to get back up again.

It was a Sunday in 2001 and I had been working hard all week. As I lay there unable to lift my head or even to turn it, panic set in. After two years of exhaustion, joint pain and insomnia, it seemed my body had finally reached its limit. It was some hours before I could muster the physical strength to get up and crawl to my bedroom.

After many tests, I was diagnosed with Chronic Fatigue Syndrome/ Fibromyalgia. I had been infected by a particularly nasty type of bacteria, in the same family as typhoid. It is very hard to kill and full recovery is uncommon. In my case, it was several weeks before I could walk more than one minute a day, or speak above a whisper.

I returned to Adelaide to my parents’ place, to be looked after. Thus, I went from trained social worker to client, from adult to child, in a moment.

During this time, three people wrote to me with the words ‘go gently’. I thought about this a lot over the coming weeks and months. As a task-oriented person, this idea did not sit well with me. I wanted to identify the problem, solve it and get on with my life. Chronic Fatigue Syndrome isn’t like that. If you push yourself, you become worse. And just when you think you’re improving, the down cycle begins once more. I had to learn to slow right down, to be still, to listen to my body, to relinquish control and just be.

I thought of Michael Leunig’s words, *These circumstances will change. This situation shall pass!* While I have improved somewhat, it is not my circumstances that have changed so much as my ability to deal with them.

I don’t believe God is punishing me. Instead, I have been sustained by God through the worst of it.

I’ve learnt to accept the good days with the bad, and to be awake to the sense of peace that can come in the darkest moments.

Marianne Vreugdenhil

* editor’s note: *Marianne’s talents include the writing of poetry and prose. One of her poems, grounded in her experience of CFS, is included in this issue.*

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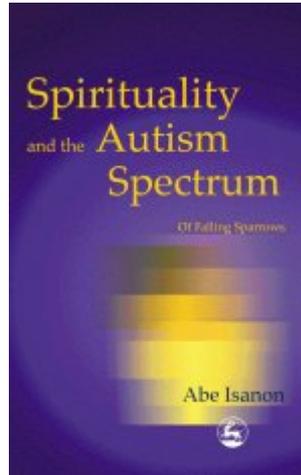
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HIDDEN DISABILITIES and the CHURCH

Review Review Review

Spirituality and the Autism Spectrum Of Falling Sparrows Abe Isanon



Jessica Kingsley Publishers
London, 2001
\$24-95
available through amazon.com

If a child is in a wheelchair, it is quite obvious that s/he has special needs that will have to be accommodated. But what of the many disabilities or special needs that aren't obvious?

Hidden disabilities/special needs include:

- ◆ Asthma
- ◆ Diabetes
- ◆ Food allergies (peanuts, food colouring, Coeliac disease, etc)
- ◆ Chronic Fatigue and similar conditions
- ◆ Deafness
- ◆ Intellectual impairment
- ◆ Mental illness, eg. anxiety disorder
- ◆ ADHD
- ◆ Allergy to bee stings

Does your program have an in-built mechanism to identify such areas of need?

Schools do it very well.

- ◆ When a child joins your group, do you ask if s/he has any special dietary needs, health or physical considerations? The Uniting Church's **Called to Care** package has forms for this purpose: see **Called to Care Fact Sheet 11**. **Called to Care** is available to all SA Uniting Churches that have done the *Called to Care* training. If your church hasn't yet done the training, you can get a copy of Fact sheet 11 by ringing **Linda Vinall** at the SA UCA Synod Office on **8236 4248**.
- ◆ Many schools have in the staff room a bulletin board of photos that identify any child with a particular health or physical condition that may need immediate first aid or special consideration. Included with the child's photo and name are details of what medication is to be administered, where it is, how much to give and how it is to be administered. You could set up a file with similar information for your helpers. Photos help adult leaders to become familiar with the children whom they need to look out for.
- ◆ **Always consult parents. Ask their permission to set up a file and record their advice.**
- ◆ **Treat any child with the respect that says "I take your needs seriously"** – without drawing unnecessary attention to any disability or health issue. Children need to know they are safe and cared for, but they also need to have confidence that they are not going to be impeded by over-protection or embarrassed by having their health condition or disability constantly held up in the public eye.

KUCA News,
Autumn 2005, p.19

Defining spirituality as "the spirit with which we confront reality (p.98)", this book focuses on the spirituality of people with autism spectrum disorders.

The author makes the point that we can only gain insight into the spirituality of those with such disorders if "such insight is grounded in the experiences of the sufferer and referenced in the reality of autism-related problems (p.55)." With that in mind Isanon, whilst avoiding stereotypes, begins with helpful information concerning the type of cognitive and emotional impairments, as well as sensory and behavioural considerations, that a person with autism, in one of its manifest forms, may experience.

Through the narratives of three people living with different forms of autism we are shown how spirituality is interpreted from the perspective of those living with autism.

We are invited to consider forms of spiritual understanding that may challenge the spiritual perceptions of some who live without such a disability. For example, Adam invites us to consider a spirituality that values experience and isolation above the rationality of church dogma, and gives priority to images that reflect mystery.

This readable book provides valuable insight into how an autistic person interprets spirituality from their perspective and, in doing so, may challenge the reader to expand their own notions of spirituality.

..... on spiritual humility

"It is not enough to be merely emotionally touched by the life of the autistic person; we must be willing to embrace the reality of being humbled by their presence. Humility is realized to the extent that we allow the autistic person to lead us into a new awareness of self, other and Wholly Other."

Abe Isanon,
"Spirituality and the Autism Spectrum: Falling Sparrows," p.116

Done dirt cheap

The heading and sub-heading on p.26 of the Weekend Australian (Nov.18-19, 2006) read :

Done dirt cheap

Sometimes disabled people can only dream of the minimum wage

The article proceeds to describe the story of 18-year-old Erica Cuskelly, who has Down Syndrome, and was offered 72c an hour to stuff envelopes for a company set up to help people with a disability.

Despite the disgust and anger expressed by Erica's parents, Bernard and Pamela, they were told that the rate of pay was legal and reflected Erica's level of productivity.

Erica's employer rationalised her paltry wage by indicating that the award wage for the job was \$10.50 an hour, but for six weeks her starting wage would be \$4.40 an hour. Her wage would then be adjusted up or down according to an assessment of her productivity.

According to Erica's employer there are about a dozen other employees with disabilities who receive about \$1.20.

The unfairness of this rate of pay is possible despite the Howard Government introducing what it called a "supported wage system" that was designed to encourage businesses to hire more workers who have a disability, as well as protecting the interests of these workers.

I have 2 issues of concern with this article.

Issue 1:

In what way is the government's "supported wage system" protecting Erica's rights, as well as the rights of those who, like her, are awarded such a paltry wage? Bernard and Pamela Cuskelly are described as trying to create as normal a life as possible for their daughter. What sense of social value and normality are they to assume that society and, in particular, the business community, is willing to confer or not confer on their daughter, as a result of this wage deal?

Sure, Erica has just entered a market-driven economy. Productivity is a key driver of such an economy. However, while it's an almost quaint thought, businesses have a moral responsibility to place a worth on their employees that goes beyond their productive capacity, and values them as people.

Issue 2:

Why does the media continue to use the word 'disabled' as an adjective when describing people with a disability?

The article refers to both 'disabled people' and 'disabled workers / employees.' Such descriptions put the person with the disability ahead of their identity as a person, and furthermore, defines their whole identity as disabled.

A person's disability should never be ignored, nor should the ongoing consequences of living with that disability, but nor should their identity as a person.

Is it really such a sacrifice of print space for the media to write 'person with a disability', rather than 'disabled person?' - Surely not.

Trevor Whitney

*a prayer
for human regard*

O God
who embraces all,

may we mirror your compassion,
creativity,
and imagination,
as we work to reshape
our society
into one in which all are valued
as people of worth,
and no one is labelled as
'economic unit'
'commodity'
'productive' or
'unproductive'.

Teach us
regard for one another,
not on the basis of
employment,
unemployment,
status,
ability or
disability,
nor for what they offer us,
or we offer them,

but for who we all are
as valued members
of your creation.

In Jesus' name we pray.
Amen



a Christmas reflection

And the Word became flesh and lived among us John 1:14

There is a tendency in some Christian traditions to focus more on the notion of the Divine Christ than the Incarnate Jesus, the one who performed miracles and spoke with other-worldly wisdom, more so than the one who walked among us and who got tired and thirsty, who cried, got angry, and who not only gave of himself to others, but, as a truly *human* being, received much from those whom he met.

Traditionally at Christmas we have focussed much more on the child who was viewed, in Matthew and Luke's birth narratives, with awe by the angels, shepherds and kings, rather than the Word of God of John's gospel, who "became flesh and lived among us." - Why is this so?

One reason is that the Divine Christ takes us away from the ordinariness and pain of human life and offers a more eternal, encouraging vision - hope beyond pain, life beyond death.

However in striving for eternity we can lose sight of Jesus as he walks with people amidst the ordinariness and pain of life. We can lose sight of the Jesus who came for those oppressed and excluded by those who didn't care or who were unsettled by the presence of such excluded people in their midst.

The Word that became flesh invites us to live in the midst of life. In responding to that invitation may we find life.

Trevor Whitney

Release

Dear God

*When the losses are too great,
I ask for strength to isolate
Each loss, to roll them slowly in my hand
To gently feel the weight of each
To trace the grazes gingerly
To touch the underbelly, bruised
To risk to know their drowning weight.*

*To take this journey safely is my prayer
As I release these losses to Your care.*

Amen.

Marianne Vreugdenhil

kid's books

Wilfred Gordon McDonald Partridge

by **Mem Fox**

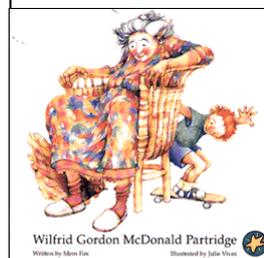
illustrated by **Julie Vivas**

published by Kane Miller Book Publishers,

1989

softcover \$7.95

Available all good bookstores



Young Wilfred Gordon lives next door to a nursing home and is best friends with 96-year-old Miss Nancy, to whom

he tells his secrets. When she loses her memory he decides to find it for her with the confidence only an innocent young child can have.

This is a beautiful, gentle book that treats the frail aged, and their accompanying disabilities, with dignity.

A great book to help kids learn more about the elderly, in a fun way.

A great book for adults to read with kids.

Websites for Disability Info / Resources

National Network for Disability and Spirituality

www.acbc.catholic.org.au/org/disability/index.asp

Helpful religious resources.

Subscription available.

L'Arche Australia

www.larche.org.au/

Faith-based communities for people with an intellectual disability.

Disability Information Resource Centre SA

www.dircsa.org.au/

Umbrella organisation for disability resources.