

DISABILITY NEWS

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Uniting Church in Australia

from the Editor....

Greetings!

A variety of disabilities are mentioned in this issue including autism, cerebral palsy, acquired brain injury, Asperger's syndrome and ADHD.

It's easy to lump all the people who live with such disabilities into the one nebulous grouping and simply think of them as "that group of disabled people." And it's easy to think of parents, friends, advocates and others who offer great care to people with disabilities as simply "carers."

But every person with a disability has a name, reflecting the importance of personal identity. And they are not simply a "disabled person." All are unique, with their own personality, talents, ambitions and desires.

Likewise, every carer is unique. They care, and also live, love, work and play in their own unique and special way.

Let's not deal in generalities. Let's affirm all people with disabilities, and their carers, as the unique people they are.

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
Pastoral Relations Committee

Hearing the Music - Graham's Story

I first met Graham in the craft room at the facility where he lived. He was about 50 years of age, and had a reasonable level of intellectual disability. He had gentle facial features and a kindly, if not somewhat retiring, demeanour. He seemed to be comfortable in the company of others, sometimes stopping to observe what others around him were doing, but never joining in with their activities. He also never said a word, and seemed content to remain in his seemingly mute world.

It was always interesting to sit with Graham as he went about his craft. His favourite activity was basket weaving, an activity he undertook methodically and with care. He was happy to give me a go and seemed tolerant of any mistake I might make.

One day a community concert band came to perform for a number of the residents, including Graham. The concert took place in the facility's hall, and with Graham assuming his seat near the middle of the assembled group of 30-40 residents the band began to take their places and proceeded to start warming up their instruments, with the usual discordant sounds emanating from horns, drums and keyboards. And immediately, quiet, undemonstrative Graham rose to his feet and started "conducting the orchestra" in the most energetic and purposeful manner. As the band started presenting their various items Graham remained standing and continued to conduct, changing his tempo in accord with the pace of the tune. He kept conducting until the last tune was complete, and as the residents applauded the musicians he sat down. With concert over "the conductor" resumed his quiet demeanour.

I had so misjudged Graham. Beneath his quiet, largely mute outward appearance there was an energy and creativity just waiting to be released. And music was the spark. Long live the music!

I should learn not to judge too quickly.

Disability Resource Website

www.sa.uca.org.au/goto/disability

Available on the UCA SA website this site offers disability resources such as Reviews, Disability News newsletter (back copies), Kid's Books, Ministry and Media items, Liturgy, Prayers, Poems and Stories.

New resources recently added.

For church & personal use.

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'Sunday Morning'

a poem and a prayer

ministry

Taking the time
to listen when
conversation
is slow

The author of the following poem is a young man with the dual disabilities of autism and cerebral palsy. Through the poems he types on his computer he shares his life experiences, offering insights beyond disability.

His poems express a plea to be seen for more than just the outer manifestations of his disabilities. In the following poem he describes a God who speaks to him beyond his disabilities, in the context of his church.

It is also a prayer to the God who is beyond comprehension, but also very near.

**Greatness untamable,
we call to You,
needy,
lifting our faces from the
minutiae of our minds
to the balm of Your presence,
blanketing our sadness.
Wealth, power, fame, security play
with our vanities,
but You, O Most High Inconceivable God,
meet us here in this room,
with gladness pouring from your eyes,
forgiveness granted,
grace slipping into the recesses
of our fractured hearts
and we sing! we sing!
then quietly slip
back to earth's boundeness,
carrying the sweetness,
the whisper of Your love,
like starlight,
leading the way.**

Engaging in conversation with a person with a particular type of disability can be a slow process. It may be because the person has a disability such as cerebral palsy, or they have had a stroke, and their words seem slurred. Perhaps, through acquiring a brain injury, a person can't verbalise their thoughts at all and need the help of a manual or mechanical communication device.

Either way, such disabilities can make conversation a slow process. In our rush to be somewhere else we may find ourselves perhaps cutting such conversation short. We may find ourselves literally talking over the head of the person in the wheelchair to the carer who is with them who speaks with greater clarity.

Such responses are disrespectful of the right of a person with disability to share their thoughts and feelings, and be listened to. How would we like it if someone simply walked away from us because we were struggling to be heard clearly?

In the church we often talk about sharing our gifts with one another. In conversing with someone with a disability who is a part of our church community two of the precious gifts we can exercise are:

patience: persisting until we've correctly heard what the other is saying (it's ok to ask someone to repeat what they said), &

time: a gift that tells the other that what they have to say is important and worth hearing.

We can be enriched by what the other has to say, and they may feel included by our willingness to put our busyness to one side.

Through such conversation we may hear God speak.

Craig Romkema,
"Embracing the Sky: Poems Beyond Disability" p.64
Jessica Kingsley Publishers
London, 2002



by Gabriela Coslovich

THE AGE

March 21-22, 2008, p.3

disability topic: **acquired brain injury / remembering**

Carol Luckins was a much-loved woman - a confidante, devoted mum and great cook.

But just under six years ago, at the age of 55, she was struck down by an extremely rare virus - herpes simplex encephalitis (HSE) - which attacks the brain, and affects one in 500,000 people of any age.

The gloomy prognosis was delivered by a dispassionate neurologist.

The virus left Carol with an acquired brain injury.

After just four days she had deteriorated to the point that she could not read a newspaper, nor remember how to flush a toilet. She could not recognise her own family, nor swallow, speak or walk. Her face became emotionless.

For Carol's husband, Garnet, and daughter, Skye, the news was devastating.

Skye, a graphic designer, sought to raise awareness of acquired brain injury by organising a photographic exhibition, highlighting how crucial photos can be in helping to retrieve memories and past experiences, and thus identity.

For Carol, albums of photos have been meticulously annotated, names placed alongside pictures, so that she doesn't forget.

Carol also keeps a journal to help her remember what happened just yesterday.

In such ways Carol's confidence is slowly returning.

Acquired brain injury is sometimes referred to as a "silent disability", with loss of memories harder to detect than some more observable physical disabilities.

links

www.bia.net.au

www.headcase.com.au

* email editor, "Disability News," for copy of article

Reviews Reviews Reviews

BOOK

Including People *with* DISABILITIES

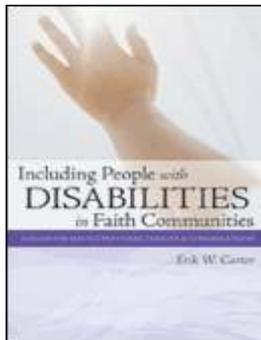
in Faith Communities

A GUIDE FOR SERVICE PROVIDERS, FAMILIES & CONGREGATIONS

Erik W. Carter

Paul H. Brookes Publishing Co., Inc.
Baltimore, 2007
\$24.95

available through all good bookstores



This book is for congregations who seek to be genuinely inclusive, i.e. hospitable, towards people with disabilities, and their families. In the shared quest for a deeper sense of spiritual growth such development can best be found with others who share such a goal. In suggesting an abundance of practical ideas concerning how congregations can develop their own local ideas for being inclusive Carter also addresses barriers to inclusion related to attitude, architecture and programming.

As more of a workbook than a book to be read from cover to cover, it provides lists of resources, reflective questions and worksheets to help congregations become truly inclusive of people with disabilities.

A resource for congregations who want to be serious and practical about inclusion of people with disabilities, and supportive of their families.

FILM

The Black Balloon

disability topic: autism / family pressures

While some films on a disability theme can be played for the feel-good factor (e.g. *I am Sam*,; *Stuck on You*), this Australian production, which was in cinemas in early 2008, deals with an intellectual disability theme with a sense of humanity and truth rarely seen on film.

We're taken into suburbia with the Mollison family. Mum (Toni Collette) is pregnant and stressed, and Dad (Erik Thomson) tries to rule a chaotic house. Then there's 16 year-old Thomas (Rhys Wakefield) who's keen to build a relationship with beautiful Jackie (Emma Ward) at his new school. Into this mix there is Thomas' severely autistic brother Charlie (Luke Ford), who is noisy, unpredictable, often unmanageable, unwilling or unable to speak.

Whilst Charlie graphically reveals to us the character of someone living with autism, the film is really about Thomas, who tries hard to care for his brother but is also desperate for "normal" teenage companionship and peer group approval. What can he do when he deeply wants to impress his girlfriend but his brother behaves obscenely in her presence?

Love and teenage angst are woven together beautifully in a realistic way. We are given an honest picture of some of the trials that are endured by families that include a child who has a major level of intellectual disability.

Recent winner of AFI Best Film 2008. Look for this on DVD.

A Christmas Reflection

"... and the Word became disabled and dwelt amongst us."

based on John 1:14

A number of years ago I read a provocative book by American disability rights activist and Christian, Nancy Eiesland, a person with her own congenital disability. The book was called "The Disabled God." It served as a call to see the Risen Christ as one who identified with suffering humanity to the extent whereby his physical woundedness (Luke 24:39) became a point of total identity with people with disabilities, hence God in Christ is the Disabled God. God becomes incarnate, one with us, to the point of disablement. The Body of Christ, the church, becomes a broken body, a 'communion of struggle' (p.108).

And yet the traditional Christmas story of Jesus as one who was born to Mary and Joseph in Bethlehem tends to often be proclaimed and celebrated as the Christ child who comes to us as a supernatural being, more divine than incarnate, more holy than the one who shares our woundedness. We sing carols that extol the baby Jesus for not crying (as if crying is a sin), and we adore images of the baby in the manger with a radiant halo enshrouding his head. We end up with a sentimental image of Jesus devoid of identity with the pain and sorrow of what it means to be a truly human being. And we end up with a church struggling to identify with a broken world and broken people.

Yes, Christmas offers great cause for celebration, however let us think beyond the manger to the Jesus of John's gospel who dwelt amongst us, who hungers, thirsts, gets angry and frustrated, who shares our joys and sorrows, and who, through woundedness, embraces the wounded, including those who live with disabilities.

At Christmas, but in all the sacraments and celebrations of the church, and in our ministry with one another and our community, may we reflect the Christ who truly dwells amongst us.

concerning woundedness

"And in every parish ..., in every home, in every heart that welcomes a wounded person, there is the quiet presence of Jesus, consoling, loving, announcing the good news."

*Jean Vanier
"the Broken Body", p.127*

* Jean Vanier is the founder of L'Arche, which are small-scale faith communities for people with intellectual disabilities which today are found world-wide.

kid's books

all cats have asperger syndrome

by **Kathy Hoopmann**

Jessica Kingsley Publishers

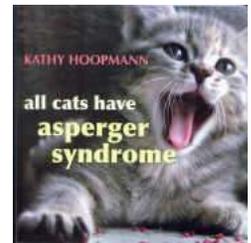
London & Philadelphia, 2006

hardcover \$24.95

Available all good bookstores

disability topic: **Asperger syndrome**
suitable for ages 5-12

This delightful book describes what it's like for someone to live with the symptoms of Asperger's syndrome. Through the use of appealing



and humourous photos of cats in all their playfulness the otherwise serious side to this disability is described in a way that is accessible to children, but also with appeal for adults who seek to better understand the syndrome. Issues associated with this syndrome, such as the reaction to being touched, and eating, are described sensitively.

A gentle and insightful introduction into the life of someone who lives with Asperger's syndrome.

all dogs have ADHD

by **Kathy Hoopmann**

hardcover \$24.95

disability topic: **ADHD**

The current follow-up to "all cats..." this book, like its predecessor, takes a humourous and insightful look at disability, but this time with active canines as the means of explaining ADHD.

