

DISABILITY NEWS

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Uniting Church in Australia

from the Editor....

Greetings!

I recently attended a rally in Adelaide calling for action on the National Disability Insurance Scheme. It was one of a series of gatherings across Australia where people with disabilities and politicians spoke of the need for the NDIS to be implemented as quickly as possible.

It is a plan to secure billions of dollars and crucial assistance for people with disabilities, and to offer vital support to disability carers, including family members, in terms of accessing vital, often life-sustaining, personal services.

Carers, such as those mentioned in this issue on p.3, offer their care with selfless devotion. They often care at the expense of personal health. Yet in their life-sustaining work their efforts have for too long gone unsupported at a governmental and local level.

Far too often the headlines are concerned with the economy and material acquisition. Yet, as the Bible and other historic documents attest, it is how we care for the most needy amongst us, including people with disabilities, and their carers, by which we should be regarded.

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Feel free to share this newsletter with your friends.

If you don't already, let me know if you would prefer to receive this by email.

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

Freedom of expression: Christopher's story

Christopher sits in his wheelchair by the window of the busy and airy activity room which is adorned with examples of artwork around the walls. Recreational staff come and go attending to the needs of various people -- helping with activities, making cups of tea, attending to administrative detail, making phone calls concerning an absent individual, assisting an unsettled soul, or attending to someone's toileting demands.

He is about 50 and lives with a significant level of intellectual impairment. He can utter a few words, has a hearty, deep-throated laugh, and will sometimes peer at you through enquiring eyes. However, it would be fair to say that his verbal and non-verbal communication skills are confined to a limited array of responses. At least that is how he has presented himself to me over much of the time I have known him.

He dresses for comfort more than style -- jeans, tank tops and old sneakers. His priorities seem to lay elsewhere. His hair is thin, graying and straggly. To my eye Christopher's visual appearance is of someone who has grown into the role of the struggling artist.

There are numerous other accommodated people who have come to this room with Christopher to participate in the social activities on offer. There are some working at jigsaws. Others are browsing through lifestyle magazines, while a couple of others are intent on separating strands of wool into colour groupings. But for Christopher it's all about the drawings.

While Christopher sometimes joins in with group activities, today, as often happens, he sits to one side preoccupied with his drawing. Despite a loud moment of panic and commotion from neighbouring Emily he proceeds to draw with considerable concentration. He continues his creative endeavours unabated, until the work is done. Then he will quite quickly set in place another piece of paper, check the sharpness of his pencils, and proceed with his next work of art.

His pictures are of people and animals, of the sun and the stars, of a world beyond this place. They show care and precision.

People such as Christopher can be so contained by the attitudes, values and behaviours of highly prejudiced people. They can be excluded because people fear them or couldn't be bothered trying to understand them.

Yet, as long as Christopher has paper and pencil and maintains an unfettered passion for his art, a part of him is not contained by the ignorance of others. He is free.

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National Disability Insurance Scheme

The National Disability Insurance Scheme is the national political issue that in recent times has become a focal point for advocacy right across the disability community. No issue has commanded as much broad attention and support in many years.

What is it, and why is it an issue that is generating so much passion across disability groups Australia-wide, and amongst people with a disability, and their carers?

The NDIS will double existing funding for disability services from around \$6 billion to \$12 billion. Importantly, it will scrap the old welfare model and install a new one of lifetime *social* insurance, whereby all taxpayers contribute. It will shift disability provision from the states to a single national body funded by the Commonwealth, from general revenue.

It will enable people with disability more choice as they get to choose what to spend on which service. Services previously unaffordable may now be financially accessible.

What can I do to learn more?

- Check out the government website at <http://www.ndis.gov.au/>
- Google 'NDIS' and read some of the web pages that detail the case for this scheme. For example, try <http://www.themonthly.com.au/case-national-disability-insurance-scheme-two-nations-anne-manne-3636>
<http://www.abc.net.au/news/2011-12-03/labor-endorses-national-disability-insurance-scheme/3710744>
<http://www.theaustralian.com.au/national-affairs/health/disability-plan-stalls-over-cost-demands/story-fn59nokw-1226269144612>
- Log in to the NDIS campaign on Facebook. It will detail latest developments and initiatives.

How can I show my support?

- Write to your local federal M.P. offering support for the NDIS, and, as matter of justice, urging that it be implemented as soon as possible.
- Lend support to campaigns in your area.

People with disability have waited long enough.
It's time for a change ... *now!*

Disability Resource Website

www.presbytersynod.sa.uca.org.au/disability-ministry

This UCA site offers disability resources such as back copies of Disability News newsletter, kid's books, reviews, relevant disability issues, pastoral care information, liturgy, prayers, poems and stories.

For church & personal use.

A Prayer for the Stranger

*God of aliens
and strangers:
make the doors
of our homes
wide enough
so all find a home.*

*God of the near
and far off:
make our hearts
wide enough
so all might find a friend.*

Part of a prayer by Thom Shuman
in the newly published
50 NEW PRAYERS
FROM THE IONA COMMUNITY
edited by Neil Paynter
and available from
Wild Goose Publications www.ionabooks.com
e-mail: wgrg@iona.org.uk.

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South Australian Books for Indian Disability Centre

In a previous edition of this newsletter (vol.6 issue 1) the various disability ministries of the Child Guidance Centre (CGC) in Hyderabad, India, were outlined. The link with the CGC first developed in 2009 when the CGC director, Dr Frank Viswanath, made contact with me with a view to seeing how the Uniting Church, SA, might support the ministry of the CGC.

Two avenues of support have subsequently emerged. Firstly, members of CGC have been able to come to Adelaide to visit various church and non-church disability facilities, with a view to gathering information that may be relevant to projects back home. Facilities visited have included Uniting Care Wesley Pt. Adelaide, Minda, Inc., as well as the mental health ministry of Rev. Mark Boyce. - Uniting Church members have assisted as hosts for these visits.



Secondly, 2 large shipments of educational books have been shipped to the CGC and to their library where training is offered to those seeking leadership positions within the facility. The books have been sourced from South Pacific School Aid, whose coordinator is Peter Kirk. Shipments have been generously funded through the International Mission office of the SA Synod. Books and journals on a variety of healthcare and educational topics are proving to be of much benefit to the centre.

However the relationship with the CGC is also reciprocal, and those able to incorporate a visit to the CGC into their overseas travels would be most welcome. Please contact me if interested in further information regarding the CGC.

State Budget funding for Disability

The SA Government's budget includes a welcome \$212.5 million in disability funding. Key funding allocations are:

- **\$61.5m** over 4 years to the SA Housing Trust for community-based homes.
- **\$106.1m** to boost support for people living with disability, and their carers.
- **\$21.6m** over 4 years to transition remaining Strathmont residents to supported community accommodation.
- **\$2.3m** over 4 years for a disability community visitor's scheme.

Source: Julia Farr Association Purple Orange Email Alert: 6/6/12

Review

DVD

what next?

BY CAMERON ROSE



Merri Community Health Services
Commonwealth Respite and Carelink Centre/Carers Links North
and
the faculty of Art Design and Architecture,
Monash University.
2011

* available free of charge from Cameron Rose
email: cam@cameronrose.com

This DVD explores the lives of five older families who care for children who have major levels of intellectual disability.

Lynn & Peter care for Paul who at age 2 was diagnosed with a cancerous brain tumour, and couldn't speak till age 5. They have concerns about relinquishing him to the care of others, and feel it would be better for him if he died before they did.

Lily, from Malta, gave birth to 2 children who acquired disabilities. Her husband died 3 years ago aged 63, and she struggles for income. She is looking for rest, and a good home for her son.

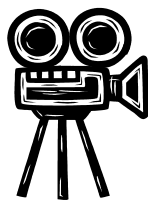
Anna & Anastasios have a son, Arthur, who was diagnosed with a disability at age 5. Their hoped-for family life was devastated. Anna is very tired, and speculates as to whether or not he can go to an institution.

Sarah had 5 children, one of whom, Diane, was born with an intellectual disability. Sarah struggled to get a correct diagnosis from medics and came into conflict with doctors who thought they knew better. Diane was taken to an uncaring institution. Sarah is 85 and still offers support for her daughter.

Hilda speaks of her husband Tom dying when their children were very young, including Glenda who was 3 and had an intellectual disability. Hilda has remarried but as an elderly woman regrets not having been able to do what she would like, when she wants.

Common carer themes include lack of appropriate and accessible accommodation for their adult children, the struggle to live life on their terms, and physical and emotional demands.

This is a thought-provoking account of carers struggling to offer quality life-time care for their children who cannot look after themselves. - *Well worth viewing.*



Disability on Film

The website www.disabilityfilms.tripod.com presents a list of 2500 films and documentaries that depict people with various forms of disability and mental illness. The following is a synopsis of just a few from the last 20-30 years worth checking out.

The Diving Bell and the Butterfly: True story. Jean-Dominique suffers a massive stroke leaving him only able to communicate by blinking his left eye. We go inside his mind, and also see reactions of those close to him.

Black Balloon: Aussie movie. When teenager Thomas moves into a new home with his family all he wants to do is fit in. But the antics of his autistic older brother Charlie make this frustratingly difficult.

My Left Foot: Based on a true story, this is a realistic portrayal of a young Irishman growing up with cerebral palsy in impoverished circumstances.

Murderball: Graphic doco of sportspeople with physical disabilities playing no holds barred wheelchair rugby.

Children of a Lesser God: James is a teacher at a school for the deaf. Sarah is a troubled, deaf cleaner at the school. Romance begins. He wants her to talk. She feels stifled in his presence. Both are stubborn.

Born on the Fourth of July: True story. Paralysed and traumatised from a tour of duty in the Vietnam war embittered Ron Kovic struggles to be accepted back home.

Elephant Man: A true story set in 19th century London. John Merrick is born with a major facial deformity which has him treated as a both a curiosity and imbecile. He strives to be treated as a human being.

Rain Man: Selfish yuppie, Charlie Babbitt, discovers that his father has died bequeathing his multimillion-dollar estate to his other son, Raymond, an autistic savant of whose existence Charlie was unaware.

Forrest Gump: The story depicts several decades in the life of Forrest Gump, an intellectually naive young man who witnesses, and in some cases, influences, some of the defining events of the latter half of the 20th century, including the 1960s flower power generation, and the Vietnam war.

A Beautiful Mind: This true story begins in the early years of young academic prodigy John Nash who develops paranoid schizophrenia and endures delusional episodes while painfully watching the loss and burden his condition brings on his wife and friends.

What's Eating Gilbert Grape?: A young couple living in mid-1950s America struggle to come to terms with their personal problems while trying to raise their two children, of whom one has an intellectual impairment.

Annie's Coming Out: Aussie movie. The true story of Anne McDonald's early life in a government institution for people with severe disabilities, and her subsequent release.

Benny and Joon: A comedy about a mentally ill young woman who finds her love in an eccentric man who models himself after legendary silent movie comic Buster Keaton.

The Water Dance: This is a semi-autobiographical story about a young writer who becomes paralyzed in a hiking accident and works to rehabilitate his body and mind at a rehabilitation centre.

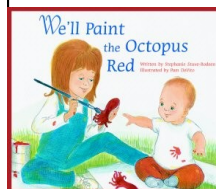
Other films worth considering: Passion Fish; Sling Blade: I am Sam; Mask; The Other Sister; Gaby; Mask; Lorenzo's Oil, Outside Providence; and, Blue Sky.

My favourite? For what it's worth - The Diving Bell and the Butterfly. Absolutely compelling.

kid's books

We'll Paint the Octopus Red

by Stephanie Stuve-Bodeen



Woodbine, 1998
from Amazon, \$10.85
topics: Down Syndrome, siblings of children with disabilities

Six year-old Emma awaits with anticipation on the birth of her baby brother or sister. She thinks of all things they will be able to do together, including a trip to Grandpa's farm, and a trip to Africa. Then, when baby Isaac is born, Dad tells her that her brother has something called Down Syndrome. Emma and her father help each other realize that this is the child they really wanted.

The book concludes with questions about Down Syndrome and answers for young children concerning the effects on siblings and family life.

There is a sequel called "The Best Worst Brother."

Australian
disability-specific online
bookstore
www.Abilitybooks.com.au/

This is an online book store dedicated to providing books and resources to support people with disability, their families, support workers, teachers and clinicians.

Resources and topics include:

- Kid's activity & game's books
- Story books
- Books for adults to read with kids
- Adult and kid's health issues
- Lifestyle

A wide variety of impairments are covered including Autism, ADHD, Asperger Syndrome, Fragile X, and Dyspraxia.

Social and lifestyle issues include pregnancy, diet, parenting, adoption, sexuality, education and social inclusion.

Worth checking out.