

DISABILITY NEWS

Vol. 6 Issue 2 Dec. 2010



email: twhitney@sa.uca.org.au

Uniting Church in Australia

from the Editor....

Greetings!

Over recent centuries people with intellectual disabilities have often been described in the most demeaning and degrading of terms - moron, mad, idiot, feeble-minded, sub-human ... to name but a few such terms. Such names have made it easier for some to dismiss people with intellectual disability as not being one with us, or even, sad to say, having less reason to live!

The people of L'Arche described on p.3, as well as Ian Brown's hard-one insights into his severely intellectually impaired son, Taylor, (same page) remind us that human life is not to be valued by the extent of one's intellect, nor by the achievement of certain social standards.

It is to be valued by their full humanity, and that they are made beautifully and fully in God's image.

Life is only the richer when people with intellectual disabilities are fully affirmed as human beings, and accepted as God's children, as we all 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 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 Committee

Pauline - a mother's story

Pauline is the mother of Matthew, a man in his mid-40s who lives with an intellectual disability. Matthew lacks the skills and abilities that are associated with an adult. He cannot read or write. He can't drive a car.

While Matthew can be a gracious host when people visit him he doesn't enjoy socialising away from home. He spends his days alone, doing what he likes best, travelling around the suburbs on trains. Sometimes he gets in trouble with others at the train station. Pauline receives the call from the police. She worries that with her son alone on the streets he can be "a loose cannon."

He doesn't get on well with people. Pauline arranged for him to go on a camp, giving her the chance to enjoy a few days respite. He was sent home on the first day having gotten into trouble with fellow campers.

Matthew doesn't want to live at home. What he really wants is to live alone in his own place. So Pauline enquires to the Housing Commission as to the availability of suitable accommodation. She's told she'll have to wait 6 years. But she perseveres, and after many calls finds a place for her son after just a few weeks.

Pauline is getting older and she fears for what could happen to Matthew if she is no longer around. She fears for his vulnerability, that there will be no one to stand up for him. As Pauline says, "Normal people don't really want to mix with people like Matthew."

She fears that his anger could get him into big trouble with the police. In the past he's been raped, and she worries that if he goes to prison he could be seriously physically violated again.

Amidst her fears for Matthew's future, and with obvious sorrow, Pauline says, "When push comes to shove I hope he dies before me."

Life for a loving mother and carer of a child with an intellectual disability can be very hard.

told with permission

*This story comes from DVD "Access Bible Study" produced by UnitingCare NSW.ACT.
- DVD to be reviewed next issue.*

Disability Resource Website

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

** please note the new web address*

Recently updated this UCA site offers a wide range of disability resources.
For church & personal use.

Index

From the Editor	1
Story	1
Disability website	1
Prayer	2
Ministry	2
Reviews	3
Christmas Reflection	4
Kid's Book	4
Stop Press	4

A prayer for openness

in celebration of the of the
International Day of People with a Disability, 2010

Holy God,

Open our ears to the deaf and hard of hearing.

Open our communities to be sacred listening places
where all are heard.

**Open our eyes to those who are blind or have low vi-
sion.**

Open our communities to be sacred places of new vision
and insight.

**Open our minds to challenge old attitudes and preju-
dices.**

Open our communities to be sacred places of new atti-
tudes, compassion and understanding of disability.

Open our arms to embrace all in our community.

Open our communities to be truly accessible and wel-
coming to ensure every opportunity of full participation
in the life of our Church community.

Together, then, let us pray in union with Jesus Christ.

I pray that all may be one, Father, just as you are in me
and I am in you. May all be one, so that the world will
believe that you sent me.

cf John 17:22-23

Bishops Commission for Pastoral Life

GPO Box 368

CANBERRA ACT 2601

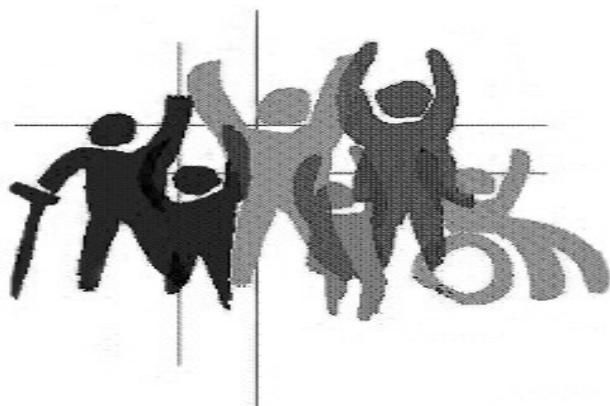
T (02) 6201 9868

F (02) 6247 6083

E disability@catholic.org.au

W catholic.org.au

*above prayer available in bookmark
form from Bishops Commission



PASTORAL CARE

**Seeing the Person,
not just the Disability**

The Titanic sank as quickly as it did because of the catastrophic damage caused to the hull of the super liner by that part of the iceberg that was below the surface.

When it comes to how we view people, and people with disability in particular, the illustration of the iceberg is helpful. There is the tip, i.e. the 10% of the iceberg that we see; and then there's the 90% mass below the surface that we don't see.

When we seek to offer care to a person with a visually obvious disability we can often find ourselves responding according to that part of them that we can immediately see. That is, we see the most obvious presenting symptoms or physical supports associated with their disability.

So we may see the wheelchair, the crutches, the seeing eye dog; or the loss of limb, the awkward mode of walking, or the twisted body. - But that is only the tip

So much of who that person is, their identity and humanity, is below the surface. Their values, attitudes, interests and ambitions; along with their likes, dislikes, loves, sexual and relational longings, faith and spiritual expression, are there beneath the surface.

When we look at a person with a disability may we certainly see their most obvious features. It helps us understand their disability. But may we also dare to make the time and effort to look beneath the surface and see the whole person, created as they are in the image of God.



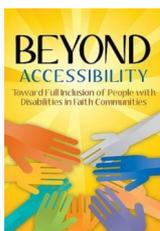
It's easy to only see the tip of an iceberg.

Reviews

BOOKS

BEYOND ACCESSIBILITY

toward full inclusion of people with
disabilities in faith communities



Brett Webb– Mitchell

Church Publishing, New York
2010
softcover \$22.95

disability topic: full inclusion in faith communities

This practical book raises the question, after your church has constructed its wheelchair ramps and large print newsletters, what next? In other words, what do you do to make people with disability feel truly welcomed and included once they are in the church and can read the news of the week. What would the church look like if it included people with disability in all aspects of its congregational life?

Divided into 2 parts the book firstly looks at the theological basis for inclusion, and then gives practical ideas for moving from accessibility to full inclusion.

A valuable guide for congregations who want to fully include people with disability.

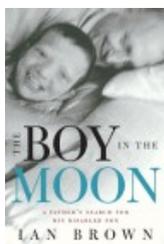
THE BOY IN THE MOON

A FATHER'S SEARCH FOR HIS DISABLED SON

Ian Brown

Scribe Publications, Melbourne
2010
softcover \$29.95

disability topics: child with rare disability;
family trauma & insights



The author's son, Walker, was born with an extremely rare genetic disease which means that, along with incredibly challenging behaviours, at the age of 12 he still wears diapers. His father struggles to answer the question that if his son's life can be seen by some as insubstantial why is it that he feels so important? The answer is hard-won.

Written with great honesty, the book is a tribute to the value of Walker, his life, and the myriad of people who sustain him, including his loving and devoted parents.

DVD - for group discussion or personal reflection

L'ÉPREUVE DES MOTS

(test of words)

Produced by L'Arche France,
2010

A film by Nicolas Favreau
Interviews by Anne Chabert
D'Hieres

Film duration: 26 minutes



This DVD, produced by L'Arche France, consists of a series of down-to-earth questions posed to a number of people, each living with an intellectual disability, who volunteered to be interviewed.

The questions include,

- Do you like being on earth?
- Do you watch the news?
- Would you say you are rich or poor?
- Can we talk about love?
- Does it make you happy to be in love?
- What is your attitude to friendship?
- What is your attitude to politics?
- Have people hurt you?
- What do you understand of death?

The questions are posed sensitively, and room is made for thoughtful silence. Answers are honest and enlightening, such as the young woman with Down Syndrome who thinks of her disability as “holes in my head.” Another lights up as she talks of love. Another struggles to speak of sexuality.

The answers and reactions come from people with intellectual disability, but they are principally the responses of thoughtful, caring people, who share, in their own way, in the joys and struggles of what it means to be human.

This is an excellent resource for enabling small groups to develop greater awareness and insights into the thoughts, feelings and lives of people living honestly with intellectual disability.

This DVD can be borrowed from the editor.

*“And if I were to say the word
'disability'?”*

L'Épreuve des Mots

Christmas reflection a love that doesn't run away

In a past issue I've mentioned a young man called Craig Romkema. He lives with the dual disabilities of autism and cerebral palsy. He is a Christian who has written a book of poems that express insight into life beyond disability. In the following poem he describes what love means to him.

"Daring Times" (for Betsy)

The whole fun thing about life
is the minutes
seemingly wasted,
in the contentment of love.
Love, with all grace and reason,
not love that uses and runs away,
but love that waits,
and holds my hand,
and cries with me,
even when my tears are hidden
beneath autistic faces.
This is contentment:
to be loved beneath the rotten talk,
and the waving,
and the rocking,
and the grinding teeth,
and the gradually aggravating testing garbage,
to be loved beneath it all,
and in spite of it all,
and through it all.
In those moments I can go on without fear,
for love is my armor,
and you are my standard bearer,
my contented, loving friend.

Used with permission
Craig Romkema

Embracing the Sky: Poems Beyond Disability, 2002
Publisher: Jessica Kingsley Publishers

Craig wrote those words for an obviously treasured friend called Betsy. She was clearly someone who was there for Craig when he needed her, who, as the poem states, did not run away, and who loved "beneath it all, and through it all." - Thank God for those like Betsy who love in such a devoted way. They give very practical expression to the New Testament notion of agape love, a love that in Paul the apostle's words,

Bears all things, believes all things, hopes all things, endures all things
1Cor.13:7

It is a love that looks beneath the surface, beneath those appearances and behaviours that turn some people away. It is a love that waits, holds hands and shares in tears.

The Jesus we celebrate at Christmas was born to love people in such an accepting, non-judgmental and devoted way, from birth, through life and death and so may we.

Kid's books

Baj and the Word Launcher

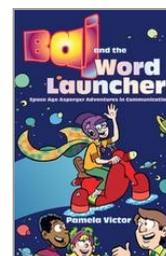
Space Age Asperger Adventures in Communication

Pamela Victor

Jessica Kingsley, 2010
\$14.95

Disability topics:

Asperger syndrome
Communication



Baj lives on the planet Aular and in many ways is like any other kid, but he has communication difficulties. How Will Baj ever learn how other people feel and why? How can he control his "jumbly" words when he gets mad?

But then Baj is given a magical communication kit that gives him the chance to better understand such social skills. An invisible Calming Cape comforts his body, helping him keep calm in difficult situations; a Word Launcher helps him choose the best words for the situation; and Listening Aids help him spot the most important words when people talk. Can these magical instruments make Baj a better communicator?

Read with a parent or other carer this book can help children with Asperger's Syndrome with verbal and non-verbal communication skills.

STOP PRESS

At the time of writing this issue Jean Vanier, founder of the faith-based worldwide network of homes for people with intellectual disability called l'Arche, has been nominated for the Nobel Peace Prize. May his nomination serve to enhance his vision of inclusion for people with such disability.