

Connections

A newsletter to support people
who are fostering inclusive parish community

ISSUE 1 2009

Life Worth Living



I recently purchased a book called *The Disabilities Studies Reader*, edited by Lennard Davis and was reading an essay by Ruth Hubbard on selective abortion and disability. She introduces the essay with an engaging reflection on ethnicity and abortion. She notes that in her country (USA) that to be born with brown skin is an indicator of significant disadvantage. People born with brown skin are more likely to end up in prison, to be sentenced to death for crimes, not complete high school and experience higher levels of unemployment etc, that is, they will suffer a disadvantage from having been born that way. Clearly brown skin is a disability compared with those born with white skin.

Hubbard poses the question, how would our society react if scientists suggested a genetic test for skin colour and routinely recommended abortion of foetuses which carried this gene? There is after all no way of knowing from the genetic screening which of these foetuses will overcome this disability and the disadvantage they may experience in society. We could not know from the outset which of them could become a president of the USA. Of course we would rightly be outraged at such a suggestion based on racist genetic selection.

Yet she notes that many in our society, not just medical personnel and scientists, but ordinary folk who have absorbed the message; genetic testing and recommendations of abortion for children detected with certain other genetic indicators is acceptable. These foetus are the ones that society calls disabled when they are born. There seems to be a willingness in our society to classify some lives as not worth living.

Many in the disability community would recognise the

phrase, "Lives Not Worth Living" (*Lebensunwertes Leben*) as a classification used by the Nazi government in Germany in the 1930's and 40's. The very first recorded exterminations of a class of people by the Nazi's were those classified as "*Lebensunwertes Leben*"- people with disabilities. Some compare the abortion of foetuses with potential disability as part of a eugenic mentality. Eugenics literally means good genes. To purify and improve the human genetic stock is the covert aim of those who recommend abortion as a treatment for detected genetic indicators.

As Christians we utterly reject the idea that some lives are not worth living. This is why we need to be vigilant about pre-natal genetic screening and the ready acceptance that abortion as the recommended "treatment". People with disability are created in the image and likeness of God and have inherent dignity and worth, along with all other people.

If our society accepts that some lives should be terminated before birth what reflection does this cast on attitudes toward children and adults with disability? Will our society see their lives as lives worth living?

In this issue we raise some of the questions about genetic screening and selective abortion in the hope that we will reflect on the deeper human values which should alert us to the value of every life, because every life is a life worth living.

Rev Anthony Gooley

Ministry Development Officer
Faith and Life Vicariate

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Contact Ministry and Community Life on ph: 3336 9714 or email: mcl.fl@bne.catholic.net.au

A Woman for our time?

Marie Stopes, honoured on a new postage stamp, is well known as a pioneer in the field of contraception. What is less well known is the influence on her work of her belief in eugenics – that by limiting the numbers of the poor by birth control it would be possible to improve the English ‘race’



It was one of the most poignant photographs so far of the US presidential race. Sarah Palin, the Republican Party’s vice-presidential nominee, cradled her baby, Trig, in her arms. A classic Madonna and Child pose. But it was one for which Mrs Palin was particularly vilified, simply because Trig is a Down’s syndrome baby.

Rather than be applauded for the courage and hard work it takes to raise a child with special needs, Sarah Palin was, according to Carol Fowler, the chairwoman of the Democratic Party in South Carolina, chosen because her “primary qualification seems to be that she hasn’t had an abortion”, while Cintra Wilson, a columnist for the online *Salon* magazine, said that Trig was “the anti-abortion platform that ensures [Palin’s] own political ambitions”.

Mrs Palin is not the first woman in the public eye to raise eyebrows over her decision about her baby. Cherie Blair chose not to have an amniocentesis test when she was pregnant with her fourth child, Leo, because of the risk to the baby, despite the relative likelihood at her age of having a child with Down’s syndrome. This was a view that went right against the grain. As a newly published report from the worldwide charity Down Syndrome Education International (DSEI), reveals government policy and pressure from the medical establishment has led to screening for genetic abnormality becoming the

norm in Britain. The study by DSEI shows that this screening, requiring invasive techniques, leads to miscarriage in between one in 100 and one in 50 pregnancies, and that around a startling 95 per cent of positive screenings are wrong.

For behind that screening policy lies a conviction that abnormality, any deviation from the “perfect”, has no place in our society.

But what the charity is really concerned about is not just the “normal” babies who are lost through this screening but whether genetic screening for physical and mental abilities and disabilities during pregnancy is acceptable. For behind that screening policy lies a conviction that abnormality, any deviation from the “perfect”, has no place in our society. For years the political and medical establishment has promoted the idea that screening is a sensible, rational option. It is a given that if abnormality is found, then the child’s life should be terminated. And just how that view came to be so popular owes its roots to a woman whose life and work is this month being given what one might call, literally, a stamp of approval. Marie Stopes is being

honoured with a stamp issued by the Royal Mail.

Stopes is, of course, best known for being a birth-control pioneer. The correspondence between Stopes and thousands of letter writers who

contacted her after publication of her bestselling volumes, *Married Love* and *Wise Parenthood*, reveal the desperation many felt at having large families they struggled to raise, the despair wrought by sexual ignorance, and the compassion felt by her for their plight. But Marie Stopes was not all that she seemed. (Indeed even her

title was misleading. That she was Dr Stopes suggested she had a medical background; in fact she had a PhD in fossil botany.) Like many of the early pioneers of abortion and birth control she was a eugenicist.

Eugenics, while long associated with Nazi Germany, has a lengthy history in Britain. The word derives from the Greek, meaning wellborn, and its followers advocate the improvement of the human race through intervention. Its beginnings can be linked to Thomas Malthus’ “Essay on the Principle of Population”, published in 1798, which expressed the fear that the poor, unless checked, would outstrip food supplies. During the nineteenth century, as the size of richer families declined, followers of

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Malthus feared that the poor would start to predominate in society. The solution was segregation of the poor in workhouses, where husbands and wives were kept apart so that they had no more children.

By the beginning of the twentieth century, the belief that those unfit to breed should be stopped from doing so began to grow in popularity. Preventive methods proposed included segregation, sterilisation, euthanasia, and abortion, as well as birth control. This desire to control population was not entirely focused on the poor; while the working classes should limit their families, many eugenicists and Malthusians were dismayed that the middle classes were having fewer children. The well-off woman was seen as shirking her duty by not improving the stock.

While the Eugenics Education Society was formed in 1907, it was during the 1920s and 1930s that the eugenics movement grew, attracting well-known intellectuals such as Sydney and Beatrice Webb and Bertrand and Dora Russell. Although the society's leading lights were on the left, and an unsuccessful bill was put forward in 1931 by a Labour MP to sterilise the unfit, there was a certain suspicion among Labour Party members that eugenics was focused on eliminating the working class. As indeed it was: Professor F.A.E. Carew, when giving evidence to the 1937 Birkett Enquiry into abortion, urged that the "slum womb" be abolished.

In contrast, as Ann Farmer recalls in her newly published study of abortion and eugenics *By Their Fruits*, the Westminster Catholic Federation told the Birkett Enquiry that it was social

conditions, not the child, that should be changed. It was a plea that went unheeded among the proponents of abortion. Ann Fureidi, chief executive of the British Pregnancy Advisory Service and one of the staunchest advocates of the right to abortion in this country, revealed in a paper on abortion given at Kent University that policy makers long focused on limiting

the children of the poor, right up to the passing of the 1967 Abortion Act.

"Parliamentary discussion of the Abortion Act explicitly discussed its use in preventing unfit mothers from having unsuitable families," she told the one-day conference.

"Contemporary medical journals discussed the validity of legal abortion alongside the need for a birth control plan for Britain to limit the numbers of the poor."

Back in the 1930s, as Ann Farmer's meticulously researched account reveals, a network of campaigners made up of Eugenics Society members belonged to a wide range of other organisations and worked across party political lines, pushing for abortion and sterilisation for just these reasons. In the midst of all this was Marie Stopes. Stopes came to prominence in 1918 with the publication of *Married Love*, which had sold 400,000 copies by 1923. In 1921, she and her husband, the aviator H.V. Roe, set up London's first birth control clinic in north London and formed the Society for Constructive Birth Control and Racial Progress. Her views went well beyond an interest in people's sexual wellbeing. "Are these puny-faced, gaunt, blotchy, ill-balanced, feeble, ungainly, withered children the young of an Imperial race?" she asked the readers of *The Daily Mail* in 1919 in an article entitled "Mrs Jones does her worst".

the harm it would cause to her own bloodline. "Mary and Harry are quite callous about both the wrong to their children, the wrong to my family and the eugenic crime".

These beliefs took Stopes to Germany, where she attended the Nazis' Berlin congress on population science in 1935. They were beliefs she maintained throughout her life, leaving her money to the Eugenics Society and helping to set up the International Planned Parenthood Federation in the 1950s, arguing that no society should allow "the diseased, the racially negligent, the careless, the feeble-minded and the very lowest and worst members of the community to produce innumerable tens of thousands of warped and inferior infants".

Such extreme language might seem outdated today, but Stopes would no doubt approve of the screening for congenital abnormality so heavily promoted by the NHS, whose end result is frequently termination. And yet the numbers of children with Down's is increasing. The number of babies born with the condition has risen by 25 per cent in the past 15 years in Britain. According to Frank Buckley, chief executive of DSEI and co-author of the charity's new report: "More people are living with Down's syndrome than ever before, with over 600,000 across Europe and North America and maybe 4 million worldwide."

All kinds of reasons could explain the increase in the number of Down's children. Women are having children later in life, thus increasing the likelihood of chromosomal abnormality. They feel encouraged to have them because other parents and charities have lobbied hard for better healthcare and better opportunities for their children.

Above all, these figures are a sign that we have made progress in the twenty-first century – not because of genetic screening but because, unlike Marie Stopes, people have learned that they need not fear those who they deem less than perfect.

Source: *THE TABLET* 27 September 2008



By the beginning of the twentieth century, the belief that those unfit to breed should be stopped from doing so began to grown in popularity.

"Mrs Jones", she went on, "is destroying the race!" The following year, in her book *Radiant Motherhood*, she urged that "the sterilisation of those totally unfit for parenthood be made an immediate possibility, indeed made compulsory." Marie Stopes' beliefs affected her own family. She cut her son out of her will for marrying a short-sighted woman, outraged at

Mums as Genetic Outlaws

Some Women Resist Pressure to Abort the Less-Than-Perfect



Society increasingly demands perfection, and babies diagnosed with problems are aborted more often than not. Some women, however, resist the pressure and bear children who have disabilities.

The stories of a number of these women are brought together by Australian researcher and activist Melinda Tankard Reist in a book titled, *"Defiant Birth: Women Who Resist Medical Eugenics"* (Spinifex Press). First-person testimonies comprise the bulk of the book.

In her opening essay Tankard Reist, founding director of Women's Forum Australia, gives an overview of the women who confront a society fearful of disability and who decide to have babies without the genetic stamp of approval. "They are, in a sense, genetic outlaws," she states.

The experience of some of the women also raises doubts over the medical profession. Some received grave diagnoses regarding their unborn children. Later, these children were born, either without any problems, or with disabilities that were much less serious than predicted. Some doctors even refused to help women who refused to abort children who were diagnosed with disabilities.

In fact, with increasing frequency women's desires are ignored. Tankard Reist recounts the case of one woman who didn't wish to be informed of any possible problems before she underwent an ultrasound procedure. On taking the image home she found on the image, nevertheless, a series of annotations of possible abnormalities. The baby was later born free of any of the conditions mentioned.

The upshot, the researcher states, is that prenatal screening, instead of giving women more power -- part of

the rhetoric of the "right to choose" -- in practice puts pressure on them to conform to social prejudices against people with disability.

The A-word

Also looming is another, more insidious, danger with genetic testing. Screening and abortion become merely a part of the routine prenatal program, Tankard Reist argues. Prior to prenatal testing the possibility of abortion might not even be mentioned and when problems are detected a full explanation of the options available might not be given.

Women, then, can become victims after innocently going along with the attitude of "doctor knows best."

Such was the case of Natalie Withers. Her fourth baby was diagnosed with heart problems and other conditions. She told Tankard Reist that the term "abortion" was not even mentioned; there was merely talk of "inducing birth" -- at 20 weeks gestation. Only when Withers was in labour was she informed that the baby might either be stillborn or die immediately. Not until after it was all over -- the baby didn't survive -- did Withers discover that children born with her daughter's condition can survive and do well if they receive the right care.

Women, then, can become victims after innocently going along with the attitude of "doctor knows best." Only too late do they discover that their own interests and preferences are passed over in favour of the conventional wisdom of perfect children, says Tankard Reist. And once they wake up to what is going on, even well-educated women can find the going

difficult if they choose to go against the preferences of medical experts.

Often the information given to women is slanted in such a way as to encourage abortion. In many cases parents are not directed to groups that would help them to understand better the nature of the disabilities involved. That in turn makes it difficult for them to know how their child might fare or what support is available.

Other difficulties involve coping with the trauma and anxiety of test results that show possible problems. Tankard Reist cites a number of studies showing that many women who are told their children suffer from defects suffer from serious shock, distress and panic. These psychological pressures can even affect the mother's well-being, and that of the unborn child.

The dangers involve physical risks too. Some observers question, for example, the frequent use of ultrasound machines without an adequate evaluation of the negative consequences. And amniocentesis, in which a sample of the amniotic fluid is taken from the mother's womb for analysis, can lead to the loss of the baby in 1 in 125 pregnancies, according to one meta-analysis cited in the book. Another study showed that this procedure caused up to four healthy babies to be miscarried for every abnormality detected.

Sometimes the tests are simply wrong. A study of 300 foetal autopsies found that the prenatal hypothesis concerning problems was confirmed in only 39% of the cases.

Dehumanizing

The eugenic mentality behind the practice of aborting handicapped children is sometimes more blatant. One survey of obstetricians in England

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and Wales, for example, found that a third of them require a woman, even before she undergoes prenatal diagnosis, to agree to abort a pregnancy if the child were found to have a problem.

Behind such a practice lurks the belief that allowing these children to be born would burden them with second-rate lives and bring misery into the world. This gives rise to a form of new eugenics masquerading under the appearance of health concerns, Tankard Reist warns. People who follow such a line of reasoning, she adds, might end up acquiescing to the selection and elimination of less-than-perfect children, a sort of infanticide.

Such a mentality mirrors the increased desire for perfection in today's society. Other manifestations of this trend include excessive dieting and the ever-spreading use of cosmetic surgery. A number of prominent geneticists and ethicists, including figures such as James Watson and Peter Singer, openly favour the use of genetic techniques to design more perfect babies.

Ever-higher health costs also contribute to the pressure on mothers to abort the handicapped. Parents who decide not to abort imperfect children

are sometimes made to feel irresponsible for "burdening" society.

Tankard Reist cites Australian geneticist Grant Sutherland, who reckoned that preventing the birth of a child with Down syndrome saves the community a million dollars or more. He has urged governments to set up public clinics to screen pregnant women.

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This financial pressure extends to other areas, such as the increasing difficulties faced by people with genetic defects in obtaining life insurance, or permission to adopt children.

Healthy Harrison

A report in last Sunday's London-based Telegraph newspaper highlighted the relevance of the problems raised in "Defiant Birth." Lisa Green was 35 weeks pregnant when her baby was diagnosed with Down syndrome, and she was offered an abortion by doctors.

The doctor, recounted Green, only

disclosed the negative aspects of giving birth to the child. She rejected the advice, and two weeks later gave birth to a baby, named Harrison, now 2 years old. He is, said the newspaper, a "happy and healthy" child, according to the mother.

In an editorial published the same day, the Telegraph referred to the practice of aborting babies in a very late stage of pregnancy. "It is very difficult," it said, "if not impossible, to explain what makes these 'terminations' different from the killing of children." Such killings will continue, so long as the new eugenics mentality prevails. (Source *Zenit News*)

The first 275,000 people killed in the Nazi euthanasia campaign to create a pure race were people with disabilities.

They were not classified in the Nazi system of classification as people with disabilities.

They were classified as:

**Lebensunwertes
Leben**

That is life unworthy of life or lives not worth living.

"Confidence and Capacity: Parish Communities knowing and supporting people with disability." Faith & Life. 2003. (Price \$19.80 within Brisbane Archdiocese or \$28 Elsewhere)

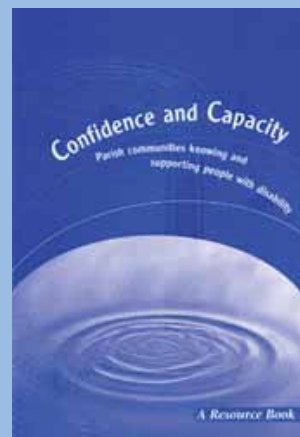
Confidence and Capacity is a book which aims to develop the confidence and the capacity of parish communities to know and support people with disabilities. The focus of the resource book is not disability per se, but the attitudes, values and beliefs of parish communities which sometimes may limit their potential for the full inclusion of people with disability in all aspects of parish life.

While the resource book is grounded in solid theories of inclusive practice the book itself is a practical resource. The resource book contains a formation program to raise awareness of disability issues in a parish and to form a disability connections group, if parishes wish to proceed this way. The formation program can be used with existing groups such as a parish pastoral council, a care and concern group or others seeking to be more intentional about inclusion of people with disabilities.

There are five sections to the workbook, with worksheets and sections to record notes. Section one is Responding to the Call to Welcome all People, section two is Learning and Action, establishing a Parish Disability Connections group, Section three, Essential Guides for Action, Section four, positive examples of intentional action and section five, resources. Some parishes may want to use the section two resources to adapt the

focus of an established group and to encourage this group to take on disability support.

This resource book was developed by Ms Trish Murdoch in collaboration with people with disabilities, parents and carers as well as people with expertise in the disability sector.



This resources can be ordered through Faith & Life 07 3336 9174 or email mcl.fl@bne.catholic.net.au

JobAccess: your one-stop information shop for the employment of people with disability



Having trouble navigating the maze of disability employment services and assistance schemes? Do you want to find all the information you need in one place? Or do you want to call someone to get the right advice, when you need it? Now you can.

What is JobAccess?

JobAccess is an information and advice service, funded by the Australian Government, which offers practical workplace solutions for people with disability and their employers. JobAccess includes a comprehensive, easy to use web site and a free telephone information and advice service where you can access confidential, expert advice on all disability related employment matters.

Who can use JobAccess?

JobAccess is a free service. It provides information specifically for employers, job seekers, employees with disability, their co-workers and employment service providers.

The web site

The JobAccess web site has information about the full range of Australian Government services for the employment of people with disability. It also has step-by-step guides on recruitment, job searching, adjusting a workplace, understanding rights and responsibilities at work and more. Visit JobAccess at jobaccess.gov.au.

The Workplace Adjustment Tool

The JobAccess online Workplace Adjustment Tool lets you find out about ideas and solutions for enabling or supporting employees as they perform different activities at work. When you find a product or solution that interests you, the online tool will link you to suppliers or services in your state or territory. The search tool also links you to a secure online application form for the Workplace Modifications Scheme.

The search tool and online forms are available on jobaccess.gov.au.

Free expert advice

For confidential, expert advice on matters relating to the employment of people with disability, contact the helpful JobAccess Advisers free of charge on 1800 464 800. JobAccess is a free service for all Australians.

The Workplace Modifications Scheme

While the majority of people with disability do not require any workplace modifications, for some job seekers and workers with disability the barrier preventing them from doing a job is a workplace that doesn't accommodate them. Sometimes what's needed is an adjustment to the work environment or tools or technology to enable them to perform a job to their full potential.

What is the Workplace Modifications Scheme?

The Workplace Modifications Scheme aims to adjust the workplace to suit people with disability. It is a pool of funds available to pay for the cost of any special equipment or adjustment that is needed to accommodate an employee with disability.

Under the Scheme, the amount of funding available for each workplace modification usually isn't limited which means there is flexibility to provide workplace solutions that really meet the individual needs of both employers and employees.

Who can access the Scheme?

Funding is available to help employers accommodate both new and existing employees with disability. To be eligible, the employee must be employed for at least eight hours a week in a job that is expected to last 13 weeks or more.

How do I access the Scheme?

You can ask your employer or employment service provider to apply for the Scheme on your behalf. Employers, self-employed workers and employment service providers can all apply for the Scheme using the online application forms available at jobaccess.gov.au.

The Workplace Adjustment Tool

The JobAccess Workplace Adjustment Tool is an online search tool that lets you explore ideas and solutions for workplace modifications and adjustments. When you find a product or solution that interests you, the tool will link you to relevant suppliers or services in your state. The tool is available online at jobaccess.gov.au.

Free expert advice

For more information about the Workplace Modifications Scheme or advice about the workplace modification or adjustment that meets your needs, contact the JobAccess Advisers free of charge on 1800 464 800.

The Workplace Modifications Scheme aims to adjust the workplace to suit people with disability.



Aussie Christian Brother leader to head PNG disability network



The Christian Brothers have announced the appointment of their former Western Australian leader, Br Kevin Ryan, as the new director of a national disability services network in Papua New Guinea.

Fifty eight year old Br Kevin Ryan will head Callan Services for Disabled Persons and be based at its national coordinating unit in Wewak, a Christian Brothers media statement says.

Br Ryan is a former Province Leader of the Christian Brothers in Western Australia and South Australia from 2002 until 2007. He has had an extensive career as an educator and in working with troubled youth and indigenous students.

He was the Foundation Principal of Clontarf Aboriginal College in Perth from 1986 until 1990 and of Catholic schools in Broome.

Callan Services was established by the Christian Brothers in Papua New Guinea in 1991 with the support of CBM and Save the Children and over the past two decades has led the way in building services for people with disabilities.

Callan Services is involved in the training of personnel to work with people with physical, sensory and mental disability. The national unit working in partnership with national and international, government and non-government partners and agencies, also addresses social disadvantage, promotes specialist health services and mounts disability prevention programs in rural communities.

Up to 200 staff throughout the country work under the Callan Services network banner with approximately 20 staff working from the national coordinating unit in Wewak.

Province Leader of the Christian Brothers in the Oceania region, Br Vince Duggan welcomed Br Ryan to the "challenging and vitally important role" and praised the efforts of Callan Services foundation director, Br Graeme Leach over the past two decades.

"Graeme has been able to influence national policy at the highest level and the rights of people with disabilities are much more honoured now than was ever the case before," Br Duggan said.



"Graeme's name has become synonymous with early intervention and inclusive education programs and his work has left a lasting landmark on the PNG education and disability services sectors.

"His vision and dedication has seen local people become qualified practitioners in the areas of special education, physiotherapy, ear and eye care and many related fields.

"We are all confident that Br Kevin Ryan with his strength of purpose, compassion and determination will see through Graeme's legacy and continue to produce a service with which the Christian Brothers and the people of Papua New Guinea can be proud," Br Duggan added.

To ensure a smooth transition, Br Graeme Leach will remain involved as a consultant at Callan Services in the early months of 2009.

SOURCE

[Christian Brothers to appoint former WA leader to replace pioneer in PNG disability services](#) (Christian Brothers, Media Release, 6/11/08)



book review

ERIK W. CARTER, INCLUDING PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES: A GUIDE FOR SERVICE PROVIDERS, FAMILIES AND CONGREGATIONS. PAUL H BROOKES PUBLISHING. NEW YORK.

A Congregational community is an ideal place to share and strengthen faith, form lasting relationships, develop special gifts and talents. Too often, though, people with developmental and others disabilities lack the supports they need to fully participate in the faith community of their choice. With this innovative guide, congregations will get the realistic how-to strategies they need to become places of welcome and inclusion for people with a wide range of disabilities. Bringing this idea to life with anecdotes, vignettes, thought provoking quotes from experts and

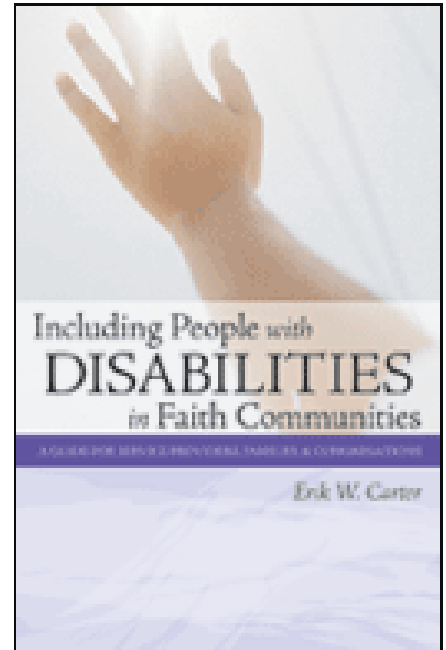
community members, and specific examples of successful strategies, Erik Carter helps readers

- ◇ Reflect on how inclusive their congregation is or could be
- ◇ Break down attitudinal, architectural, and programmatic barriers to inclusion,
- ◇ Develop meaningful religious education programs and other religious activities
- ◇ Discover and actively support the spiritual preferences, strengths and needs of people with disabilities,
- ◇ Plan, fund and implement bold communitywide inclusive efforts,
- ◇ Pursue inclusion beyond congregational activities, responding to peoples needs for social relationships, leisure activities, employment and transportation

To make inclusion work in any faith community, this practical book gives readers workable strategies for identifying markers of welcome, encouraging community outreach and

gathering important information about the support needs of people with disabilities and their families.

Erik W Carter PhD is assistant professor, department of Rehabilitation Psychology and Special Education, University of Wisconsin-Madison, USA.



Sharing Your Story

Have you checked out the resources on disability on our website Focus on Welcome and Inclusion? There is a lot of material that individuals and parishes can use to raise awareness and promote inclusive practice. Go to www.bne.catholic.net.au/fwi and check it out.

Perhaps you would like to submit your story? In our story section we are looking for stories to inspire and to let people know that inclusion works and gives life to communities and individuals. If you want to share your story on our website you can do so by sending a typed version by post or by email as an attachment.

By Post	By email
Faith and Life, "Sharing Your Story", GPO Box 282, Brisbane, 4001	mcl.fl@bne.catholic.net.au Put <i>Sharing Your Story</i> in the subject line

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