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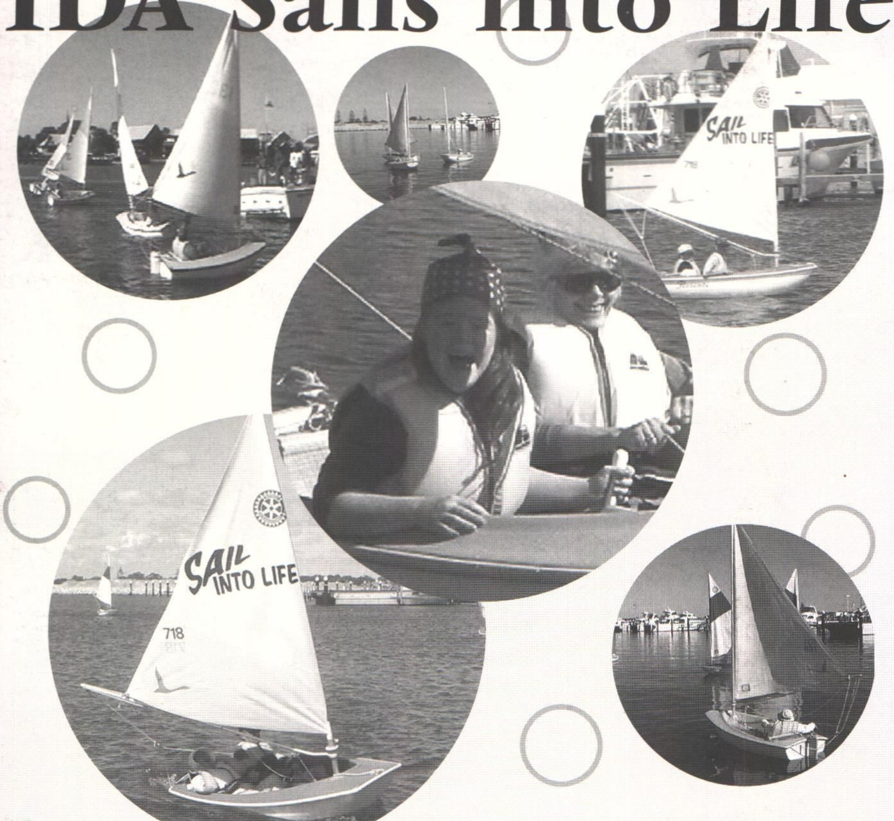
INTELLECTUAL DISABILITY Australasia

IDA Sails into Life



with a focus on local initiatives and a commitment to bringing up to date information, news and ideas to its members.

Inside:

- *Focus on Western Australia*
- *Extracts from national and local conference papers*
- *Region Reports*
- *Latest on the Brisbane Conference*
- *Information on the Awakenings Festival*
- *Two Book Reviews!*
- *More information on upcoming conferences*
- *New initiatives from IASSID*

...and more

Magazine of the Australian Society for the Study of Intellectual Disability

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are not necessarily those of the
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Editor: Sue Peden
Phone: (08) 9381 6680
Email: pedens@dsc.wa.gov.au
Editorial Assistant:
Ross Tudman
Advertisers:
Rates are available, on inquiry,
from the editorial assistant at
krvt3@bigpond.com
Editorial Address:
78A Cheltenham Rd,
Croydon, NSW, 2132
Membership and Subscription Information:
1800 644 741
hmoore@med.usyd.edu.au
Artwork:
Karen Vance
krvt3@bigpond.com
Printed by:
Unik Graphics

Contents

Editorial

This issue of IDA is a 'bumper' double issue, with twice the number of articles and more information than usual.

The production process has also taken an innovative turn, with the Western Australia Regional ASSID Council volunteering to produce IDA whilst we are 'between editors' This has been an interesting process as the team have learnt the skills of proof reading, editing and ensuring there is an exciting variety of reading for our members.

So, as you might expect, the focus is pretty much on some of the *'Best of the West'* with several articles from Western Australian contributors and in particular a feature on a fantastic initiative, sponsored by Rotary, *'Sail into Life'* The Sail into Life group takes the concept of inclusion and community a little further along the road. People with intellectual disabilities, physical disabilities or no disabilities at all compete on an equal footing in that most Australian of sports, sailing.

Other regions are not forgotten, and it is with great pleasure that we include for the first time a regional update from our latest member, New Zealand. Other regions of course have provided information on their latest projects and initiatives. And of course there is a range of other information, articles and contributions from around our regions.

On page 1. there is information about this year's Conference. For those of you who missed out this year, the South Australian regional update informs us that planning for the 2004 conference in Adelaide is already well underway.

ASSID is running another annual membership drive competition. This year the prize will be a copy of the ASSID publication, *'Positive Behaviour Support for People with an Intellectual Disability: evidence-based practice promoting quality of life'* All that you need to do is write your name on the top of the new membership form and encourage a new member to join using your form.

The winner will be announced in the next issue of IDA.

We can't all be winners, but we can all own a copy of the book, written by Keith McVilly. The book is available from the ASSID secretariat and is only $55.00 for members. The book is an essential resource for all professionals, students and educators in the field as well as providing valuable information for support workers. This issue includes two book reviews, so take a look at how some of our local writers and researchers are informing the field.

This edition of the magazine contains a number of articles edited from conference articles from both National and local conferences.

IDA will be returning to its regular format in 2004, with a new editor and lots of news and information to enjoy. Remember this is your magazine, and your contribution is always welcome.

AS.S.I.D. WA. have enjoyed the opportunity to contribute to this edition of IDA. In all, we in Western Australia know you find something that will interest you in the pages of the magazine.

Best wishes to you all,

Susan Peden

(acting co-editor)

Never forget that you are
invited to
contribute!
Send your news, views, letters,
reports on best practice to
hmoore@med.usyd.edu.au

National Conference Update

Imagination & Innovation
38th National Conference

Program Update

Members of the Program Committee for the ASSID Conference in Brisbane in November were especially pleased with the standard of abstracts submitted from our Australian researchers, practitioners and services across all states as well as papers from our latest regional branch members from New Zealand. It is of special interest for a national conference that several papers were submitted from people in the United States and Europe including Harvey Switzky, Eric Emerson and Laurie Powers.

Of course the IASSID Special Interest Research Group on Ethics held its meeting concurrently with the conference. Conference delegates and SIRG members had opportunities to attend presentations across the conference and SIRG programs thus expanding opportunities for exchanging ideas and knowledge and building networks across the world.

We deliberately did not pre-determine streams at the outset. It was decided to cast a wide net around the broad theme of Imagination & Innovation and see just how innovative we could be. The program was organised around six themes. In keeping with the overall imagination theme we tried to develop some fresh approaches to clustering papers in different and new ways. They were:

Policies, Paradigms and Law

In this stream there were papers and presentations about overarching issues that impact upon the lives of people with intellectual disability. This stream included Marcia Riouxs Keynote address and several insightful papers about new paradigms around intellectual disability and broader policy issues. We included papers that address questions of legal and criminal justice issues. We were also delighted to have Billy Edwards from the Office of the Los Angeles County Public Defender to speak about his work defending people with intellectual disability on death row. Harvey Switzky also gave us an up to date exploration of the paradigms around intellectual disability and Trevor Parmenter acted as rapporteur and summarised the developments from the conference in the final session.

Individuals, Families & Communities

Supporting ordinary lives for people with intellectual disability in families and communities is a key mission for ASSID and is at the heart of much of our collective effort. In this stream we gathered papers that addressed a range of topics about the experiences of people with intellectual disability and their families. Tim Stainton and Gordon Grant set the tone for this stream which covered topics such as disability across the life span; family support; parents with intellectual disability; friendships and community development.

Services, Supports and Practice

How do we develop more flexible and innovative approaches to service provision? Are there any new ideas out there? We think so. In this stream there were papers about new service models and interventions; ways of improving practice; staff attitudes and development; ethics in service provision and rural services and supports. A number of keynotes also related to this stream.

Health & Well-being

This very popular area of research, policy and practice forms a substantial stream which includied keynotes and workshops from Nick Bouras and Geraldine Holt. These papers covered the latest developments in health issues for people with an intellectual disability. Papers covered topics such as GP perspectives, polypharmacy, women's health and specific syndromes. This stream also included the papers on dual diagnosis.

Learning and Personal Development

This steam contained papers describing adaptive behaviour, skill acquisition and development in academic, social and behavioural domains across the lifespan. It focused on initiatives for both children and adults including educational and school-based learning as well as opportunities for adults and post-school learning. Topics included literacy, communication and social skills. Carl Haywoodds workshop on dynamic assessment was interest to those who attended this stream.

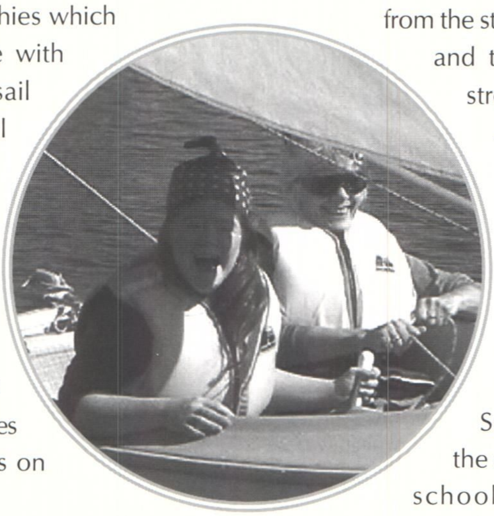
Research

In this stream were papers and workshops on researching and publishing about intellectual disability. This stream addressed issues surrounding the research process including ethics, methodological issues including invited speaker Gordon Grant's workshop on participatory research and JIDRds Editor Roger Stancliffe's presentation on how to write a journal article.

>> Sail Into Life <<

The Rotary Sail into Life program brings the joy and fulfillment of sailing to all Australians. Sail into Life aims to make the experience of sailing available to all those keen to encompass the positive values and life skills that are the foundation of sailing itself.

Jamie Dunross, a Paralympian gold medallist for sailing, set up Sail into Life using Access 2.3 dinghies which could be modified to enable people with profound physical disabilities to sail independently. Jamie modelled Sail into Life on Sailability which has branches all over the world, however with one important difference. Jamie wanted to set up a project which would include anyone who might not usually have the opportunity to sail. He envisaged Regattas and competitions where people with disabilities could sail competitively against others on an equal basis.



The end result demonstrates the ability of small minorities to make a real impact on the ways communities develop.

As Ted Kuntz of PLAN Canada (Planned Lifetime Advocacy Network) says (quoted PLAN website 2003),

"That's the gift of disability, that it is forcing us to recreate community."

The project had strong backing from many parts of the local Mandurah/Murray community in Western Australia from the start. However, it is people with disabilities and their families who have provided the strongest leadership.

The project is national. It offers an opportunity to network with people from many different places. However it's primary strength is to create local sustainable community networks with particular advantages for people with disabilities.

Support has come from every part of the community, from local businessmen to school students, across all socio-economic groups, ages, religions. People with disabilities and their families have retained leadership roles, and are now being enthusiastically invited to become members of Mandurah Offshore Fishing and Sailing Club and use their facilities and take part in dinghy training.

A new book:

"Quality of Life and Disability"

An Approach for Community Practitioners,

has been written ***by Roy Brown (South Australia) and Ivan Brown (Canada)*** and was published in May 2003 (ISBN 1 85302 005 3 US $24.95.)

The book is available from Jessica Kingsley Publisher:
www.jkp.com   Email post@jkp.com   Tel +44 (0) 20 7833 2307   Fax: +44 (0) 7837 2917

A review of the book will be published in the next edition of IDA

Depression in People with a Developmental Disability

The Experience of the Centre for Developmental Disability Health Victoria - Mary Burbidge

(extracts from a paper presented at the 37th Hobart National Conference)

The clinical work of the CDDHV encompasses secondary consultations with people referred to the Centre by their treating doctor. Patients are assessed and returned to the care of their GP with a detailed report of the assessment, investigations, medication changes and management suggestions.

The clinical files and the computer database relating to clinical work constitute a rich resource to support the Centre's research role in the field of developmental disability health. The research arose out of our impression that CDDHV clinicians were seeing a large number of patients with definite or probable depression and that we were prescribing a lot of SSRI anti-depressants, often with pleasing results. This article attempts to document and analyse this clinical impression.

Aims of the research project:

1. To determine the percentage of patients who may have had a diagnosis of depression;
2. To investigate the symptoms which are indicators of depression in this population;
3. To determine the percentage of patients who are treated with Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants and other antidepressant medication;
4. To examine the indications given for use of antidepressant medication in this group; and
5. To discover what information is included in the CDDHV records about the effectiveness of treatment with various antidepressants and how well these medications are tolerated by this population.

Methodology

Files were reviewed and classified either as cases or non-cases of depression.

Cases included patients who were taking an antidepressant when they were first seen and/or were prescribed an anti-depressant during the course of their care by CDDHV clinicians and/or were to be prescribed an antidepressant by their GP on the advice of a CDDHV clinician.

Non-cases may have been on an antidepressant in the past. Files were selected randomly and reviewed until data on 100 cases and 50 non-cases had been collected.

In addition the writer reviewed the files of 103 consecutive new patients seen from the beginning of January 2000.

Inter-rater reliability

Information was extracted after a thorough reading of each file. Sometimes the interpretation of information required clinical judgement and extrapolation from file notes. To give some validity to this type of data collection an inter-rater reliability exercise was undertaken. Twenty files (every fifth file) from the 103 consecutive files were independently reviewed by a senior CDDHV clinician and the two datasets were compared. Key items were given a Kappa Index, a statistical indication of the degree of agreement between observers.

Kappa scores indicating a substantial level of agreement between raters were obtained for:

- level of intellectual disability
- disturbed sleep
- recent weigh loss
- low mood
- efficacy of antidepressant treatment.

Findings

The rate of occurrence of 'caseness' and depression in the CDDHV patient group in 2000-01

Of the 103 new patients 46 (45%) fitted the definition for 'caseness' (i.e. already on antidepressants or prescribed/recommended antidepressants by CDDHV clinicians)

Antidepressants were prescribed for three reasons –

- Depression was diagnosed (44%)
- Depression was suspected and a therapeutic trial was undertaken (32%)
- An anti-depressant was considered appropriate for treatment or therapeutic trial for other conditions such as anxiety, Autistic Spectrum Disorder, Obsessive Compulsive Disorder, incontinence (24%)

cont. on page 6

Book Review:

Disability and Society: Challenges in the 21st Century

by Roy I. Brown

Australian Society for the Study of Intellectual Disability Inc. SA Branch, 2003.

Available in Australia from ASSID (SA) Inc.
c/- 108 Kermode Street, North Adelaide, SA, 5006.

Reviewed by Ruth Davey,
B.Sc.(Hons), M. Pol. Admin

This succinct monograph, authored by Professor Roy Brown, formerly Foundation Professor and Dean of The School of Special Education and Disability Studies at Flinders University of South Australia consists of two chapters. The first chapter contains the 2001 Hilary Johnson lecture presented prior to Professor Brown's departure from the Australian academic scene. The second chapter encapsulates highlights from the Options Report resulting from the evaluation of Options Coordination, a service initiated by the South Australian government.

The Hilary Johnson lecture examines current and future challenges faced by people with disabilities and their families. It sets the scene for change in the current difficult climate of economic rationalism in Australia. Many of today's pertinent challenges facing people with disabilities are brought to the fore.

Professor Brown points out that modern society is at least prepared to discuss issues such as inclusion versus exclusion, institutionalisation versus family care and support and segregation versus community living. He discusses the dichotomy evident in a society where we see advances in technology on the one hand, whilst on the other hand, we do not meet the basic needs of those desperately needing support.

A number of topical issues are discussed, including environment and genetics. In such areas, the required response is seen as 'multiple and integrated' and requiring judgement by appropriately trained professional personnel. Professor Brown advocates for both undergraduate and postgraduate training of personnel from multidisciplinary backgrounds, occupational therapy, speech therapy, disability educators and medicine to address both the forces for change and the systemic change itself.

The difficult area of 'labelling' is touched upon, together with other quality of life issues. Quality of life is extended to include issues of family well being, an area of increasing research both overseas and in Australia. He concludes by emphasising the scientific value of disability studies and the personal challenge faced by us all in recognising disability, a precursor to working towards community acceptance and inclusion.

The second chapter, "Options Report and Beyond" is based on the work carried out by Professor Brown when he was Chair of the Committee on the Evaluation of Quality Services for People with Disabilities (May, 2001). The final report was submitted to the South Australian Minister in June, 2000. Five agencies work together under the banner of Options Coordination to provide case management, service brokerage and service provision for people with disabilities. Options Coordination had been in operation for 5 years at the time of the evaluation. Although the evaluation covered a state government scheme, the report highlighted challenges which frontline workers were likely to face in any country. This in turn raised a number of important issues faced in the selection and training of staff and the availability of resources. The author points out that the recruitment process was hampered through the government process of selection from within their ranks where candidates had wide ranging levels of expertise and training from a number of disciplines, not necessarily related to disability.

A recurrent theme throughout both chapters of the monograph was the emphasis on the importance of education of personnel working in the disability sector and the value of training for people with intellectual disabilities.

The reviewer commends this book to practitioners and those interested in reading more about the field of disability.

Depression in People with a Developmental Disability

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In the 103 consecutive patients seen at the CDDHV from January 2000, depression occurred at a rate of between 24% and 42%.

The people seen at the CDDHV have been referred by their treating doctor because there are difficulties being encountered in addressing their needs. This leads to the CDDHV patient group being different in some ways from the general population of adults who have a developmental disability.

A major difference between the study population and the general population of people with

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"Come, You Are Loved As You Are"

by Kathryn Hamann

(extracts from a paper presented at the Hobart Conference)

I have a son and a husband with ASD - autism spectrum disorder. I floated the idea for a church focused parent support group at the end of last year.

It was the Baptist Witness which first ran an article on the idea of a support group and we were ecumenical from the beginning. In fact, we have members from all the major church groups: Catholic, Uniting Church, Anglican, Church of Christ, Baptist and Presbyterian.

It took us several months, but eventually, we decided that the group name would be Cross-Purposes and our newsletter the "Swallow" is published four times a year.

Our members consist of families, parishes, clergy, and professionals. We have links to organisations both within and beyond the church. There is help out there but parents, church communities and clergy often do not know where to go or whom to approach. One of our main goals is to establish a database of groups which may be of help or interest to our members.

Approximately 67 % of our families have at least one child with autism spectrum disorder and, while this may reflect my links with the community, I think that it is also because the parents of children with autism are finding it a very hard road to gain inclusion of their children. I have, of course, no data to confirm this - it is just a sense.

So, if church is so difficult, why bother at all?

I know some of you may disagree but I believe that we are spiritual beings and those with autism should have the same right to decide whether to explore that aspect of themselves or not. They should have the right to select their own faith. They should also have the right to decide what aspects of the faith they wish to engage in.

A man with ASD - let us call him Frank - who is seeking a parish and, I am ashamed to say it, has meet with much rejection, said to me: *"My parents are Christian and that is what I want to be as well."* He also added that he found the language used in church very difficult to understand.

As Frank and I talked further, he told me that he found the word love difficult.

One of the things that we are aware of as parents is that we need to find ways to use language or find other ways such as using a visual medium to communicate our faith, to communicate the love of God in Christ to our children.

And we are aware that we need help from professionals to do this. We need to listen to those such as Temple Grandin and Frank who can tell us when what we say gives no meaning or is stressful and unhelpful.

I asked an adolescent with high-functioning autism who is a committed Christian and has attended church from infancy, *"Does the word love bother you?"*

The reply was:

"Love is such a strong word. It makes me ..."

Then his body seemed to shiver and he went on:

"We are sensitive you know ... and we think of love as like on TV that man - woman stuff. That is not what you mean -

You know I did not know what an emotion was until I was in Grade 4. You know when you learn them, not grow up with them, they don't feel quite connected with you.

In fact, I think I act them. Yes, act them - more than being real."

Cross-Purposes began with a simple aim of making Sunday mornings possible - less stressful for all the members of the family. It was driven by a deep desire for our children to have the same rights and opportunities as so-called "able" children.

Lesley Matthews, when she addressed the members of Cross-Purposes earlier this year, said the basic rights of people with disabilities are:

ACCESS - full participation;
FREEDOM - to choose a lifestyle and the freedom to conform or to contrast;
INDEPENDENCE - from exploitation and abuse.

We, as parents, want our children to have access to worship, to Christian formation, to sacrament and if, they choose, to able to live out their calling as members of the body of Christ.

We have a deep desire for our children to be accepted, loved and honoured as they are.

The mission statement of Cross-Purposes is to enable all families to bring their children to Christ and to worship together.

The word disabled does not occur because we want this for all our children regardless of ability or disability.

Cross-Purposes has three main functions:

Support,
Education,
Advocacy.

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"Come, You Are Loved As You Are"

. . . continued from page 7

Support

We support each other by listening to each other's stories and by praying for one another.

Often the diagnosis of a child brings a crisis in faith and listening to how other parents have worked through these issues can be helpful. In fact, it can be an event that brings alive/deepens our faith.

Even if faith is not important to you or if you regard it as a foolishness, if you are working with a family committed to their faith then you need to understand how important and central this faith is to them. If they are struggling with faith issues then they may need a spiritual director to work them through. The most common question that arises at diagnosis is - *"How, if there is a loving God, could he allow this to happen to our child?"*

To find an answer requires a stepping away from the question, an abandonment of the human perspective and a move into how does God see our child? It requires a leap of trust that we walk not alone but with the God who will bring us through no matter how tough the journey. So, when at our son's original diagnosis, I was told not to take him to church because he would find it too distressing and produce his worst behaviour, I could not accept that advice. It has been a hard journey but worth it.

Education

We hope to encourage churches to become communities based on mutuality and a place where our children's gifts can develop; where our children can find a home.

We would like churches to be inclusive.

Currently, a minister can be theologically trained and never hear the word "disability" and, therefore, when faced with a family with a member who has a disability, the minister may not know how to respond or have little understanding of the challenges we face as a family; the pain we carry; the sheer exhaustion we so often suffer from.

And, in fact, although the church knows about ramps for wheelchairs, they are not aware that for children with ASD need a very different kind of ramp and often more than one. So we hope to be invited to churches, to theological colleges to share our stories to break down the attitudinal barriers that exist.

Advocacy

For some families who have been attending the church before their child was born, their church community may know them well and may have walked the journey with them leading up to, and beyond, diagnosis. Although the community will need information about how to make church a welcoming place where the child can feel at home and although the community may need to know how to teach the faith or even what parts of the faith to teach, inclusion comes naturally.

One can never assume, however that a church community knows anything about autism and even what they think they know may actually be worse. Often you may be opening up a whole new world to them.

And if you find yourself taking the parish on a whole new journey, you must accept that there are going to be people who are reluctant to set out.

So, we hope to help parents prepare for meeting the parish, to go with them to assist them in building bridges with and within their parish.

So, in summary, there are three areas Cross-Purposes feel we need to look at to make church practical.

The individual

For example, social stories could help the child understand the unique complex social situation that he or she is faced with in church and so help him or her to feel comfortable and secure.

The environment

For example, the church needs to set up a quiet secure withdrawal place. It needs to look at what sensory input might be stressing the child. It needs to look at the language used. And is the rest of the parish putting too much pressure on the child in the desire to be friendly?

Activities

Something that will vary from child to child but have to start from what he likes to do. Music and singing seems to be one thing nearly every parent tells me their children love. They seem to learn the hymns very quickly.

But, most of all, the hearts of those in the parish have to be open, and their eyes opened to see in our children the face of Christ.

For we as families, need companions, not people up there trying to do good to us, but companions willing to walk with us on our journey.

Please keep your contact details up to date

with your State Councils at the main ASSID database.

Contact Helen in the secretariat. Phone: **1800 644 741** Email: **hmoore@med.usyd.edu.au**

Images from the WA ASSID Regional Conference for 2003

From the top:

- *WA Council Members: Ralph Kober and Frances Buchanan*
- *Delegates at the conference*
- *Associate Professor Mark Rapley, from Murdoch University in WA*
- *WA Councillor, Janine Smith with delegate, Lesley Bowerman*
- *Kate Randall, ASSID WA President with Kerry Allen, the Keynote speaker for the conference*

Who Do You Support?

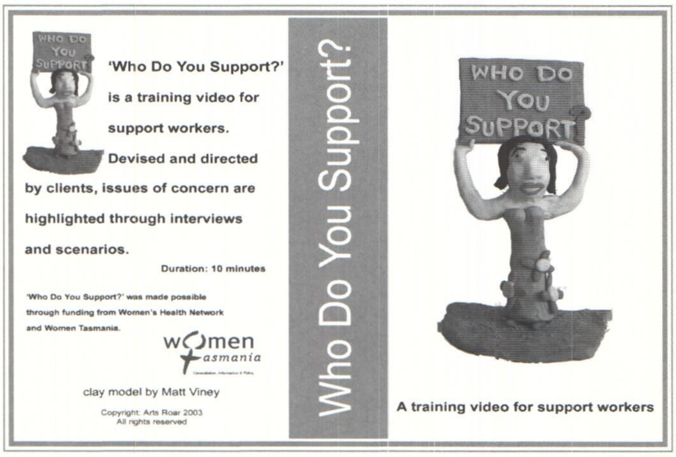
"Who Do You Support?" is a training video for support workers devised and directed by clients. Issues of concern are highlighted through interviews and scenarios.

The Video was previewed at the recent ASSID Tasmania Regional Conference and was acclaimed by all at the conference as a 'must have resource' and something that should be 'compulsory viewing' for all direct support staff. The video portrays a series of every-day interactions (both positive and negative) between people with disability and their support staff, from the client's perspective. The video is thought provoking, at times provocative and highly educational.

Project Background:

This video was developed as part of a broader project called Safe as Houses a collaborative initiative by the Tasmanian Women's Health Information Service (WHIS) Disability Services Tasmania, Laurel House - Sexual Assault Service and Family Planning Tasmania, in Launceston.

All services spoke of safety for clients living independently in the community, as being an issue that needed addressing. They decided to work together to produce safety training resources, each service concentrating on a specific safety issue: Disability Services - Safety in the Home; Northern Sexual Assault Group - Safety in the Community; Family Planning - Safety in Relationships. Arts Roar, an accessible arts project based in Launceston was commissioned to produce accompanying resources.



'Who Do You Support?' is a training video for support workers. Devised and directed by clients, issues of concern are highlighted through interviews and scenarios.

Duration: 10 minutes

'Who Do You Support?' was made possible through funding from Women's Health Network and Women Tasmania.

clay model by Matt Viney

Copyright: Arts Roar 2003
All rights reserved

Who Do You Support?

A training video for support workers

Community Consultation:

A number of issues were revealed through community consultation including the relationship between support workers and clients. Clients expressed concern about not being listened to / being over ruled / old fashioned ways of thinking and a lack of real control over their lives. As a result of these discussions, Emma Butler (Arts Roar secretary and participant) suggested that a video be developed by clients that highlighted their needs. "Who Do You Support?" is the result.

For more information / to order "Who Do You Support" email: artsroar@fastmail.fm. Phone 0422 900 9575 or 63 433467. Write to P.O.Box 898 Launceston Tasmania 7250

'Safe as Houses' is funded through Women Tasmania's Small Grants Program and The Women's Health Network.

Win a Prize now!

*You could win a fabulous prize **just by encouraging a friend, colleague or organisation to join ASSID** before December 31, 2003.*

Write your own name on the top of the application for membership and have a friend, colleague or organisation fill in the details to join ASSID and send it to the address on the form by December 31.

The winner will be announced in the next edition of IDA.

Parents with an Intellectual Disability

A report on a survey project into the needs of the population residing in the Perth Metropolitan area.

Edited version of a paper presented at the ASSID W.A. Conference, September 2002.

by Jodyne Higgins and Christopher Coopes

Background:

"Parenthood is almost universally acknowledged as being a complex and demanding social role. Numerous commentators have lamented the lack of adequate preparation of parents to undertake arguably the most important job in the community, namely, raising the future generation of children" (Sanders & Dadds, 1993:26).

Being a parent, as any parent will tell you is not an easy job. Personal factors (such as one's own childhood and upbringing, skill levels, personality and adaptability) as well as environmental, social and financial factors all impact on one's competency at parenting. Parents who have an intellectual disability are therefore often at a disadvantage, given that their skill levels and adaptability may not be as high as the general population, and that a large proportion of people with intellectual disabilities live in high-risk areas, have minimal family or other support and rely on social security as income (Llewellyn, no date).

While it is not known how many parents in Australia have an intellectual disability, it is known that the number of parents with an intellectual disability is on the increase. A survey of international and national literature indicates that historical attitudes towards parents with an intellectual disability have been predominantly negative, with the belief prevailing that they were unable to parent competently. Consequently, the majority of adults with intellectual disabilities were not given the opportunity to become parents - being forcibly sterilised and/or segregated from the opposite gender.

Of those who did become parents, many became the subjects of various studies and intense scrutiny. Several of these early studies were largely biased and had a deficit approach, making sweeping generalisations that all parents with intellectual disabilities were incompetent at parenting and likely to abuse and/or neglect their children. These studies also generally neglected to consider the environmental, financial and social factors that may impact on parental competency. Consequently, parents with an intellectual disability often had their children forcibly removed from their care at higher rates than parents without an intellectual disability.

Internationally, rates of child removal for the children of parents with an intellectual disability range between 40 - 45% (Accardo & Whitman, 1989; Gilberg & Geijer-Karlsson, 1983 & Mirfin-Veitch et al, 1999).

Within Australia, rates of child removal amongst parents with an intellectual disability appear at a higher rate than that of the general population. For example a NSW 2000 review of 285 Department of Community Services Court Care Applications found the population of parents with an intellectual disability to be over-represented, and their children were more often made wards (55% vs 33%), made subject to a higher frequency of medium term orders (25% vs 5%) and placed out-of-home with non-family (44% vs 23%) than children whose parents had no disability (McConnell et al, 2000).

Studies into the population today are more asset-based and objective - primarily focussing on identifying risk factors predicting incompetency in parenting and researching the impact of parenting supports and services in reducing this risk. Thus while the children of parents with an intellectual disability are at considerably higher risk than the general population of experiencing abuse, neglect and/or developmental delay, more and more studies are showing that if the proper preventative supports and parent-training are sensitively delivered to these families, this risk can be significantly reduced and parenting can be a positive experience for the entire family.

"Children's destinies are not fixed by having a mother or father with learning difficulties... [rather] good enough parenting is related to the amount of support available to the parents and their children..." (Booth & Booth, 1997:2).

Methodology:

In September 2002, Disability Services Commission in Western Australia commenced a survey project into the needs of the population of parents with an intellectual disability residing in the Perth Metropolitan area. The study used a mixed methodology approach, with the data being obtained from service deliverers through a structured questionnaire.

The questionnaire consisted of seventeen questions and was distributed to all the Local Area Coordinators (LACs) involved with families where at least one parent had an intellectual disability. One questionnaire was completed for each family, and for the purpose of the study the term 'family' was used to denote any individual who was a parent, regardless of whether or not the child was currently in their care.

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South Australia

The SA branch has been busy making preliminary preparations for the 2004 Australasian conference. We have been in contact with a number of prospective key note speakers and are pleased that some have indicated their availability and willingness to present. We believe we will have an impressive and exciting 'line-up'. We have a venue booked (The Hilton) and have made arrangements with a conference organising company to assist us in this venture. We have also sent out information to various individuals and agencies to ensure that all are aware that Adelaide is hosting the conference in 2004 and to invite them to participate or contribute. We feel on track. Our next challenge is to secure sufficient sponsorship to assist with keeping registration costs affordable.

Other than this, the SA branch was pleased with the turnout for the 'Meal with the Minister' in April when approximately 60 people were in attendance, with representation from government and non-government agencies as well as service providers, parents and advocacy groups. The Minster discussed her vision for people with an intellectual disability, made herself available for questions and mingled. Feedback from those who attended was that the evening was an outstanding success.

On October 30th we are planning an AGM to be held in conjunction with an event co-sponsored by ANGOSA (Association of Non Government Organisation in South Australia) with Professor Bob Cummins speaking on the topic of "Quality Services, Individualised Services and Quality of Life - Is there a link?" At this time, we will also be launching a 'hot off the press' ASSID (SA) publication 'Disability and Society – Challenges in the 21st Century' drawn from lectures given by Professor Roy Brown in 2001.

Other projects 'on the drawing board' include the goal of increasing the SA branch's level of engagement with tertiary institutions in SA (We want to hold events on the campuses of each of the three Adelaide universities giving them an opportunity to present research that they are doing in the area of intellectual disability to a broader audience.)

Richard O'Loughlin

Victoria

Victoria has a very active council with an exciting number of events held over the year. Most recently a special ASSID dinner was held for over 30 guests in October.

The Victoria Regional Council will as usual be coordinating the direct care workers conference in Melbourne and planning the A.S.S.ID. program for the coming year.

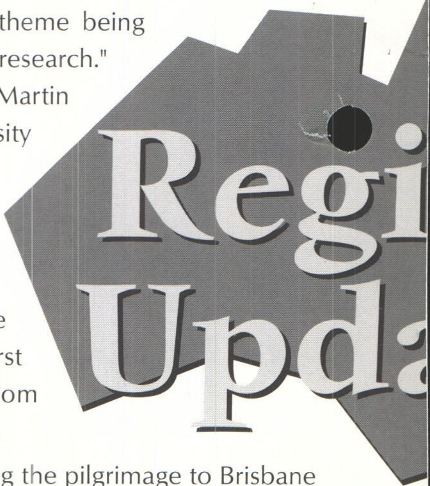
New Zealand

After more than a decade of inaction, NZASID was revived at an inaugural meeting in Christchurch last year. With some generous assistance from ASSID, a firm basis was established for us to move forward.

Our thanks for advice and encouragement also go to Bill Taylor and Karen Nankervis.

We are currently looking at how we can mount a wider membership drive and anticipate our first Regional Conference to be held in Auckland on 3rd and 4th October will provide a solid platform from which we can build.

A hard working Conference committee has managed to put together an exciting programme at short notice with the Conference theme being " Sharing: stories, practice, research." Keynote speakers include Dr Martin Sullivan from Massey University here ,and two well known stalwarts of ASSID, Dr Christine Bigby and Dr Bob Cummins. We welcome our Australian guests and hope that this will simply be the first of many visits we have from colleagues across the Tasman.



A number of NZers are making the pilgrimage to Brisbane to take part in the 1st Australasian Conference, and where we look forward to becoming a full member of the new Association.

Western Australia

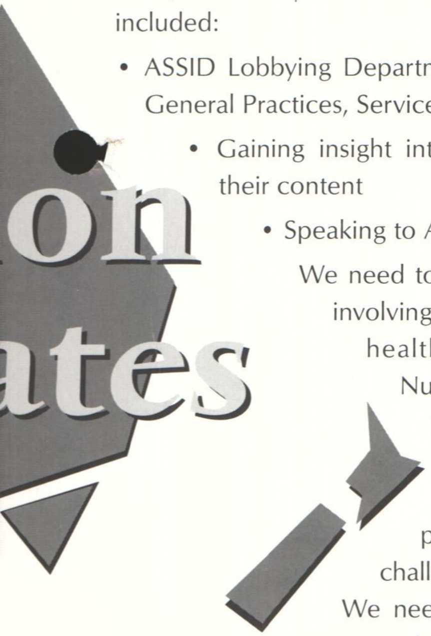
Western Australia held its annual State Conference in September. As usual there was an interesting selection of papers and presentations from service providers, as well as opportunities for academic discussion. The state conference attracts a broad range of people who want to know more about local initiatives as well as best practice ideas and approaches. This year the key note speaker was Kerry Allen, an interesting and exciting speaker who talked about some of the broader issues in service provision for people with disabilities.

Kerry is Deputy Chairperson of the Cerebral Palsy Association of Western Australia and is a member of the Ministerial Advisory Council for Disability in WA. She was born with cerebral palsy, and in addition to her work as a private disability awareness and communications consultant Kerry is a mother and step mother to six children.

To celebrate the end of 2003, WA regional council are hosting a social evening in December for members on the banks of the Swan river.

New South Wales

Conference held in Albury July 10-11th entitled Health and Wellness in People with Intellectual Disabilities. The conference was a success with around 140 participants, Helen Beange was the opening address with Dr Lyn Lee as a keynote speaker. All the presenters were interesting and well attended and the feedback was very encouraging. Our panels related to health issues for 4 groups; people with disabilities, families, health professionals and service providers resulted in a number of key issues being identified and presented back to the audience on day 2 with a summary of key issues at the end of the day. A number of people volunteered to be on a committee chaired by Jenni Avery which will start to look at these key issues, which included:



- ASSID Lobbying Department of Health, for Nurses in General Practices, Services to Group Homes
- Gaining insight into educational programs and their content
- Speaking to AMA. Commonwealth Health

We need to be in a position of strength, involving professional bodies related to health professionals, Deans of Nursing and other allied health professionals. Look at contact time / clinical time – provide resources to allow professionals to cope with all challenges that come their way. We need a clearer model of care – encouraging generic services to use the model. Promotion of a professional support network for generic services once skilled up.

Finally, a Position Paper

- need to identify best practice
- raise profile of disability
- primary health care integrated into all services
- knowledge and power to parents from a central agency
- attitudes – publicity, lobbying

The AGM was held on the 17 October after two symposiums by Vivienne Riches on a Support Needs Assessment Tool and Barbara Anderson on Client Risk Assessment. The AGM followed with Tony Tinlin being elected President, Linda Goddard Vice President, Jenni Avery continues as Secretary and Barbara Anderson was elected Treasurer. We look forward to another exciting year and look forward to meeting you around the State.

Queensland

With the Conference well and truly underway, Queensland has not had a minute to focus on any activities other that the preparations for this huge event. The range of papers, symposia and other attractions have been enormous and everyone has worked really hard to pull off yet another fantastic event. 2004 will see the Council taking a well earned rest before planning commences for a number of exciting initiatives later in the year. A full report will appear in the next issue of IDA

Tasmania

Tasmania is revelling in the success of the 2002 National conference held in Hobart in November at the Wrest Point Casino. It was a lot of hard work however it was well worth the effort, especially since we got to meet so many interesting people who have now become part of the Tassie network. Our theme for the conference was entitled "Developing and Enriching Communities". A CD copy of a small portion of the conference proceedings will be sent to every national conference delegate and is also available to all our state conference delegates in October. So be on the lookout for the CD if you were a national conference delegate in Hobart

Due to the success of the National Conference, the current Tasmanian ASSID committee have been very enthusiastic about forging alliances with other peak bodies in Tasmania and hoping to offer some exciting training / workshops in the coming year. We are liaising with the Institute for Applied Behaviour Analysis (IABA) to support some forthcoming training seminars entitled 'Positive Approaches to Solving Severe Behaviour' to be held at the Woolstore Theatrette on the 14th, 15th, 16th and 17th of October 2003. When we were approached in February to assist IABA to come over from America it appeared to be an exciting project for the ASSID committee and it has been proved to be a successful venture with registrations out numbering all our expectations.

In August, ASSID Tas were successful in applying for and receiving a computer and accessories thanks to an initiative by the Department of Premier and Cabinet entitled "Computers for Community Groups". The computer, along with ASSID's past files and information are housed at 94 Charles Street, Moonah for use by the President and other members.

For the state conference this year the committee decided to follow-up on a few of the presentations from the national conference last year. Thus the keynote speakers were chosen because their papers last year were very well received and left delegates wanting more information. Thanks to Matthew Bowden, Di Brokenshire and Keith McVilly for attending and agreeing to keynote for what proved to be a very successful and informative conference held on the 1st and 2nd of October.

Darryleen Wiggins, *President ASSID Tasmania*

Parents with an Intellectual Disability

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The questionnaire sought information regarding three primary areas:

1) Population demographics (family size, family type, the number of children with disabilities, ages of children and residence of children)

2) Parenting support and services utilised by families (both formal and informal supports and services)

3) Perceived areas of need for Support and Service development.

Findings:

The information collected from this study identified 46 families in the Perth Metropolitan area where at least one parent had a diagnosed intellectual disability, however this may be an underestimation. Questionnaires were completed for 41 of those 46 families.

Population Demographics

The population profile of families having a parent with an intellectual disability in some areas reflected the profile of the general Australian community. For example, the 41 families in this study had a total of 86 children - the average being 2 children per family, which is slightly higher than the 2000 Australian average of 1.75, but lower than the 2000-2005 world average of 2.68. The age distributions of children were also similar; with the greatest proportion of children being of school-age, followed by early childhood ages and post-school ages.

Of the families identified, just under half (41%) were single-parent families where the mother had an intellectual disability. Approximately one third (31%) were two-parent families where the mother had an intellectual disability, and around one eighth (12%) were two-parent families where both parents had an intellectual disability.

With respect to child residence, the study identified 59% of children living at home with the parent with an intellectual disability, 22% of children living in foster arrangements and 13% of children living with other family. The remainder of children lived either independently or with their adopted family.

Of the families studied 44% were identified as having children with a diagnosed developmental delay or intellectual disability, which translates to 37% of all the children of parents with an intellectual disability.

Services and Supports Utilised

Utilisation by these families of support services provided by Disability Services Commission (DSC) was varied. 41% of families were identified as having no DSC support of any kind.

Parenting supports and service utilisation external to the Commission was also varied. 20% of families were identified as having no support of any kind, while 58% used mostly or all informal supports (the most frequently identified types were extended family and friends). The remaining 22% used mostly or all formal services and of these, Department of Community Development services and Local Community Parenting Groups were identified as the most frequently used.

Perceived Need Areas

Difficulties and areas of perceived need for these families were in many respects similar to those experienced by Australian parents in general. Behaviour management, home safety, child stimulation, routine management, supervision issues and child emotional development were some of the key difficulty areas for most families. Other frequently identified areas of difficulty included parental self-care (such as social networking and personal health care).

Families were generally identified as experiencing difficulties in multiple areas (each family on average experiencing difficulty in 7 out of a possible 20 areas) and a large proportion of families additionally experienced environmental and/or social factors such as low-income, isolation, limited literacy and numeracy that also may significantly impact on parenting difficulties.

Summation:

The issues facing parents with an intellectual disability appear to be multiple and various. The findings of this study indicate that while the needs of parents with an intellectual disability are highly complex, they are not altogether dissimilar to the needs of other parents. This is also supported by numerous other studies, which identify that parents with an intellectual disability often experience similar areas of parenting difficulty as well as utilise similar services and supports (Feldman & Case, 1999; Walton-Allen & Feldman, 1991 & Tymchuk, 1995).

Studies such as this one however, provide the opportunity for the needs of families to be explored at various levels. A second phase of the project is now in progress where families will be asked for more detailed information about what would help as well as inviting information on parental satisfaction of those services.

The desired outcome of this phase is to develop a more comprehensive picture of parenting service usage by parents with an intellectual disability (such as barriers to service usage, positive qualities of services, gaps in service availability) and then develop a service provider

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News from IASSID

International Society for Quality of Life Studies (ISQOLS), 2004 Conference: "Philadelphia Freedom"

By Ralph Kober

ISQOLS is an international interdisciplinary society of academic and professional researchers who share a common interest in promoting and encouraging research in the field of quality of life studies. Members come from a variety of backgrounds, including, but not limited to, psychology, social work, economics, and marketing.

ISQOLS next conference will be held in Philadelphia, from 10 to 14 November, 2004. Of particular interest to members of ASSID is the fact that for the second time in the history of ISQOLS conference there will be a specific track on papers dedicated to the quality of life of persons with a disability. It was thought that given the theme of the conference was Advancing Quality of Life in a Turbulent World it was considered appropriate to have a dedicated track relating to people with disabilities. The previous time, such a track was held, it proved to be one of the most popular of the conference, in terms of number of papers presented, and attracted internationally renowned researchers from Australia, Asia, North America, and Europe.

I would encourage anyone interested in attending or in presenting a paper to contact me (Ralph Kober) by email (Ralph.Kober@uwa.edu.au). For more information please visit ISQOLS web page

(http://marketing.cob.vt.edu/isqols/)
or go directly to the conference web page
(http://caster.ssw.upenn.edu/~restes/ISQOLS/PHL2004_Call.doc).

New IASSID Journal

IASSID, in partnership with the Tosinvest Sanita Organization and Blackwell Publishing has established a new international journal – the Journal of Policy and Practice in Intellectual Disabilities. The journal, a peer-reviewed publication that will come out four times a year, is designed to provide a forum for evidence-based policy and practice research articles and analyses related to people with intellectual and developmental disabilities.

JPPID will focus on policy development, service design, working methods and treatment procedures, financial, administrative and legal frameworks, and approaches to service user empowerment which are formed by research. Articles solicited include report research, analyses, reviews, theoretical constructs, and other work exploring both tested ideas in policy and practice and possible future directions. JPPID is also soliciting brief reports of practice experiences documented by evidence-based research or data-based outcomes. In addition, JPPID is soliciting briefs or abstracts that translate and comment on work previously published in non-English journals, announcements of relevance to IASSID members, and reviews of relevant publications.

Members interested in submitting a manuscript to JPPID should review the "Instructions for Contributers" found on www.iassid.org. If members and colleagues wish to contact the JPPID, please communicate with the Editor, at jppideditor@aol.com.

Parents with an Intellectual Disability

continued from page 14

framework for working with families with an intellectual disability.

For further questions or queries related to the project, please contact Jodyne Higgins on (08) 9301 3796 or Christopher Coopes on (08) 9301 3898.

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2003 Awakenings Festival

at Wesley Performing Arts Centre in Horsham

Rita Eldridge entertains on her piano accordion at the launch of the 2003 Awakenings Festival at Wesley Performing Arts Centre in Horsham. Pictures courtesy of Wimmera Mail-Times.

More than 600 performers from across Australia gathered at the 8th Awakenings Festival in Horsham in Western Victoria from 21st to 26th October 2003. Our next issue will contain festival highlights from this celebration of all abilities, also known as the '*event of a million smiles*'.

From left, Awakenings volunteer Julie Facchin, Awakenings Executive Committee chairperson Anne Richards and Rita Eldridge at the launch of the 2003 Festival.

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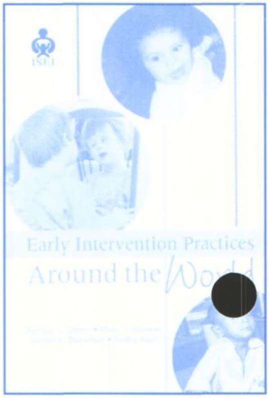
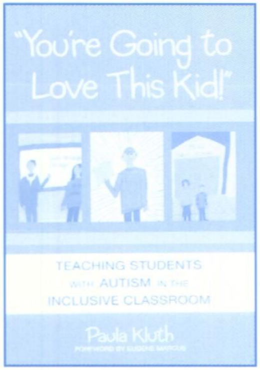
Early Intervention Practices around the World

Samuel L Odom, Marci J Hanson
James A Blackman, Sudha Kaul



This book discusses effective early intervention practices at work in 13 countries. Readers will learn about innovations in four areas: service delivery models, family support, professional development and organizational support. Each chapter looks at early intervention in one country, discussing the social, political and economic contexts, describing the challenges and successes in implementing them, and information on the application of the lessons learned.

May 2003 · 1 55766 645 8 · HB · 384pp · Springer Publishing



'You're Going to Love This Kid!'

Teaching Students with Autism in the Inclusive Classroom

Paula Kluth

Finally education professionals have a strategy-filled guidebook for including students with autism in both primary and secondary school classrooms. Alive with powerful first-person accounts that give readers insight into the experience of having autism, this book shows educators how to adapt their own classrooms to support student participation in classwork, school routines and social activities. Professionals will learn creative ways to:

- understand the attitudes, values and actions that support inclusive schooling;
- adapt the physical environment for students with autism, who may have heightened sensitivity to factors like temperature, sounds and smells;
- foster friendships and social relationships between students with and without autism;
- plan challenging, multidimensional lessons that encourage all students to participate.

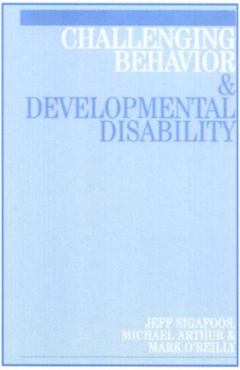
April 2003 · 1 55766 614 8 · PB · 304pp · Brookes Publishing

Australian author

Challenging Behaviour and Developmental Disability

Jeff Sigafoos, *University of Texas, Austin*
Michael Arthur, *University of Newcastle, NSW*
Mark O'Reilly, *University of Texas, Austin*

This text provides evidence from wide-ranging fields to further a better understanding of the nature of challenging behaviour in people with developmental disabilities. It also offers a clearer delineation of the basic principles that guide assessment and intervention. Th[illegible]uthors explore the various individual t[illegible]social context and environmental factors that influence the development and persistence of aggression, self-injury, extreme tantrums and other common forms of challenging behaviour. Reliance on the more typical, technique-driven approach is discarded in favour of an evidence-based method that focuses on the basic principles that underlie effective interventions.



July 2003 · 1 86156 378 7 · PB · 150pp · Whurr Publishers

Making Self-employment Work for People with Disabilities

Cary Griffin
David Hammis

W[illegible]e support of rehabilitation personnel, vocational counselors, school transition staff and community programs, self-employment is a viable option for adults with significant disabilities. This title provides the guidance professionals need to help individuals start and maintain their own small businesses.

features

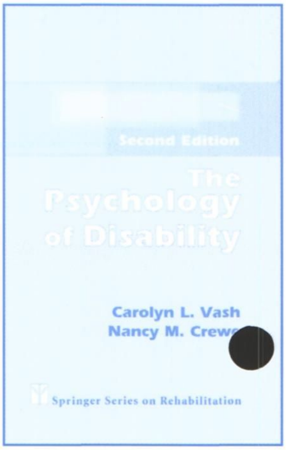
- person-centered business planning and its primary components
- a thorough overview of marketing tactics, finances and social security
- photocopiable worksheets

August 2003 · 1 55766 652 0 · PB · 242pp · Brookes Publishing

The Psychology of Disability

2nd edition

Carolyn L Vash
Nancy M Crewe



The *revised* edition of this classic text describes changes that have come out of the Americans with Disabilities Act, as well as technological advances, new legislation and evolving health care systems. It addresses the growing interest in racial and ethnic diversity, and includes an exploration of spirituality and disability, as well as a look at new partnerships that have developed within the community.

November 2003 · 0 8261 3342 8 · HB · 384pp · Springer Publishing

The Young Deaf or Hard of Hearing Child

A Family-centered Approach to Early Intervention

Barbara Bodner-Johnson
Marilyn Sass-Lehrer

This scholarly text will help early interventionists, education professionals, speech-language pathologists and students navigate the many complex issues associated with this field. Contributors equip readers with the solid research, key concepts and current developments they need to know as they establish partnerships with families and their deaf and hard-of-hearing children. Valuable insights will be gained from research models that focus on early intervention, team approaches to early education and early signs of literacy. Readers will learn to:

- look at specific educational factors, such as inclusive practices and the challenges of identifying and educating deaf children with multiple disabilities;
- examine major family-centered issues such as family rights, support and advocacy;
- consider the family, community and cultural and linguistic contexts of young deaf children.

June 2003 · 1 55766 579 6 · PB · 384pp · Brookes Publishing

Promoting Social Success

A Curriculum for Children with Special Needs

Gary N Siperstein
Emily Paige Rickards

This research-based curriculum aids professionals in improving the social skills of students with mild to moderate disabilities, and their peers. Field-tested with 400 elementary school students, the program focuses on developing the cognitive skills behind appropriate social behavior, rather than teaching children a set of specific behaviors to enact. The book provides 66 activity-based lessons on social skills, organized around topics that build on each other. Each 30–45-minute lesson provides a list of materials, descriptions of the activities, variations for more advanced and less advanced students, and suggestions for reinforcing throughout the school day the skills that have been acquired.

October 2003 · 1 55766 674 1 · Spiral bound · 544pp · Brookes Publishing

Steps to Independence

Teaching Everyday Skills to Children with Special Needs, 4th edition

Bruce L Baker, Alan J Brightman, Jan B Blacher, Louis J Heifetz, Stephen R Hinshaw, Diane M Murphy

Already a trusted resource for thousands of families, this lively book gives parents of children from age 3 through young adulthood proven strategies for teaching them the life skills they will need to live as independently as possible.

What's new

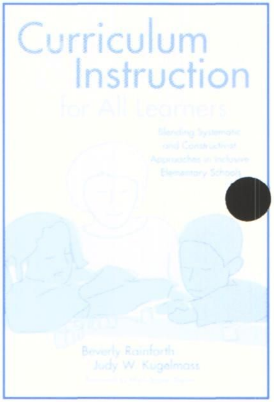
- An expanded section on managing behavior problems.
- A new chapter on technology that reflects recent advances.
- A new chapter on strengthening partnerships with other teachers in the child's life.
- A companion website with downloadable blank forms from the book, and more internet resources.

December 2003 · 1 55766 697 0 · PB · 352pp · Brookes Publishing

Curriculum and Instruction for All Learners

Blending Systematic and Constructivist Approaches in Inclusive Elementary Schools

Beverly Rainforth
Judy W Kugelmass

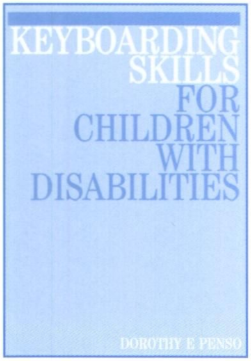


This textbook helps teachers to bridge the gap between two key approaches to classroom teaching: systematic (teacher-directed) instruction, which is found in most special education services, and constructivist (child-centered) instruction, which is often found in progressive general education. Through current research and case studies, professionals will learn how to combine the strengths of each approach to address such issues as:

- cultural and linguistic diversity in the classroom;
- balanced literacy instruction;
- inclusion of students with challenging behavior and/or severe disabilities;
- project-based learning.

September 2003 · 1 55766 610 5 · PB · 302pp · Brookes Publishing

Keyboarding Skills for Children with Disabilities



Dorothy E Penso

Children who have difficulty with handling a pen or pencil, or who have problems with organizing movements at a cereb[illegible] level are at a great disadvantage in school, no matter what their intellectual and academic levels may be. Personal computers and electronic keyboards can revolutionize the lives of children with these difficulties, enabling them to perform in the classroom at a level commensurate with their peers. The author provides accessible information about the children who are likely to benefit from using personal computers and electronic keyboards, and how to teach keyboarding skills to such children.

1999 · 1 86156 101 6 · PB · 225pp · Whurr Publishers

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Positive Behaviour Support for People with Intellectual Disability: evidence-based practice, promoting quality of life

by **Keith R. McVilly**

B.A.., Grad. Dip. Psych., M. Psych. (Clinical)
MAPS & Member of the APS College of Clinical Psychologists
Clinical Psychologist & Research Fellow, Centre for Developmental Disability Studies, University of Sydney, Australia

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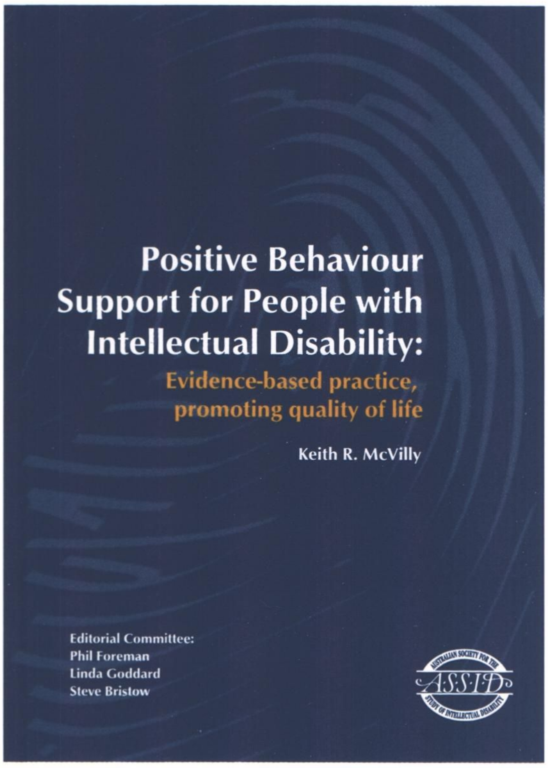

Positive Behaviour Support for People with Intellectual Disability:
Evidence-based practice, promoting quality of life
Keith R. McVilly

Editorial Committee:
Phil Foreman
Linda Goddard
Steve Bristow

This accessible book is an essential resource for support workers and other disability professionals, educators and students in the intellectual disability field. It provides evidence-based information to help the reader understand *challenging behaviour*, to develop and implement *behaviour support plans*, and monitor those plans to ensure their ongoing effectiveness. Clear guidance is provided on ethical and legal principles underpinning *behaviour support*. Examples of charts and forms provide materials for use in practice. Combining cutting edge research and contemporary best practice, this practical book presents a holistic, bio-psycho-social approach to *behaviour support* designed to promote *quality of life* for people with disability.

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Depression in People with a Developmental Disability

continued from page 6

an intellectual disability (ID) is the greater proportion of more severe levels of ID and under-representation of people with mild ID in the CDDHV group.

This suggests that the generic health system is more able to cope with the health care challenges of adults with mild intellectual disability, or that challenging behaviour, so often the precipitant of a referral to CDDHV, is less of a problem in this group.

Other points of difference are the higher proportion of CDDHV patients living in Community Residential Units rather than with family, the greater percentage from non-English speaking backgrounds and higher incidence of Autism Spectrum Disorder in the CDDHV group.

Some part of these differences could be due to the fact that the CDDHV population includes only adults, and that the definitions may not strictly correlate.

The main factor accounting for the differences between the two groups is seen in the reasons given for referral to the Centre. Seventy-nine percent (79%) are referred because they have challenging behaviour and thirty percent (30%) because there is concern that they may have a psychiatric illness.

The writer looked at a number of loss factors - past and recent (last 3 years) bereavement and illness/absence of self/major carer, change of accommodation, change of day placement or other major loss or stress in the past 3 years. The group as a whole had experienced a high level of loss with 70% experiencing at least one of these things and many experiencing several. Recent bereavement showed the greatest difference between the two groups.

It used to be said that people with more severe degrees of intellectual disability did not have the capacity to understand death or appreciate the loss of an important person, and so this would not lead to depression. Our experience at the CDDHV does not support this view. Particularly for those living with family, illness or death of a prime carer can lead to a cascade of change and loss that can be very destabilizing.

Reason for use of antidepressants

Antidepressants were prescribed for a variety of reasons. Grouped as follows:

1. Depression Diagnosed - where there was evidence in the file that a reasonably confident diagnosis of depression had been made.
2. Therapeutic Trial - where the clinician suspected depression but where the diagnosis was not clear and the response to therapy was to help clarify the diagnosis.
3. Other - this covered a number of indications (diagnosed or suspected) such as anxiety disorder, obsessional compulsive disorder, autistic spectrum disorder and nocturnal eneuresis.

Depression was the indication for use in 45 % of cases and a therapeutic trial for suspected depression in a further 37%.

Several anti depressants were sometimes used for one person during the course of their involvement with the CDDHV. For the 139 cases, 156 episodes of antidepressant use were examined.

In 13 cases the use of the anti-depressant was suggested by the CDDHV clinician but there was no further follow-up, so no information was available about whether it was prescribed, its efficacy or side-effects.

In 22 cases the efficacy at 12 weeks was unclear from the file and 17 cases had ceased the medication before 12 weeks.

Efficacy

Efficacy was estimated on a very loose basis, at 6 weeks and 12 plus weeks, from evidence in the files. This is very unscientific so it was reassuring there was substantial inter-rater reliability on assessment of efficacy as judged by the Kappa score.

Mood, Sleep, Weight and Behaviour Charts are commonly used by CDDHV clinicians as a tool in both assessing patients and in monitoring progress and efficacy of treatment.

After excluding cases where there was no follow-up, 70% showed improvement of some degree at 6 weeks and 58% showed improvement at 12 weeks.

This is not as good as the drug companies lead us to expect and probably not as impressive as the researcher was expecting from past clinical impression.

Closing Comments

Although this analysis does not provide definitive answers to many of the questions raised in the research aims, a number of findings are of some interest and could form the basis for developing targeted research questions for more defined studies on this subject. eg:

- Percent depressed
- Indicators of increased probability of depression
- Indicators of need for anti-depressants
- Effectiveness

VOLUNTEER FRIENDS
Creating Friendships

The Volunteer Friends Program is one of the proud winners of the Best Practice Award, Certificate of Recognition at the Tasmanian State A.S.S.I.D. conference on the 1st and 2nd of October 2003. The conference was a great event with many topics being close to the path we are now following, so I thought I would let you know a little bit about the Volunteer Friends and how we are going in Launceston, Tasmania.

The Volunteer Friends Program began in June 2002 as an initiative of People Integration. The aim of the program is to assist adults with an intellectual disability to form friendships with other people in the community. The people we are assisting currently reside in six group homes operated by Northern Residential Support Group INC. (N.R.S.G. INC) in the greater Launceston area.

On the surface it appeared that these 24 adults are integrated into the mainstream community with their homes looking like anybody else's across town. They, for the most part, participate in activities/outings during the week and weekends. Upon closer inspection though, it was realised that this group of people didn't participate in a true sense of the word, but were merely present, usually as a group, supported by paid staff. Another observation was that this group often accessed specialised "generic" services.

In order to extend independence and the level of participation, and gain natural, quality of life experiences, the Volunteer Friends Program was founded. We achieved this by tapping into a valuable resource in the community, volunteers. The program began with the aim to increase community awareness, recruit volunteers, conduct information sessions, provide a coordinator for support and carefully match these volunteers to the residents who chose to participate.

Achievements/changes in the past year:

- The original training program for volunteers has been completely revamped and is now known as information sessions. Topics concentrating on friends and friendships dominate with communication, standard/duty of care, insurance, confidentiality and medication all given a fair hearing as well. The sessions end on the topics of volunteers and the benefits of the volunteer friend program.
- The Mayor of Launceston City Janie Dickenson has come on board as Patron of the volunteer friends. This has been of great benefit to us re. Ms. Dickenson is very community focused and is highly respected and respectful towards all people. Another advantage has been the press following the Mayor receives at openings/launches and such like.
- A Sponsorship/Partnership campaign was launched to assist the volunteer and their friend. This was done by formally writing to Clubs, Companies and individuals requesting their assistance. Volunteer friends did not ask for money (although we would not say no if offered) but by a system where people could sponsor in the form of tickets or passes to events in the community, memberships to clubs, assistance to access events and so on. Volunteer friend's has six major sponsors and perhaps a dozen more who this year contributed in a variety of ways. One offs, for example, is the local football club donating four passes for the season or twelve tickets to the netball finals, sixteen tickets to the Ballet, these are utilised by the volunteers and their friend. Although these may seem small the benefits and variety of community participation and the fact that they are a renewable resource is highly valued.
- Why reinvent the wheel? Networking has been a valuable resource for volunteer friends. Information has been gained from Queensland around student/staff training around supporting friendship and relationships and ways of connecting with others in the community. This training of community mapping and friendship support will allow a greater understanding of friendship opportunities and an awareness of the barriers associated with some people who have an intellectual disability.

Volunteer perspective

"This was all new to me, but the friendship that has been formed has benefits for all concerned. From the volunteer perspective, the friend can get out and about, not only just in the community but mixing with people in community activities. This includes things that can be small locally up to large events at the Silverdome where thousands of people attended. The impact of these outings on my friend in particular, has realised a long lasting positive outlook and approach, happening on a day to day manner."

"What I can see is the flow on effect to friends/peers for both the volunteer and the friend - they realise the 'can do approach'. Basically means 'I can do that too'. Encourages active participation across the board."

"Generally I have been rapped with the involvement with volunteer friends - the friendships, in particular, with the residents from Northern Residential Support Group. Contact with friends, family and staff has been supporting and encouraging."

"You go into this as an unknown quantity - but it is now far from that"

Andrea Banfield - Launceston Tasmania

Supporting Change

Third Disability Support Workers Conference

27th & 28th November 2003
The University of Melbourne: Old Arts Building.

Have you ever wondered how many other people from all over Victoria are doing the same job as you, and have the same questions that you need to be answered?

Disability Support Workers are all encouraged to attend the Disability Support Workers Conference. These two days in November will be held at the Old Arts Building at The Melbourne University. This is in the third year of the conference and each year it is becoming more popular with direct support staff.

Come along and meet other disability support workers, build your networks, acquire new skills in workshops gaining knowledge that you can use in your workplace. Workshops presenters will include Ray Murray (NZ) who has extensive experience in Active Support.

Over the two days there will be national and international keynote speakers who are all leaders within the field of disability. Keynote speakers include:-

- Gordon Grant (UK) who had done significant work with people with intellectual disability and their families involving resilience and coping strategies, and social inclusion.
- Patricia O'Brien (NZ) whose research interests and areas of publication cover advocacy, inclusive schooling and de-institutionalisation.
- Keran Howe (Aus) is chair of the Disability Advisory Council Victoria and has worked in the field of health and in disability as an activist, social worker, and researcher for more than twenty years. She is currently Manager of Women's Social Support Service at Royal Women's Hospital.

Opportunities will be provided for you to meet and interact with these and other presenters at the conference in workshops, run by the keynote speakers and other colleagues, over the two days.

As in previous years the Disability Support Worker awards will be presented as part of this conference. The ceremony will be held in the Grand Buffet Hall, Melbourne University . This will be at 3.00pm on Friday 28th November. These awards recognise the outstanding contributions that Disability Support Workers make to the lives of Victorian people who have a disability. These awards will be presented by the Minister for Community Services, the Honorable Sherryl Garbutt MP. This is a catered ceremony and included in the cost of registration.

So take the opportunity to attend the Disability Support Workers Conference that happens once a year, and further your knowledge and skills in the disability field.

For information regarding the Disability Direct Support Workers Conference please phone: 9925 7975 or email dswconfwerence@rmit.edu.au

For information regarding the Disability Direct Support Worker Awards please contact: Bernie Ross at bernie.ross@dhs.vic.gov.au

The Australasian Society for the Study of Intellectual Disability, Victorian Branch; RMIT University, Department of Psychology and Disability Studies; and the Department of Human Services proudly support the Disability Support Worker Conference.

VOLUNTEER FRIENDS

continued from page 18

The volunteer friends program began with the concept of enhancing the quality of life for adults with an intellectual disability. By matching these adults with individuals who in turn would further the integration process through introduction to family members, friends and their social groups. These networks enable residents to develop meaningful friendships with people who are not paid staff. We envisage that through a volunteer the resident may also make many other friends.

The program has been successful in terms of the diversity of community integration, the quality of the volunteers themselves with their age range, understanding, openness to new ideas and their sense of realising their own potential. Through practical assistance the friends themselves are actively connecting to the community through choice, promoting a positive image while building self esteem, confidence, life skills and companionship.

Barbara-Jean Bakes

Coordinator Volunteer Friends

08.10.03

Getting Serious about Health

Dr Seeta Durvasula

Lecturer in Developmental Disabilities

Centre for Developmental Disability Studies, University of Sydney

Health is always a favourite topic for the media and the public. At the time of writing this article, we have a new Federal Health Minister and the medical indemnity crisis has been put on hold, at least for the time being. Add to this the perennial favourites, "hospital waiting lists" and "new wonder drugs", and the topic of health is seldom out of the public eye. Unfortunately, the dramatic headlines don't always reflect some of the deep and structural inequalities we have in health in this country. This is especially true for people with developmental disabilities.

What is the problem?

Evidence of the unequal health status of people with developmental disability has been available for many years. While those with a mild intellectual disability have a near average life expectancy, it is significantly reduced for others with intellectual disability (Patagia et al, 2001; Bittles et al, 2002). The mortality rate of people with intellectual disability in northern Sydney, an affluent part of city, has been shown to be almost 5 times that of the local general population (Durvasula et al, 2002). A review of deaths of people with developmental disability in government funded accommodation services in NSW showed that a number of deaths could potentially have been avoided with greater staff supervision, and timely medical care (NSW Community Services Commission, 2001). Numerous other studies have found high rates of health problems in this population, whether in institutional or community care. Conditions such as epilepsy, oral health problems, mental health disorders, vision and hearing impairments, nutrition and endocrine disorders occur more frequently than in the general community (Beange et al, 1995; Bowley & Kerr, 2000; Einfeld & Tonge, 1996; Janicki & Dalton, 1998). These conditions are frequently chronic, multiple and complex. There is also worrying evidence of life style related health problems with greater rates of obesity and lower levels of physical fitness than in the general population (Beange et al, 1995; Messent & Cooke, 1998).

For far too long, we seem to have accepted with equanimity the lower life expectancy, unnecessary deaths and higher rates of chronic health problems seen in many people with developmental disability. These same health indicators would cause shock and outrage had they occurred in any other group in our affluent country. While families and clinicians have long recognised the true nature of the problem, governments and organisations have been slower to respond. In recent decades, the major focus has been that of social integration of people with developmental disability. While this is important and necessary, health has not always been imbued with the same significance. This is now slowly changing.

Health of people with developmental disability has been a focus of numerous conferences and meetings this year. These have included the NSW ASSID Conference in July, the IASSID (International Association for the Scientific Study of Intellectual Disability) Health SIRG meeting on Health Disparities in August, and the November AAMR (American Association on Mental Retardation) National Health Forum on Reducing Health Disparities.

The main national health conference of the year in Australia, Perspectives on Health in Developmental Disability, was held on June 26th-28th in Sydney. It was hosted by the Centre for Developmental Disability Studies (CDDS) in conjunction with the Association of Doctors in Developmental Disability (ADIDD). Several key themes emerged from this conference:

- People with developmental disability have unequal health outcomes compared to the rest of the population, with higher rates of chronic and sometimes complex health conditions
- A comprehensive, life span approach to health care is essential
- Health promotion and preventative health measures play an important role in this population
- Social and economic determinants of health such as discrimination and poverty, as well as biological and psychological factors need to be addressed
- High quality basic and applied research underpins any measures to improve health outcomes in people with developmental disability

So while there is a gathering consensus that health is an important issue for people with developmental disability, there is less agreement about what should be done about it. The following is a discussion of some possible strategies.

Education of general practitioners and other health professionals

It has been shown that while people with intellectual disability see their general practitioners (GPs) at least as frequently as others in the community, health problems

Book Review:

The Social Construction of Intellectual Disability

Author: Mark Rapley, Associate Professor of Psychology, Murdoch University.

Review by: Kate Randall

In this account of intellectual disability the author invites us to step outside of the conceptual frameworks that we live and work in and question our assumptions about people, in particular, people who are considered to have a cognitive impairment.

Through conversational and discourse analytic techniques the ways that intellectual disability is constructed as a social category are considered in great depth, exposing logical flaws in many of the concepts, tests, questionnaires and other measures that we take for granted when assessing peoples' competencies. This is a great book for anyone who works with people with intellectual disabilities in any capacity. Its relevance stretches far beyond the client/carer and client/professional relationship examples used, into everyday interactions where we are constantly demonstrating our own and evaluating others social and occupational skills and abilities.

Rapley begins by creating an ethno methodological context for his argument through discussion of recent work in discursive psychology and its relevance to the field of intellectual disability. He then goes on to consider the language of intellectual disability', that is, the definitions, classifications and assessment criteria that are used to create the diagnostic social and moral category of intellectual disability within which people can be placed and treated accordingly. The major focus here is to look at the ways that intellectual disability is created as a concept rather than described as a naturally occurring entity that simply requires observation and classification.

In the second part of the book a series of case studies are considered, some of which involve the application of psychological assessment techniques and some that involve general everyday conversation. These examples show some of the ways that people who are described as intellectually disabled are also produced as socially and morally incompetent by those who work with them. Alternative examples are then given to highlight people described as intellectually disabled demonstrating an understanding of and the ability to apply complex, subtle and culturally relevant rules of social interaction. These demonstrations serve to question popular knowledge regarding the social competencies of people with intellectual disabilities and indeed the notion of intellectual disability itself.

This is a well-researched, well-grounded and powerfully expressed challenge to traditional psychological accounts of learning disability. The Social Construction of Intellectual Disability will be available through the Cambridge University Press in February 2004 and can be pre-ordered at Amazon Books or through CUP by logging on to http://titles.cambridge.org/catalogue.asp?isbn=0521005299

Getting Serious about Health

continued

continue to be under-diagnosed, diagnosed late, or inadequately managed (Beange et al, 1995; Webb & Rogers, 1999). One reason for this is likely to be the insufficient knowledge and skills of GPs in this area (Lennox et al, 1997). This is also true for other health professionals in the generic system. Education of general practitioners in this field has been recommended, and is already taking place, for example through the Centre for Developmental Disability Health Victoria, and the Queensland Centre for Intellectual & Developmental Disability. CDDS has also been involved in several educational activities:

- In collaboration with the NSW Cervical Screening Programme, CDDS has developed guidelines and education sessions for general practitioners on preventative women's health for women with disabilities
- In a project for NSW Health, CDDS has developed, evaluated and is implementing a training package for hospital staff on the needs of people with disabilities who are in hospital
- Staff of CDDS and the Faculty of Health Sciences, University of Sydney have developed and teach a web based postgraduate course (Graduate Certificate/Masters in Health Science, Developmental Disability) for health professionals.

Another tool that has been developed to guide health practitioners, families and carers on the health surveillance and interventions required, is in the form of Health Guidelines for Adults with an Intellectual Disability. These were developed by the Health Special Interest Research Group (SIRG) of the International Association for the Scientific Study of Intellectual Disability (IASSID). The guidelines address the most common health conditions seen in people with developmental disability, and make recommendations for their management. (Health

Guidelines are available on the IASSID website: http://www.iassid.org/pdf/healthguidelines-2002.pdf)

Expert multidisciplinary team support

However, education is seldom the only answer. While GPs can refer to sub-specialists such as neurologists and psychiatrists for specific management issues, there is still the need to do a comprehensive assessment of the overall health and social circumstances of the individual. It is unrealistic to expect an individual GP to develop the necessary expertise to deal with the multiple and complex conditions, compounded by communication difficulties and fragmented history, when he or she may see only a handful of patients with developmental disability.

A more effective approach would be the involvement of multidisciplinary teams of medical and allied health professionals with expertise in developmental disability. Such teams would provide invaluable support to general practitioners (and other health professionals), who can then attend more confidently to their patients with developmental disability. The NSW Council for Intellectual Disability in its submission to NSW Health has argued for the establishment of such teams. This is not a novel concept, but one that already works effectively in the form of Aged Care Assessment Teams (of geriatricians and allied health professionals) for elderly people with complex problems. Such systems do not work in "parallel" with the generic system, but support and complement the work of GPs and other health care practitioners who continue to provide the primary care.

In the Netherlands there has been recognition by the government of the need to develop such expertise in this area of health. A three year specialised training programme for doctors in intellectual disability medicine has recently been established at the Department of Family Medicine, Erasmus University Rotterdam.

Preventative health and health promotion

While people with developmental disability have high rates of life style related health risks, they have difficulty in accessing mainstream health promotion and health education activities such as fitness, healthy nutrition and injury prevention programmes. Those programmes devised specifically for this population tend to be short term and not always well evaluated. High quality research and evaluation are essential prerequisites to the development or adaptation of health promotion programmes to the needs of people with developmental disability.

Engaging with the general health system

Dialogue with the professionals and bureaucrats in mainstream health sector is vital to understand the current trends and policy initiatives, and to also raise their awareness of the health needs of people with developmental disability. For example, it is important that we participate in the current debate about childhood obesity, as this has major implications for children with developmental disability. Any proposed State or National strategies need to be applicable or adaptable to the needs of children with developmental disability.

A successful example of such participation in the mainstream debate was at the recent Australian Health Care Summit held in Canberra on August 17-19th, 2003. This Summit was organised by the Australian Health Reform Alliance, which comprises professional, consumer and advocacy bodies, including NCID (National Council on Intellectual Disability). The aim of the Summit was to discuss strategies for improving Australia's health system. Representatives of several disability advocacy groups were among the 250 delegates, and it was through their participation that the issue of the health needs of people with disabilities was able to be placed on the national agenda. A key principle of the resulting Communiqué was "Equity of health outcomes - irrespective of socio-economic status, race, cultural background, disability, mental illness, age, gender or location". The recommendations, while addressing general problems in the health sector, are highly relevant to people with developmental disability, especially in the areas of equity of access to health care, care coordination for those with chronic illness, and funding for new initiatives in mental health. (A full list of members of the Australian Health Reform Alliance, a list of delegates, papers presented at the Summit and full text of the Communiqué are available on the website: http://www.healthsummit.org.au)

Conclusion

The health needs of people with developmental disability can be complex, and there are no simple solutions. Education of health professionals is necessary, but needs to be underpinned by expert support. The primary responsibility for the health care of this population needs to be assumed by Departments of Health, both at the State and Federal levels. Generic health promotion programmes need to be made accessible and adapted to the needs of people with developmental disability, and to do this we need to engage with the mainstream health sector. We also need to participate in discussions about tackling some of the social and economic determinants of health. Finally, governments must make a commitment to high quality research that informs the development of effective health interventions in people with developmental disability.

Getting Serious about Health **continued**

We all see good health as being fundamental to our quality of life and expect a quality health service that meets our needs. People with developmental disability should not have to expect anything less.

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Note: This article is adapted from, and is an expanded version of an item that appeared in a recent edition of the CDDS Newsletter

ASSID-L

A mailing list for people with an interest in intellectual disability.

Access to this list is included as part of *"Australian Society for the Study of Intellectual Disability"* membership and is intended to improve communication between us all.

ASSID-L operates in the same way as any e-mail list.

To subscribe, send a message to **ddu@med.monash.edu.au**, leaving the subject line blank. In the body of the message, type 'subscribe ASSID-L (your email address)' - making sure you put your email address in! Then, sit back and smile, you will be notified in a couple of days.

Upcoming Events . . .

19/3/2004 - 20-3/2004

Australasian Academy of Cerebral Palsy and Developmental Medicine's 2004 Conference. 'New Dimensions'

Place: Carlton Crest, St Kilda, Melbourne

The international keynote speaker is leading researcher in childhood disability, Professor Peter Rosenbaum of Canada.

31/3/2004 - 1/4/2004

National Accommodation and Community Support Conference
"My Life - Who is in Charge?"
People with disabilities - more than spectators in their own homes

Place: Hotel Sofitel, Melbourne, Vic

4/6/2004 - 19/6/2004

12th World Congress of the International Association for the Scientific Study of Intellectual Disabilities

Place: Montpellier, France
Website: www.iassid.org

21/7/2004 - 24/7/2004

One World: Many Childhoods
- Strengthening Early Childhood International Links

Place: Melbourne, Vic
Contact: The Meeting Planners,
91 - 97 Islington Street, Collingwood, Vic 3066
Phone: (03) 9417 0888
Fax: (03) 9417 0899
Email: omep@meetingplanners.com.au
Website: http://www.omepaustralia.com.au/

This is the XXIV World Congress of The World Organisation for Early Childhood Education will be a unique opportunity to highlight OMEP's concern for early childhood development across the world. and will provide opportunities to explore issues such as children in difficult circumstances, innovation in service delivery, indigenous children's needs and services and children's health and social services.

25/7/2004 - 27/7/2004

Sixth Biennial National ECIA Conference - Broadening the Vision: Building Cohesive Communities for Children and Families

Place: Melbourne, Vic

The Victorian chapter of Early Childhood Intervention Australia (ECIA) invites participants to the 6th biennial National Conference which will focus on the benefits that the provision of inclusive, positive, community oriented opportunities bring for children with additional needs and their families.

9/11/2004 - 12/11/2004

39th ASSID Annual Conference

Place: Adelaide, SA

The upcoming events column can only be filled if ASSID members let us know what is going on. Any conference or event – local, regional, state based, national, international, ASSID or not – can be notified free of charge in the upcoming events section.

*Just email **hmoore@med.usyd.edu.au** and put **'IDA:upcoming events'** in the subject line and it will be passed to the IDA editor to go into the next available edition.*

Include name/title of event, date(s), time(s), venue(s), contact details and a few words – a very few words – of information. It's a great way of reaching potentially thousands of workers in the field of intellectual disability and in allied areas.