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INTELLECTUAL DISABILITY Australasia

Conferences are a lot of learning, and a lot of fun

ASSID National Conference, 2002
Hobart, November 13th - 16th, see inside for details.

Inside:

Magazine of the Australian Society for the Study of Intellectual Disability

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Contents

Editorial

Several times recently I have been in circumstances – conferences, meetings, assessments, workshops - where one or more people have commented or complained (politely, of course) that there is not enough information around in intellectual disability services. In many ways, this is the case – we certainly don't know enough. However, I will be honest and say that it also seems to me that what Robert Hughes called the 'culture of complaint' is all too often the first response. Workers, advocates and even self-advocates alike tend to complain about the lack of resources, often well before looking around to find what is truly available. The result is that many staffmembers remain unaware that there is a enormous amount of knowledge, information and innovation available *if only they reach out for it*

Of course not all workers and advocates in the field of intellectual disability have the same access to knowledge resources. If we picture the 'field' as a large, multi-branched tree then, if you are on the trunk – which, realistically, is composed of the 'older' services such as academic and some medical and psychological services – you have access to journals and libraries and other like minded people with whom you can discuss. But if one of the smaller branches (special education, the therapies) or a manager, or a professional who is called in now and then, you are out on a branch separate from others. If you are a direct care worker you can be said to be stuck out the end of a thin branch and it is very hard not to feel that you are swaying in the wind...

Which is where ASSID steps in, or should step in. The mission of ASSID is: *To provide and promote mechanisms for the generation and sharing of knowledge and debate among people working in the field of intellectual disability.* To fulfil this mission, though, ASSID needs an active membership, a group of individuals who are willing, whenever possible, to refer their colleagues and friends and co-workers and family members to the wealth of research and thought and best practice that is available through this magazine, through the Journal of Intellectual and Developmental Disability, and through the networks that through being a member of ASSID you have ready access to (if only you reach out, of course).

Importantly, each and every one of us should attend the National Conference and encourage other people to do so, too. While many of us learn well-enough through reading, many of us learn better by what we hear and experience and conferences provide an excellent forum for learning and discussion as well as meeting places for like-minded people. So, please enter the competition in this quarter's IDA – join up a friend to ASSID and win a great prize – and, more than that, sign yourself up for the conference and a terrific time in that gem of a city, Hobart from 13th – 16th November, 2002.

Ann Penhallurick

Registration form for the

ASSID National Conference

Hobart (Nov. 13th - 16th)

available on **page 20**
or from Mike Annand

Tel: +61 3 6234 1424
Fax: +61 3 6231 5388
Email: mail@conventionwise.com.au

You haven't forgotten, have you?

You haven't forgotten, have you, that Hobart is one of the most beautiful and restful cities in the world? And Virginblue now flies to Hobart and Qantas is eager for your business so that the cost of travel to Tasmania is now extraordinarily cheap? (Try the net-deals for both airlines).

You couldn't have forgotten that the ASSID National Conference is the major national event for researchers, practitioners and advocates who work in support of people with intellectual disability. It would be impossible to forget, surely, that the exchange of ideas and information that occurs at the conference is essential to development of best practice and the highest possible quality of life for people living with intellectual disability.

Hobart's fabulous Salamanca Markets

But, just in case you have forgotten:

37TH ASSID NATIONAL CONFERENCE

Developing and Enriching Communities

13th - 16th November, 2002

Wrest Point Casino, HOBART

For **Registration** see page 20 or
Mike Annand Convention Wise
Tel: +61 3 6234 1424
Fax: +61 3 6231 5388
Email: mail@conventionwise.com.au

Abstracts to optia@netspace.net.au or
montagu@netspace.net.au

More info:
www.rmit.edu.au/departments/ps/assid/tassie2002

And, in case you don't know yet –

There are some exciting local and international speakers coming to the ASSID conference and this may be your only chance to hear them speak, to ask them questions and to have a drink with them over dinner.

And - Salamanca markets on Saturdays are the perfect place to buy delightful and delectable Christmas and other presents (perhaps a little treat for yourself...?) The conference will even start a little late to let you get there. As well as that, Tasmania cheeses, fresh produce and wines are among the best in the world (and there really are no export duties if you are taking any of these back to the mainland!)

There is a remarkable range of hotel and self-contained accommodation available in Hobart. So, find a friend, and share a quaint cottage or a salubrious suite with spa!

(Contact Tourism Tasmania, or just type in Tasmania, Accommodation and you'll find info. Try wotif.com closer to the date).

You could win a fabulous prize just by encouraging a friend, colleague, organisation to join ASSID before November 10th this year.

Write your own name on the top of the application for membership (enclosed), have a friend or colleague or organisation fill in the details to join ASSID and send to the address on the form by November 10th.

Win a prize now!

Get Connected!

To get up-to-date information from Australia, the US and the UK, why not subscribe to one of the free electronic list serves noted below. If you know of other useful WWW sites, let us know at IDA so that we can share that information with ASSID members around the country.

Are you currently subscribed to our very own ASSID-L electronic information service? As well as providing a source of information, ASSID-L enables ASSID members to ask questions and get advice from other members around the country and overseas. If you would like to log-on, send an e-mail request reading "Subscribe ASSID-L - YOUR E-MAIL ADDRESS", together with your name (and if possible your ASSID Membership Number) to: ddu@med.monash.edu.au.

Information sites to try out

Australian Institute of Health and Welfare
[http://www.aihw.gov.au]

The Australian Institute of Health and Welfare is a statutory authority of the Commonwealth of Australia. The Institute is governed by a Board that is accountable directly to Parliament. It provides the latest facts and figures on the health and welfare of Australians. You can subscribe to AIHW's free 'new release alert' services, in the fields of either 'health' or 'welfare'. To subscribe to the 'health' alert list, send an e-mail to: join-health-release-notice@lists.aihw.gov.au. To subscribe to our 'welfare' list, send an e-mail to: join-welfare-release-notice@lists.aihw.gov.au.

Disability Studies Quarterly
[http://www.cds.hawaii.edu/DSQ/index.html]

The Disability Studies Quarterly is a peer reviewed journal available (free) on-line. It is produced by The Centre on Disability Studies, University of Hawaii at Manoa, for The Society for Disability Studies. You can access current and past issues of the journal at the WWW site above and receive regular notifications by registering you e-mail address at: http://www.cds.hawaii.edu/email/signup.asp

Disability World [www.disabilityworld.org]

Disability World is a bimonthly web-line of international disability news and views published by The National Institute on Disability and Rehabilitation Research (NIDRR) - one of three components of the US Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education. You can receive an automated notification and link to the free journal by registering your e-mail address at the WWW site noted above

iCan [http://www.ican.com]

iCan is a US based organisation established to identify the 'product and service needs' of people with disability and to bring these to the attention of the commercial sector. It also publishes a free monthly newsletter, which includes a summary of many useful web links. You can subscribe to the "iCan Monthly Bulletin" by registering your e-mail address: http://www.ican.com/registration/newuser.cfm?regtype=full

SARA - Scholarly Articles Research Alerting
[http://www.tandf.co.uk/sara]

SARA - Scholarly Articles Research Alerting - is a service designed to deliver by e-mail, tables of contents for journals published by Carfax, Martin Dunitz, Psychology Press, Routledge, Spon Press or Taylor & Francis. This service is completely free of charge and you can select to receive alerts by "key word", "title", "sub-category" or "main category". You can register your e-mail address by following the www link at: http://www.tandf.co.uk/sara.

The Disability-Research Discussion List
[www.jiscmail.ac.uk/lists/disability-research.html]

The Disability-Research Discussion List is an international e-mail discussion list administered by the Centre for Disability Studies at the University of Leeds, UK. The list (started in December 1994) is the largest of its kind in the world, and provides a forum for discussion on all aspects of research within the field of disability studies - theoretical, political and practical. The list is intended for all those interested in research as it affects on disabled people both in the UK and internationally. It provides a forum for the exchange of ideas, information and news, particularly among researchers working within a social model approach. The list provides an opportunity for researchers, students and disabled people to share their ideas, experiences and research findings. It is also an excellent place to ask questions or seek information. You can join the list by sending the message "join disability-research your name" to: JISCmail@JISCmail.ac.uk.

- Keith McVilly

Keep your contact details up to date with your State Councils at the main ASSID data-base.

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

Win a prize now!

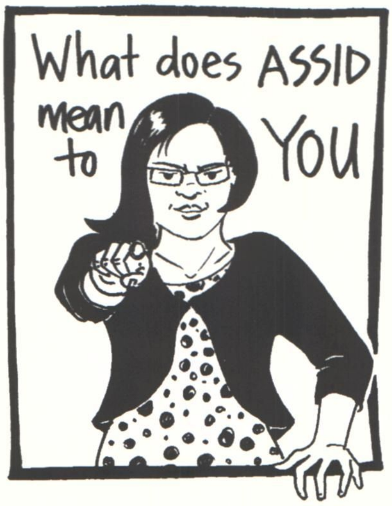
You could win a fabulous prize just by encouraging a friend, colleague, organisation to join ASSID before November 10th this year.

Write your own name on the top of the application for membership (enclosed), have a friend or colleague or organisation fill in the details to join ASSID and send to the address on the form by November 10th.

ASSID, like most similar organisations, relies on income from membership to fund most of its activities. So the more members, the better value each of us gets for our money. More importantly, the more members, the better able ASSID is to provide services that will truly lead to the enhancement of quality of life for people with intellectual disabilities and their families.

So, go out and spread the word! There is a membership form in this copy of the magazine. As long as you are an existing, paid-up ASSID member, all you have to do is write your own name - prominently - at the top of the application form and then hand it over to a dedicated friend or colleague for them to fill in their own details. Post the form and membership fees to the appropriate address and your name will go into the hat to WIN!

***Children with Disabilities* by Mark Batshaw will be donated by MacLennan and Petty publishers as the first prize in the New Membership Draw.** This comprehensive book of approx 900 pages is well worth having - and it could be yours just for signing up a new member to ASSID before November 10th, 2002.Here is a description of the book (provided by MacLennan and Petty): *This fully illustrated, comprehensive resource has all the essential information on disabilities. It features extensive coverage of genetics, heredity, pre- and post-natal development, specific disabilities, family roles, and intervention. This highly regarded reference includes information on substance abuse, AIDS, Down syndrome, Fragile X syndrome, behaviour management, transitions to adulthood, and health care in the 21st century. Other important topics are: ethical choices in health care, organ donation, sexuality issues, anxiety disorders, intervention strategies for children of drug-dependent mothers, treatment of hearing loss and middle-ear disease, and withholding treatment. New chapters address early intervention, special education, and sports and leisure.*



Second and third prizes will be copies of *Intellectual Disability and the Law; Contemporary Australian Issues.* This is a terrific book which is highly recommended reading - it's not at all stuffy and provides a wealth of information around all facets of interacting with the lay - from communication issues to the functions of the Public Guardian.

The Membership Drive prize will be drawn at the 37th Annual ASSID National Conference in Hobart (November 13th - 16th, 2002)

Discussion forum?

Reading newspapers, magazines, journals, watching television, surfing the net; all of these are excellent ways of obtaining information (even if, at times, it's information you'd rather not have!). All too often though, in this seemingly ever-busier world, information takes the place of interaction and discussion. There are many inherent problems with this stacking of information: the difficulties of assessing which is reliable, being able to work out what has practical application, the impossibility of comparing so much information, the difficulties of synthesis and analysis and so on. More than that, it is simply not as enjoyable gaining information that is 'told to us' (usually by written means): there's much more enjoyment to be had in the exchange of information and the commentary and discussion around it. A prime reason for joining ASSID must always be to not only glean more information but to have a network of like-minded people with whom to discuss information.

Anthony Raitman, a Victorian ASSID member and one of the most energetic contributors to our list-serve ASSID-L, recently raised the question of whether ASSID-L could broaden its scope as a discussion forum. Here is, in part, a letter he circulated on ASSID-L.

Dear all,

> *I have been watching with interest the use of this list and it has primarily been a source of information sharing by way of question/answer, details of something happening around the country/world or forwarding interesting articles.*
>
> *I am interested to know whether people consider this to be a useful forum in which to provide feedback or comment on articles which appear in the Journal of Intellectual & Developmental Disability (or any other journal for that matter). Without offending the author of course as they are likely to see/read the comments that people make.*

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Day Options for Older Adults with a Disability: An Overview

Christine Bigby, School of Social Work and Social Policy, Latrobe University

The following is a summary of a study which aimed to "identify the issues for governments, community service providers, people with a disability and their carers associated with the development and provision of day support services for older adults with a disability and make recommendations to address these issues".

Who are Older People with Disabilities?

Considerable diversity exists among the sub-groups which make up the population of older people with a disability, in terms of the type and severity of their disability and the rate, nature and impact of the ageing process and requirements for supports. The current cohort of older people with disabilities is predominantly those with an intellectual disability. Though the numbers of older people with a disability will continue to be small relative to the aged population in general, they are likely to increase significantly over the next 20 years.

Commonwealth Stare Disability Agreement (CSDA) specialist services currently cater for small numbers of older people. At this stage, comprehensive planning for older people with disabilities is impeded by a lack of data at both National, State and Territories level.

Perceptions of Older People with Disabilities

Service providers were extremely concerned and motivated to improve the circumstances for older people with a disability. However, a prevalent and incorrect assumption that premature decline associated with ageing was a phenomenon applicable to all people with disabilities at a given age was found.

> Though the numbers of older people with a disability will continue to be small relative to the aged population in general, they are likely to increase significantly over the next 20 years.

Service providers had a tendency to use "getting older" or being an "older person" as an opportunity to change programs, provide more flexibility related to individual need and preferences - generally to improve a person's lifestyle. A trend was found however, for services to include younger people with higher support needs in programs for older people. Little reference was made to the more active images or participatory and productive roles of the aged associated with the Federal Government's Healthy Ageing Strategy, while the older people with disabilities typically had an active and varied view of later life.

Barriers to Effective Provision

The main barriers to effective provision of day support services for older adults with disabilities are:

- Restrictive program boundaries at every level, (in particular, rigid boundaries between accommodation and day support and between disability support and other program types such as HACC) and few incentives for program collaboration around an individual.
- Lack of a leadership role, and limited staff knowledge and expertise in disability, aged care and community sectors.
- Limited resources to support access and community participation.

Characteristics of Specialist Programs for Older People with Disabilities

Key criteria for effective delivery of services to older people with disabilities were identified. These criteria combined aims and objectives sought for older people and identified characteristics of service delivery to achieve these. They were:

- Provision of choice and individualised planning.
- Maintenance and strengthening of social networks.
- Support for participation in the community.
- Maintenance of skills.
- Opportunities for self-expression and sense of self.
- Promotion of a health and a healthy lifestyle.

Conclusions

Lifestyle Support not Day Programs: A working definition of day support services suggested is, " provision of support of varying intensities provided to individuals or external organisations during the waking hours, which facilitates people with disabilities to access activities and pastimes of their choice that are meaningful to them, which increase their quality of life and which may also ensure their personal safety".

Responding to Changing Needs Rather than Transition: The nature of a person's disability significantly affects the nature of day support services they require as will their prior connection to day support services. Reframing of the concepts of transition and retirement to flexible continuing support involves assisting individuals with disabilities in planning for and understanding older age. However, this should be a part of lifestyle planning across the life course, as many issues associated with successful ageing stem from earlier lifestyles.

Responses to Those Outside the Disability System: The approach of service adaptation rather than transition potentially disadvantages those people ageing with a disability who are outside the disability day support system. The practice of an upper age limit for entry into CSDA funded community access services makes late life entry to such services difficult - if not impossible.

> Older people with disabilities are not (currently) included in promotional material on healthy ageing.

Access to the Community and Aged Care System: Utilising the aged care system presents significant barriers for older people with disabilities in terms of both appropriateness and accessibility.

The Interface of Accommodation and Day Support: The nature of a person's accommodation plays a pivotal role in the type of day support they can currently access and can pose considerable cross program challenges. The argument that the cost of accommodation services would increase if people were allowed more ready access to their home during weekdays cannot be accepted in isolation from funding for day services and is a poor basis for service planning.

Making Healthy Ageing a Reality: Older people with disabilities are not (currently) included in promotional material on healthy ageing, and disability service providers have little training and education about the impact of ageing on health or the importance of an active lifestyle.(could be two separate quotes) Staff within mainstream community leisure services and aged care services, as well as many staff in disability services, demonstrate little understanding of older people with disabilities, often perceiving disability in the simplistic terms of physical accessibility.

Choices To Be Made About To What Extent To Support The Quality Of Life: The results of this study support the conceptualisation of day support in the broadest terms of lifestyle support, where supports are planned cooperatively around and by that individual. Issues relating to the optimum funding level for older people with disabilities are part of this broader trailing of individualised funding.

Services are Struggling to Respond to People's Changing Needs Regardless of the Reason: Any change in a person's motivation, capacity or health status is at risk of being attributed to older age. In general, services are having difficulty changing the nature of their service response over someone's lifetime.

Recommendations

The following recommendations have implications for the CSDA agreement, each state and territory disability and aged care policy frameworks and the practice of individual disability services. While many of the recommendations depend on national policy directions, others will be able to be implemented by service providers or for particular individuals in their local communities.

Many of the issues are applicable to day support services for all age groups, not just older people. The service challenge is greatest for the current group of older people with disabilities and their carers.

Recommendation 1: State/territory-based policy for older adults with a disability

Policy and service development responsibility for older people with disabilities should rest with State/Territory disability programs in order to ensure ongoing and relevant support to people with disabilities across the lifecycle.

Each State and Territory should develop policies for older people with disabilities that promote access for all people seeking day support. This includes those who are ageing outside as well as inside the disability day support service system already.

This means:

- Endorsement of the Healthy Ageing Policy and the adoption of "ageing in place" policies for older people with disabilities to replace notions of retirement and transition from current day support.
- Discontinuing the practice of a maximum age for entry to disability services.
- Additional funding is required for several groups - those moving from open and supported employment and those presenting for the first time at older age.
- Developing policies that describe the principles to guide service delivery to older adults with disabilities and the required service outcomes, including:
- Describing day support in terms of lifestyle support and meaningful time use with aims of offering choice, strengthening social networks, participation in the community, skill maintenance, development of self-expression and a healthy lifestyle for older people. Thus, day support services should provide planning and support around the individual's total lifestyle and across

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program boundaries. Policies should also involve cooperation between all services including community, aged care and disability as appropriate for an individual in a given locality.

- The key service characteristics for delivery of day support are an individualised, planned, flexible approach.
- No one type of service model is recommended. But it is strongly suggested that either a comprehensive individualised lifestyle planning approach form a component of the day support service or that such planning be undertaken by a separate agency and precede the development of specific day support options offered by a specialised day support service.

> Policies should also involve cooperation between all services including community, aged care and disability, as appropriate for an individual in a given locality.

Broader Community and Service Development Tasks

It is recommended that the following types of community and service development tasks are explored, trailed and implemented:

- Action strategies to promote and support inclusion for older people with disabilities in community leisure programs.
- Recognition of resource demands to support access community facilities.
- Develop strategies and incentives for coordination around individuals between day and accommodation providers (and other providers).
- Cessation of the practice that people cannot return to their supported accommodation at certain hours.
- Develop protocols regarding access to Aged Care Services.
- Recognition that community development must occur in addition to individualised funding and development of initiatives to extend physical and social access, and programmatic options to underpin individual approaches.
- Address the issue of net widening and the confounding issues of other groups (e.g. younger people with high support needs).
- Develop the capacity of day support services to respond to changing needs and interests over time.
- Remove barriers to service entry that are based on notions of double dipping. Adoption of coherent criteria for entry to services based on a coordinated and integrated service system around individuals.

Increased Understanding of Healthy Ageing

- It is recommended that the competencies (skills, knowledge and attitudes) for staff working with older adults with disabilities are identified and there is development of a comprehensive training strategy on successful ageing concepts for staff at all organisational levels.
- Notions of healthy lifestyle are injected in all programs for people with disabilities across the life course to ensure people with disabilities; staff and carers have a strong knowledge and commitment to this notion.

Demonstration Projects

- The development of demonstration projects in different states is to further develop suggested key elements of service delivery and stimulate further debate and discussion on models of service delivery. Such projects would also model cooperation between sectors and foster the adoption of positive healthy ageing approach.

Such projects would consider:

- Packages of funding between different levels of government and policy sectors (e.g. between State and Commonwealth).
- Incentives for partnerships for agencies and the development of responses to changing needs over a lifetime.
- Recognition of the lead role of disability in regard to linkages with aged care, community leisure and health programs.
- Aged care/HACC "top up" to disability to avoid parallel services and reduce referral to nursing homes.
- Differentiation of the needs of older carers from those of older people with disabilities for whom they care whilst maintaining links between an individual and older parents in aged care.
- Role of brokers to manage the coordination between agencies.

Recommendation 2: Improved data bases to enable better prediction

- It is recommended that, The CSDA minimum data set collections and ABS disability surveys include questions regarding age of onset of the major disabling condition.
- States/ Territories and Commonwealth develop strategies to predict the number of people who will present for the first time at older age. Such strategies would reduce crisis responses currently occurring when for example, older carers suddenly discontinue care (e.g. due to ill health or death).

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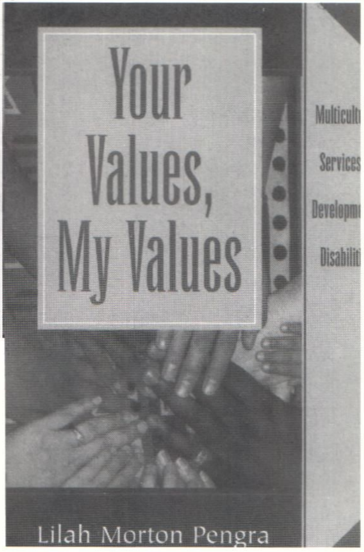
Interview with Dr Lilah Pengra



What Dr Lilah Pengra calls Big-V values – concepts such as normalisation and inclusion – have had, and continue to have, enormous impacts on how disability services are designed, run and delivered. There is often debate, as there should be, about whether the concepts and/or their effects are the best we could have and those debates will hopefully continue to rage for the foreseeable future.

At the same time it is very important to 'think outside the square'. There is a danger that we become so caught up in debates about whether, for example, normalisation has worked or not, we don't see there are many other ways of addressing the issues that concern us.

Dr Pengra is an anthropologist who is well able to think outside the usual parameters of disability services. She doesn't talk about Big-V values, except in passing; her concerns are with the small values that shape individual lives – and hopes, aspirations, and ways of going about everything from selecting furniture to whether or not to attend a funeral.

I was lucky enough to spend a day with Lilah Pengra when she in Australia recently. At the end of it I thought she might never come back – in my enthusiasm to show off our beautiful coast-line I took her down a track that a mountain goat would consider impossible (it was fabulous when we reached the ocean, wild seas, rock pools and nobody else game enough to be anywhere near the surrounded-by-waves ledge we adopted). Lilah agreed to answer a few questions for IDA – and she is coming back in November! (must have been the Tasmanian camembert we had for lunch).

IDA: Your book, Your Values, My Values, and the workshops you have recently given in Brisbane, Sydney and Wollongong have already made a real impact in Australia. The idea of considering 'small v' values - personal and cultural values - rather than relying on 'big V' or all encompassing values such as normalisation seems to have struck a real chord with people in the field of intellectual disability. Could you give IDA readers an impression of how you came to make these distinctions and why you see they are so important?

Lilah: I was hired to be the director of a small agency providing residential and vocational supports to 14 adults, seven of whom were Lakota. I knew nothing about services for people with intellectual disability but had worked with Lakota people in several other settings. I wish I could say that I thought about the theory of normalisation and moved beyond it. The truth, however, is less elegant. The agency was in the process of losing its license because of poor services. I was simply trying to improve conditions as rapidly as I could and thus used strategies familiar to me from my previous experiences in human services and my training in anthropology. When I finally had time to read Wolfensberger's work, I was pleased to see that he had originally (and repeatedly throughout the years) cautioned that normalisation had to be considered in the context of the cultural background of the person receiving services. Practice, however, fell far short of this dictum. I suspect that was the case because so few people in the field of intellectual disability have training in anthropology.

IDA: True. Anthropology is not a discipline or profession usually associated with intellectual disability. Can you tell us a little more about what it is in the 'anthropological way of thinking' that adds a new dimension to current approaches?

Lilah: Although it is not currently quite as pronounced, historically the contrast between psychology and anthropology is that the former used quantitative methods to look for the causes of behaviour and the latter used qualitative methods to ask people the reasons for their behaviour. The behaviourist approach from psychology has added much to our repertoire of strategies to help people cope with challenging situations and to change potentially mal-adaptive responses. However, when behaviourist approaches are used exclusively, we risk accepting an unexamined, and in my opinion mistaken, assumption that people are incapable of making values-based decisions about their behaviour. The cognitive approach from anthropology ensures this dimension, particularly when service provider and receiver have different values. In other words, the service provider can not determine just by observing a person's behaviour what it means to that person. It's like trying to learn a foreign language by listening to it without having access to a dictionary. Understanding the values that give meaning to behaviour, through discussing values with family

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Queensland

With the two Sharing the Road conferences now behind us (Brisbane and Cairns), we are now looking ahead to our State conference and AGM in September. Sharing the Road was again a resounding success, with about 512 registrations for Brisbane and 180 for Cairns. One of the reasons that the conference is so successful here is the quality of the speakers that we are able to attract and this year was certainly no different. In Brisbane, Ruth Cromer provided the opening Keynote and addressed a very appreciative audience indeed (she received a standing ovation) - and things just got better from there, with a wide range of speakers providing personal and professional accounts of supporting people with a wide range of disabilities and being supported themselves. In Cairns, Mike Letch of the Yooralla Society of Victoria got some lively (and at times uncomfortable, I suspect) discussion happening around supporting people with disabilities to have an active sex life and Anne Cross talked about what it actually means to support people to "Be themselves" on a daily basis. Nick Lennox and Niki Edwards from the Developmental Disability Unit also ran one day workshops at both conferences on issues in supporting people with a dual diagnosis.

And then there was Lilah Pengra! Lilah ran two one-day workshops at the Brisbane conference on providing peson-centred, values-based services to people with developmental disabilities. The response from all participants was overwhelmingly enthusiastic, so much so that we are investigating the possibility of having her come back in November to provide a regional workshop and follow up workshops for those who attended at the conference.

Certainly there will be no lack of attendees at Brisbane and we are looking for partners within Qld and interstate to host further workshops at that time. If you are interested in having Lilah conduct a workshop in your area, please contact

Chris Montgomery on (07) 3404 3086 or at

cmontgom@disability.qld.gov.au for further information.

Tasmania

The big news is the upcoming conference, of course. Developing and Enriching Communities is a theme that certainly encourages considerable discussion and it is hoped that the conference will be a way of sharing information and also provide an opportunity to develop innovative ideas for further research and practice. ASSID-Tasmania is working overtime to provide an event that all participants will remember for a long time into the future – so, please put this date in your diary now! (see page 3 for further details)

ASSID 37TH NATIONAL CONFERENCE

Theme: Developing and Enriching Communities
Venue: Wrest Point Casino, HOBART
Inquiries: Mike Annand
Convention Wise
Mures Building, Victoria Dock
Hobart TAS 7000
Tel. +61 3 6234 1424
Fax +61 3 6231 5388
Email mail@conventionwise.com.au

Despite the concentration on the conference, on the 26th July ASSID – TAS auspiced two highly successful interactive workshops for carers. Dr Chris Bigby flew in from Melbourne to facilitate the workshops and provided some evidence based research on the needs and expectations of carers. The workshop was co-facilitated by David Wareing, Occupational Therapist and Masters student, with Val Baxter, Social Worker, both of whom work in the Resource Team at Disability Services, Tasmania.

The morning program offered paid carers the opportunity to understand current research concerning the changing nature of care for adults with intellectual disability who have lived at home, and the adaptations which clients and staff undergo so as to achieve a positive transition into formal care.

The afternoon program commenced with a reprise of Chris Bigby's research, co-facilitated by Connie Bruckard from the Carer's Respite Centre and Lena Mitchell, head of the Service Co-Ordination Team at Disability Services.

The workshop was designed to enable family carers to synthesise the evidence of social networks, and discuss creative solutions to future care. The workshop was particularly useful as it enabled all participants to think positively and develop relationships with each other in a non confrontational manner.

Wendy Wolf

wendy.wolf@dhhs.tas.gov.au

South Australia

In SA we recently held a successful event " Genetics and Intellectual Disability - Recent Findings and their Implications". Dr Jozef Gecz discussed his research, illustrating how much was known and the extent of that which has yet to be discovered. He managed to convey his commitment and passion along with the sense of excitement he felt in being part of this particular research frontier. Associate Professor Eric Haan, with 'an eye on the horizon' gave a summary of some of the implications of this research. Professor Haan introduced the concept of proteomics - the science of determining precisely how the genome acts in terms of the proteins it its coding generates. There was discussion as to how such mechanisms may be utilised therapeutically. Professor Haan also discussed the identification of risk factors for particular health conditions to enable health practitioners to provide pertinent information to people at risk, (consider, for example, coronary heart disease, diabetes, breast cancer or PKU). Implications in terms of public health policy were discussed. ASSID, SA feels it is useful to be kept informed of such developments, to enable us to engage in informed debate.

Other 'irons in the fire' include ongoing work on producing a publication of transcripts of two key presentations by Professor Roy Brown. Although we have not been able to organise the proposed cosponsored event with the Australian Association of Cognitive Behavioural Therapy we are still working on the notion of a conference with the focus on innovative practice, were we might co-opt members of the AACBT to present (ie rather than getting practitioners who work with people with an intellectual disability to talk about applying CBT, lets get practitioners who work with CBT along to discuss how they can work with people with an intellectual disability).

We continue to pursue a dinner with a particular 'influential decision maker' who at this stage remains elusive. We are anticipating holding an event at the end of October with a panel of speakers, looking at the last 20 years in disability in SA and considering the next 20 years. The AGM will be held in conjunction with this event, with the option of going on for drinks and a meal afterwards. We are awaiting confirmation from our last speaker before disseminating information about the AGM and event in timely fashion. See you there.

Richard O'Loughlin for the SA branch
rolstmarys@esc.net.au

Western Australia

WA's next big event is a one-day seminar on 20th September on "Individualised funding and service brokerage-an international perspective".

Speakers will be Steve Dowson of Emprise International (UK) and Brian Salisbury of Kwantlen University, British Columbia. The seminar aims to provide participants with a comprehensive account of the main principles and components of the Individualised Funding model and current developments in that area. The Annual General Meeting will be held at the conclusion of the seminar."

WA continue to be active and energetic - but encourages new members to become involved to keep that activity level going!

Janine Smith
National Councillor
janinesm@dsc.wa.gov.au

Victoria

The time is drawing near and preparations are well underway for one of the main features for Victorian ASSID this year...the Direct Support Worker CONFERENCE in November.

Since our last update we have also significantly progressed with ideas and plans for furthering the development of a NETWORK of Disability Direct Support Workers (DSW). However, the main shape of this group has yet to be formed and will be created by participants of the DSW Conference.

Other recent news is that the DSW AWARDS will again be hosted at the evening event of the DSW Conference. The DSWA are a combined initiative of ACROD Victorian Division, Council of Intellectual Disability Agencies (Vic) Inc., VICRAID and the Department of Human Services, Disability Services. The Awards are presented to DSW who have been nominated by service users, peers, management or anyone who thinks they excel in providing services to people with a disability.

More immediately the State Conference, titled "The road ahead: challenges in our time", will be held in Melbourne on August 28, 2002. Soon after the State Conference is the Annual General Meeting that we are holding again in the studio of Arts Project Australia on October 3, 2002. Later in October we will be conducting another Research Seminar that the Department of Human Services Victoria has agreed to host. All in all, we certainly have enough to keep us out of mischief for the rest of the year.

Until next time,

Alex Phillips
Email: Alex.Phillips@med.monash.edu.au

State Updates continued page 10

NSW state update

The biggest event to report for this edition of IDA was the State Conference entitled "Making A Difference", held on 5th & 6th July at the University of Wollongong. Trevor Parmenter presented the Opening Address, with key note addresses from Tony Shaddock and Bob Davis. We had two very full days with papers covering issues relating to:

- **Health –** HIV; respite care; health care access; collaboration for grief; Antacids; deafness, Implanon.
- **Education –** training support workers; inclusion of disabilities in curriculums; support for people with disabilities at TAFE; Multi-sensory environments and education; The Autism Association; Sports Ready Program.
- **Participation –** A Living Skills certificate for people with disabilities; New Standards for people with disabilities concerning issues they have with their accommodation service; assisting people with disabilities to make friends.

Discussion Forum

continued from page 5

Since Anthony sent out this letter there has been some discussion along the lines he has suggested – but not enough! To achieve an excellence of 'service' and knowledge within the 'field' of intellectual disability, it is essential that ASSID-L continues to do what it already does – which is send out references and notifications and questions and answers. But ASSID-L can be better than that, it can offer an opportunity for us all to engage in informed analysis and opinion on the 'importance' or application or relevance of some of this enormous load of information that we have. So, get out those keyboards one and all, and start talking!

Want to take the opportunity for discussion?

To subscribe to ASSID-L, 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.

Win a prize now!

Write your own name on the top of the application for membership (enclosed), have a friend or colleague or organisation fill in the details to join ASSID and send to the address on the form by November 10th.

- **Employment –** Competency based wages system; Illawarra Workwise – a series of modules that increase the level of expectations of young people within their workplace; Changing the concept of participation income; Work to Retirement – Case Study.

There were also strands related to Self Determination, Behaviour Management and Case Based Funding.

After lunch on the Friday we held a Panel Discussion asking "Are we making a difference?" and a table of responses was drawn up from this. See more details on page 18. We felt that this could offer ASSID (NSW) some guidance for the future, the directions that we take and particularly within our seminars and conferences.

I would like to thank Isla, John, Lynn and Sian, a particular thanks for James Cook from Wollongong University who was involved in the organisational tasks. Also a big thank you to the Greenacres Drama Group who gave a great performance of songs from the musical hit Grease. It was a successful conference with plenty of positive feedback during and following the conference.

Regards **Linda Goddard**
State President
lgoddard@csu.edu.au

Day Options for Older Adults with a Disability: An Overview

continued from page 8

- Further investigations occur in examining and planning the different pattern of access and need for day support services for different disability groups

Recommendation 3: Role of Aged Care

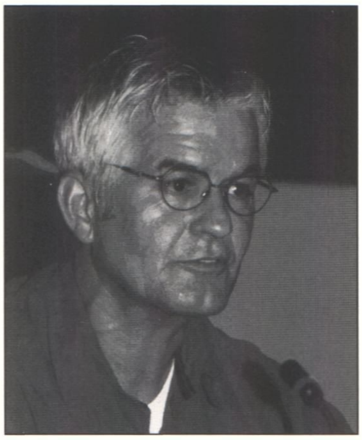
- It is recommended that the Aged Care system should take a lead role in ensuring that services for the frail aged are accessible and responsive for older people with disabilities who have additional age related disabilities and frailty.
- Professionals within the Aged Care system should have basic training in current values, attitudes and strategies for providing support to and communicating with older people with disabilities.
- Public education and positive aging publicity should include older people with disabilities in order to promote strong positive role models of aging for this group and the wider community.

Copies of the full report and a literature review are available on request from the Disability Division of DHS Victoria, (chris.allen@dhs.vic.gov.au, tel: (03) 9616 8367, or a short version of the report can be downloaded from the DHS website: www.dhs.vic.gov.au

What's going on, Health:
Report from the Netherlands

A year ago IDA published articles by Assoc. Prof Nick Lennox of the Developmental Disability Unit at the University of Queensland and by Dr Robert Davis and Ms Jenny Morrison of the Centre for Developmental Disability Health, Victoria (IDA, Vol. 22 #3). Both articles raised serious concerns about the efficacy of the current practice of treating the health needs of people with intellectual disability under generic health services, particularly given that most General Practitioners usually have very little training and support in the specific needs of people with disability. Both the Developmental Disability Unit at the University of Queensland and The Centre for Developmental Disability Health, Victoria as well as the Centre for Developmental Disability Studies in NSW are working hard to provide education and development for medical practitioners as one of the means of improving the health and well being of people with intellectual disability. All three centres acknowledge the imperative for an Australia-wide strategy in health care for people with intellectual disability.

The problems that both Nick Lennox and Bob Davis addressed are not unique to Australia. The following article is an edited version of the paper presented by Frans Scholte at the IASSID conference in Seattle in 2000. Dr Scholte is president of the Dutch Association of Physicians for persons with Intellectual Disability and, like his Australian colleagues has, during his many years experience, promoted the importance of having specialised training available for medical practitioners who provide health care for people with intellectual disability.



Frans Scholte was born in 1948 and studied medicine at the Groningen University. He started to work as a physician (general practitioner) in an institute for persons with intellectual disability in 1975 and continues to work to this day as a physician for just this group of patients.

In 1991 Frans (co-)authored two case reports, published in Journal of Medical Genetics.1,2. Both of the articles led to the recognition of a new syndrome (OMIM 181515 Scholte syndrome, OMIM 212710 Cataract-ataxia-deafness-retardation syndrome). He is president of the Dutch Association of Physicians for persons with Intellectual Disability.

Presentation at the IASSID Congress 2000 in Seattle
(edited by IDA)

Frans A. Scholte, AVG,president of the Dutch Association of Physicians for Persons with intellectual disabilities (NVAZ).

Introduction

This year a three-year training course will start for physicians wanting to work with people with intellectual disabilities. This may sound remarkable, and perhaps even paradoxical in a time which is characterised bynormalization, integration, and community support.

Why, then, do we need this specialized training course?

Medical education

First I must tell you something about the history of academic medical education. Until the 1970's, in the Netherlands, all medical students followed the same medical studies which took seven years. After that period one could either start working as a general practitioner, or enter a specialization programme. So in those days the general practitioner was not a specialist. Institutions for Intellectual Disability people employed their own doctors, and they were general practitioners.

In the early nineteen-seventies however, a more specialized education for general practitioners was implemented. At first the specialization took one year, and nowadays it takes three years. However, a special training course for practitioners for Intellectual Disability-patients did not exist.

Professionalization

More important are the results of practical experiences and research. Since the early nineteen-seventies doctors working in the institutions began to exchange their experiences and practical knowledge. They started writing articles in their own magazine. In the years that followed more and more research was done. This resulted in the first protocols. Also, the first physicians for Intellectual Disability people took their doctor's degree.

This process of professionalization was very much stimulated by the foundation of the Dutch Association of Practitioners for Persons with Intellectual Disabilities (NVAZ) in 1981.

There was a growing awareness that people with

Continued on page 14

Intellectual Disability can have specific problems related to their mental handicap. This awareness was based on practical experience and research. General practitioners who have only a few people with Intellectual Disability as their patients, cannot be expected to have knowledge and experience of all these specific problems. In the past decades practitioners in institutions for Intellectual Disability people did gain such specific knowledge. The NVAZ insisted that such knowledge should not disappear as a consequence of de-institutionalisation of people with Intellectual Disability. In some countries this has already happened.

Education of practitioners for persons with Intellectual Disability

The three year training course for practitioners for persons with Intellectual Disability consists, like all specializations, of a practical part and an academic part: four days a week of practical work, and the fifth day spend at university.

During the first year, the future practitioner for Intellectual Disability works for four days a week in a care centre for people with Intellectual Disability. The second year is for extern work experience: four three-months-periods in, for example, genetics, psychiatry, neurology, orthopaedy and motorial revalidation.

In the third year the future practitioner is still concerned with care for and support of persons with Intellectual Disability, but now rather as a consultant for persons who are not living in an institution. Part of this third year is also spent on a research-assignment.

Specific problems

What are these specific problems?

First we should realise that the larger part (some 75%) of the whole group of persons with Intellectual Disability does not have any specific medical problems at all. In the Netherlands, such people may either live at home with their parents, or they may live by themselves with a certain measure of support, or they live in a community home. Most of their problems can be dealt with by a general practitioner.

About 25 % of the whole group of Intellectual Disability persons however, are living in an institution. They are moderately, severely or profoundly handicapped and often have more than one handicap. Additional handicaps can be spastic paresis, epilepsy, orthopaedic problems, visual or auditory impairments, behavioural problems, psychiatric diseases and gastric-oesophageal-reflux disease (GORZ). The combination of a mental handicap and autism is a well known cause of serious behavioural problems.

Very often, somatic and psychological problems are associated with certain syndromes. The best known example is of course Down syndrome. But most syndromes have their own associated morbidity.

Thus, not only for the cause of genetic counselling, but also for better understanding and support during life, it is very important to know the etiologic diagnosis.

Severely and profoundly mentally handicapped persons are often difficult to examine and their reactions may be difficult to understand. They have few capacities to express themselves. Behavioural changes can have many causes, including medical ones. In these cases, careful observation and examination are required. Medical care for people with Intellectual Disability requires a certain attitude, requires time for examination but also for discussions with parents and care-givers; as well as time to consult with psychologists and paramedical therapists.

What is happening in The Netherlands?

Yes, also in The Netherlands Intellectual Disability people are leaving the institutions to go and live in community settings. Consequently they will use community facilities, including the care of a general practitioner. However, there are also specialists available to support them with their specific problems. One of these specialists is the physician for persons with Intellectual Disability. S/he is available as a consultant for general practitioners, and other specialists. And s/he has patients of their own.

It is expected that the physicians for people with Intellectual Disability will be organised regionally, joining forces with psychological and paramedical therapists. Increasingly, also, research will be stimulated as a result of the appointment of our first professor in medical care for persons with Intellectual Disability at the Erasmus University in Rotterdam, Dr. Heleen Evenhuis.

Finally, we are sure that these developments will contribute to the improvement of the quality of life for persons with intellectual disabilities.

Update, 2002: A major problem for this moment and for the years to come is an increasing lack of both general practitioners and specialist practitioners (AVGs).

Frans A. Scholte, AVG
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f.scholte@wxs.nl

Further Reading:

Scholte FA, Begeer JH, Van Essen AJ: Unknown syndrome: mental retardation with dysmorphic features, early balding, patella luxations, acromicria and hypogonadism. J.Med.Genet.28: 140-142, 1991 (PubMed Intellectual Disability: 2002488)

Begeer JH, Scholte FA, Van Essen AJ: two sisters with mental retardation, cataract, progressive hearing loss and polyneuropathy. J.Med.Genet. 28: 884-885, 1991 (PubMed Intellectual Disability: 16611780)

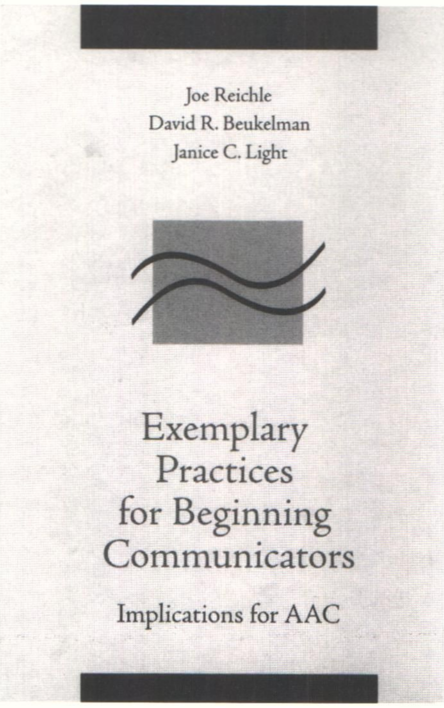
Must Reads:

Exemplary Practices for Beginning Communicators: Implications for AAC

Joe Reichle, David Beukelman and Janice Light eds, Paul Brookes, Maryland, 2002

Available in Australia from
MacLennan and Petty,
Suite 405, 152 Bunnerong Rd,
Eastgardens, 2036
Phone: 02 9349 5811,
Fax: 02 9349 5911,
email: macpetty@zip.com.au

Reviewed by Ann Penhallurick, Speech Pathologist and Psychologist.



Joe Reichle
David R. Beukelman
Janice C. Light

Exemplary Practices for Beginning Communicators

Implications for AAC

This 490 page volume, the second in the Augmentative and Alternative Communication Series, represents the most recent developments in both research and practice in the field of AAC - which although it is often thought of as 'symbol communication' incorporates a wide variety of modes, including graphic, auditory and gestural communications. The book is timely and important - too many children and adults with intellectual disability (and/or physical and sensory impairments) are 'given' augmentative communication systems with little consideration of the potential for that particular system to be useful for the particular person, or of the potential for the system to be effectively 'trained' and used in the multiple environments that a person interacts in.

This volume, each section written by an author or authors with considerable expertise in the specific area they address, has chapters detailing essential pre-requisites to AAC: Bonnie Utley writes on 'Visual Assessment Considerations for the Design of AAC Systems' and Krista Wilkinson and James Halle on 'Considerations in Teaching Graphic Symbols to beginning Communicators'. Reflecting also that there is more to AAC than getting simple needs met Janice Light, Arielle Parsons and Kathryn Drager provide an excellent chapter on developing communication: 'There's More to Life than Cookies: Developing Interactions for Social Closeness with Beginning Communicators Who Use AAC'.

Siegel and Cress's early chapter 'Overview of the Emergence of Early AAC Behaviours: Progression from Communicative to Symbolic Skills' is particularly well written and is accessible even for the lay reader. It provides a good overview of communicative functions, intentionality, the role of communication partners and the importance of dynamic assessment. This latter does more than take static measurements of an individual's present skills, instead comparing independent skills with those demonstrated when partner support's available. Importantly, as the authors argue, dynamic assessment 'provides information about a person's rate of learning, which can help decisions such as how quickly to introduce new communicative forms or new tasks...'(p48).

My concerns with the book are that it is often too dense - the final chapter, for example, 'The Role of Language Comprehension in Establishing Early Augmented Conversations (Rose Sevcik and Ann Romski) is essential reading but hard to 'get at'. Romski and Sevcik are established researchers and writers in the field of AAC but, in this piece in particular, what they have to say is only really accessible to the already initiated, those who already have a high level of familiarity with the technical terms and concepts in the chapter. Presumably this reflects the book's target audience as being speech-language pathologists, psychologists and special educators with a specific interest in AAC - but to me it seems a great pity that either the original brief or the editing did not allow for a more lay-reader friendly approach. AAC stands or falls in the efficacy of day to day implementation - and this is rarely the province of the specialist.

Also, as a speech-language clinician of many years experience, I would have liked the book to be organised differently. The sections on pre-requisite considerations come in the second half of the book and the chapter on the role of language comprehension comes at the very end -in practical application these are the aspects of AAC that need to be considered first and should not be placed in such a way that they can be seen as addenda. Each chapter in this book more or less stands alone but the knowledge gained from reading the whole book is essential for truly effective development of AAC.In all,

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members, reading about the person's cultural background, and using various values-based assessment tools, is the "dictionary" for understanding behaviour in a more complex way.

IDA: Much of your work has been with the Lakota: how 'translatable' do you think this is to the Australian context?

Lilah: First, working with any culture that is different from one's own gives one a feel for the method and problems involved in a cognitive approach. The "how to" translates to the Australian context quite easily even when the content of specific values differs. For example, beliefs and values associated with social classes are somewhat different between Australia and America. However, methods of discovering values associated with different classes (or religions, geographic locations, genders, sexual orientations, lifestyles, etc.) are the same as well as the importance of understanding those differences when providing support services. Second, saying that there are differences between cultures does not mean that the values of those two cultures are mutually exclusive. There are patterns, themes, and regularities when a large sample of cultures is studied. There are, if you will, "clumps" of values that are consistently found together. For example, Lakota and ATSI peoples share some values as do the working classes of America and Australia even when other of their values differ.

IDA: That's why the description in your book about the differences between present-oriented and future-oriented people rang a bell. I am future oriented and know people who are present oriented. The understanding that as context and circumstances change decisions might need to be changed and that these could be valid reasons for cancelling a bus or organising a totally different day from the one originally planned seems radical but very important. Should we incorporate both orientations into services for people with intellectual disability?

Lilah: The point of values-based services is to identify differences in order to teach skills and provide supports without challenging values. In my experience, many Lakota, not just Lakota with intellectual disability, are criticised for being impulsive when they are making decisions from a now-oriented point of view. When the cluster of values associated with a now-orientation are identified (person and relationship rather than task and time orientation, group rather than individual focus, adaptation to rather than transformation of the social and physical environment, and multi-tasking) then the implied criticism of requiring a now-oriented person to act in a future-oriented manner can be precluded by offering appropriate services. Because we work with people, not with cultures, and because they might have been exposed to and learned from many different cultures, some of which are now-oriented, others future-oriented, and some combining aspects of both orientations, we must be very careful not to attribute unfamiliar behaviour to a supposed intellectual deficit. That is a round-about way of answering your question! I think all human services, not just services for people with a label of intellectual disability, should incorporate a range of values because we are living in a multicultural world. We can learn from each other as well as learn to work together even when we have opposing values.

IDA*:* That leads me back to our starting point. Your book is about 'small v' values rather than 'big V' values. Does this approach conflict with or move beyond social role valourisation?

Lilah*:* Wolfensberger recommended a "two-pronged approach" -- to normalise people's lives and change social attitudes toward them. The first "prong" clearly has had a comprehensive impact on services. The second "prong" has not been as successful. Many people now have a better quality of life but most of the rest of society still see them as first and foremost a person with an intellectual disability, with all the attendant devaluation and marginalisation that label continues to carry. If attitudes were based on what people with intellectual disability actually do, the roles they play, and the successes they achieve, then those negative judgments should be changing. But they are not. The "trait" of "intelligence" is seen in western, industrialised, class-based societies as one of the reasons why some people get ahead and others do not. Although upward mobility is largely a myth, the idea of it keeps us on the merry-go-round, reaching for the gold ring, and relegates people with the label of intellectual disability to the waiting line, hoping for a turn that will never come. It is time, I think, to learn from the American civil rights movement of the 60s ("Black is beautiful") and the women's movement of the 70s ("I am woman"). We need to provide the supports that will assist people to say "I am who I am and I reject your right to judge me. I have my own values." Perhaps in Oz it might be called the Ned Kelly theory of advocacy!

Opportunity to host workshops with Dr Lilah Pengra:

After a recent very successful 'tour' of south-east Qld and coastal NSW, Dr Lilah Pengra, author of *Your Values, My Values: Multicultural Services in Developmental Disability* (reviewed in IDA March 2002) will return to Australia for most of November. Some dates are still available for your organisation to host a workshop with Dr Pengra. Contact Chris Montgomery at cmontgom@disability.qld.gov.au, phone 07 3813 3304 for more info as soon as possible!

Call for ASSID Distinguished Service Citations 2002

Each year, at the National Conference (this year Hobart, November 13-16th) members of ASSID who have given 'above and beyond the call of duty' are recognised with a Distinguished Service Citation. This hardy group of volunteers need not necessarily be state or national council members but they are all people who have made a significant contribution to making ASSID an effective organisation.

Nominations for ASSID Distinguished Service Citations for 2002 are invited for consideration / ratification by National Council and presentation at the Hobart National Conference, in accordance with ASSID National Council By-law 9.2.

Nominations, from State Associations, are to be forwarded by Friday 25th October to The Secretary, e-mail: kmcvilly@med.usyd.edu.au; or post: PO Box 3241; PUTNEY, NSW, 2112.

Nominations, from State Associations, are to be accompanied by a short profile detailing the person's involvement in and contribution to ASSID.

You can discuss you ideas and suggestions with members of your state executive. If you don't have their contact details, you can contact:

The National Office Manager, **Helen Moore**
for contact details- tel: 1800 644 741 or
e-mail: hmoore@med.usyd.edu.au.

Celebration of Ability

With the 3rd of December just around the corner, preparations for the International Day of People with a DisAbility are heating up. Across Australia, people from a variety of organisations are working hard to make their event bigger and better than ever before.

For those of you who don't know about the International Day, the aim is to raise community awareness about disability issues - and it's a fantastic excuse for a celebration!

Celebrate

International Day of People with a DisAbility

3 December 2002

The International Day foundations can be traced back to October 1992, when the United Nations declared 3 December the International Day of Disabled Persons. Five years later, Australian community representatives renamed the event the International Day of People with a DisAbility to emphasise the abilities of people with disabilities, a theme that is further articulated in the catch phrase Celebration of Ability.

Australians mark the day with a wide range of events, both large and small, in the country and the city. It is a day that encourages people in the community to unite in a celebration of diversity, a Celebration of Ability. So let's make this year the best ever!

For information on how you can join in, contact NICAN on 1800 806 769 or visit the website www.nican.com.au

Are we making a difference?

At the July NSW State ASSID conference a panel, convened by Linda Goddard and including Helen Beange, Mary Ellen Burke, Helen Malony, Cath Mullane, Trevor Parmenter, Chris Peters, Neil Preston, and Tony Tinlin, addressed, with the aid of the energetic audience, the question of whether or not we are making a difference. The following summation of responses highlights both some positives and negatives and offers suggestions regarding how we can do it better in the future.

Are we making a difference?	**Can we do it better?**
YES - employment, via training we are moving towards people reaching their potential.	Need to work with consumers to find out if they think that we are making a difference, what do they want?
YES Major changes since the 50's,families & teachers working together. People with disabilities are 'allowed' to form relationships, live together, and more.	Build upon what it is that people want, ask them what they want.
YES Greater appreciation of health issues	WE can always do it better, dual diagnosis requires a collaborative approach.
YES, ASSID has made a difference.	Education for ALL health professionals.
YES The establishment of community health support systems in the 70's, move from large centres to the community.	Still 2000 people living in institutions, how do we help people move to the community.
YES BUT worry about the equitable distribution of resources.	Promote equitable distribution of resources.
NOT FOR ALL People with mild intellectual disability missing out, government not taking responsibility, yet they are the largest group.	Consultation, research, lobbying. Listen to the voices of people. Are the needs increasing as they get older? How many people with mild Intellectual Disability live in prisons, on the streets etc.
YES People are living in their own homes, making own decisions, being assertive.	How many people do in fact feel empowered to make their own decisions?
YES Major changes in the schools, from paternalistic approach to an educational one, all children can learn, right to learn, LRE. Example of best practice.	Hear more about best practices, use as role models. Need to move from continuums to looking at cycles.
YES BUT but some group homes are as bad as institutions are sometimes made out to be.	There is good and bad in all things, promote best practice, raise the standards, utilise resources.
NEGATIVE: Anti-professional approach to service provision. Anti-specialisation. Deprofessionalisation of services.	Major organisations need to facilitate a professional approach Promote & respect specialisation, informed decision making.
YES BUT Still have a huge amount of unmet need.	What are we going to do about it?

- Linda Goddard, for ASSID NSW

Resources:

Ausrapid newsletter is available:

Ausrapid is an organisation for athletes with a disability. If you would like to know more about this group, contact them at their new address:

Ausrapid
63 carrier St, Benalla Vic, 3672, phone: 03 5762 7494 fax 03 5762 3560 email: ausrapid@ozemail.com.au

Video and print resources.

The Western Sydney Intellectual Disability Support Group is an extremely active group of parents, family members and advocates. They produce and/or distribute a number of resources as well as hold regular meetings, put out a newsletter and have regular special events. Resources include:

When I'm Gone.

An introduction to wills and estate planning for parents of people with an intellectual disability. By Stephen Booth for the Intellectual Disability Rights Service.

If Those Walls Could Talk.

This is a video documenting the impressions and memories of people with an intellectual disability and their families associated with a large institution.

Other publications include: *Money Matters, Why Move?* and *Policies for People.*

Contact WISDSG for details and prices (some are free!) on 02 9334 0573, fax 02 9334 0578 or PO Box 249 Ermington, 1700

NCPAD - the NATIONAL CENTER on PHYSICAL ACTIVITY and DISABILITY

A monthly publication available. Not a subscriber? Sign up for this free monthly electronic newsletter by sending an e-mail to: Listserv@listserv.uic.edu with this message in the body of the e-mail:

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Book Review

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however, this book is essential reading for all speech pathologists, special educators, psychologists and other professionals working with people with intellectual disability (whether or not they currently make much use of AAC). Government departments and NGOs would be wise to encourage their staff to read the entire volume – without the information that is available here, valuable resources will be wasted designing 'communication programs' which do not suit the needs of the person supposed to use them. Similarly *Exemplary Practices for Beginning Communicators: Implications for AAC* should be available in university libraries and should be on appropriate reading lists as soon as possible.

Information exchange

Call for Papers

Special Issue of AJMR on Aging and Developmental Disabilities

Guest Editors

Tamar Heller, Ph.D., University of Illinois at Chicago, Marsha Mailick Seltzer, Ph.D., University of Wisconsin, Madison, Marty Wyngaarden Krauss, Ph.D., Brandeis University

Type of Papers in the Special Issue

Submissions will concern research on aging and intellectual and developmental disabilities including: a) reports of empirical quantitative and qualitative research, and b) research reviews and critiques.

Topics could include age-related changes, demographic trends, family caregiving, environmental accommodations, public policies, and programmatic interventions.

Submission Information

All submissions should be sent in electronic format, as an attachment, to the AJMR editor, William MacLean, Jr., Ph.D. by e-mail, maclean@uwyo.edu. The deadline for submissions is January 15, 2003. The issue will be published in November 2003. All submissions are subject to peer review.

Please refer to the "Information for Authors" section of a recent American Journal of Mental Retardation (AJMR) for further information on the format of submissions. AJMR uses APA format for references and manuscript preparation.

Preliminary Inquiries

If you plan to submit a manuscript for consideration, please send a note of intent to Dr. Tamar Heller at theller@uic.edu stating the working title and the general content. Notes of intent should be sent prior to November 1, 2002.

Down Syndrome Association of NSW

Families' Weekend Conference

11th - 13th October 2002

Professional s welcome to attend information day, Saturday 12th October.

Ph. 02 9683 4333
http://members.iinet.net.au/~dsansw/FamConf.html

ASSID 37TH NATIONAL CONFERENCE

13th - 16th November, 2002

Developing and Enriching Communities
Wrest Point Casino, HOBART
Inquiries: Mike Annand, Convention Wise
Tel: +61 3 6234 1424 Fax: +61 3 6231 5388
Email: mail@conventionwise.com.au

Developing & Enriching Communities aims to bring together a wide spectrum of approaches to meeting the needs of people with intellectual disabilities and to explore the differences and similarities of these models in constructive ways. This conference is about helping each other in an environment where it is becoming increasingly difficult to find new direction to ease the burden and ensure the provision of a range of community support. The programme promises to be stimulating and topical with Australian and international keynote speakers and a variety of workshops, symposia, discussion groups and presentations.

Conferences are also about meeting people and the planned social activities will provide opportunities for enjoyable interaction along with a large slice of Hobart hospitality. Delegates will have an opportunity to visit Tasmania's Government House, one of Australia's most beautiful vice-regal residences, dance the night away at the Conference Dinner and explore the renowned, bustling Salamanca Market on Saturday morning

Accompanying partners and families will be well catered for as the state offers a multitude of natural and cultural attractions. We imagine that a number of participants will be keen to explore the wilderness areas and Tasmania's historic past.

This is an opportunity for you to fulfil that long-held dream to explore Tassie and make that visit at this wonderful time of year – experience the waterways and wilderness, the highlands and heartlands, past and present while witnessing first hand resource developments that aim at maintaining the clean green image of our "Natural State".

CONFERENCE REGISTRATION FORM

TAX INVOICE

PERSONAL DETAILS

Title: ________ Surname: ____________________ Given Name: ____________________
Preferred name on lapel badge: ____________________
Organisation: ____________________
Business/Private Address: ____________________
____________________ Postcode: ________
Phone: ____________ Fax: ____________ Email: ____________

REGISTRATION

(tick the appropriate box) All costs are in Australian dollars and are GST inclusive

ASSID MEMBER	☐ Early Bird Full Registration (before 30th June)	$400.00 each		= $ ______
	☐ ASSID Student Full Registration (before 30th June)	$260.00 each		= $ ______
	☐ Full Registration (after 1st July)	$470.00 each		= $ ______
	☐ ASSID Student Full Registration (after 1st July)	$290.00 each		= $ ______
	☐ Day Registration ☐ Wed ☐ Thurs ☐ Fri ☐ Sat	$140.00 each	X ____	= $ ______
	☐ ASSID Student Day Registration ☐ Wed ☐ Thurs ☐ Fri ☐ Sat	$100.00 each	X ____	= $ ______
NON ASSID MEMBER	☐ Early Bird Full Registration (before 30th June)	$420.00 each		= $ ______
	☐ Full Registration (after 1st July)	$490.00 each		= $ ______
	☐ Day Registration ☐ Wed ☐ Thurs ☐ Fri ☐ Sat	$160.00 each	X ____	= $ ______
CONCESSIONS	Available to health care card holders. Proof is required to be provided with the registration form.			
	☐ Full Registration	$100.00 each		= $ ______
	☐ Day Registration ☐ Wed ☐ Thurs ☐ Fri ☐ Sat	$40.00 each	X ____	= $ ______
Conference Dinner Ticket		$75.00 each	X ____	= $ ______
(NB Morning, afternoon teas & lunch are included in the cost of full & day registration)			**TOTAL**	**$** ______

☐ **I wish to attend the Government House Reception** ☐ **Extra ticket** **Name:** ____________________

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