What's going on - conferences

Christine Bigby was one of a number of ASSID members who were able to attend the IASSID conference in Seattle at the beginning of August this year. IASSID conferences are held only every four years and the 2000 event was the last under 'our own' international president Trevor Parmenter. Chris reports for us on the conference, in particular on the strand on ageing which, as many of you would know, is Christine's special interest - resulting recently in the publication of her book 'Moving on Without Parents' (McLennan and Petty/Paul Brookes, 2000), launched at the IASSID conference. (Congratulations to Christine and our thanks for the report back, too.)

Report back IASSID

11th World Congress of the International Association for the Scientific Study of Intellectual Disability: An Ageing Experience.

Christine Bigby  Seattle August 1-6th

This was my first trip to the US and but my third to an IASSID World Congress, an event held every 4 years. I therefore had some idea of the scale of this conference but nothing could have prepared me for the complexity of the program nor the inordinate amount of time required just to work out who was speaking, about what, when and where.

I did manage to work out who the keynote speakers were but as to their credentials for this role and why they were selected these remain a mystery. For me, the only disappointing aspect of the whole conference was the excessive bias towards medical research in the keynote addresses. I did not expect to hear a medico talking about "my favourite syndrome" at a conference on intellectual disability at the beginning of the 21st century. I thought we had progressed beyond a medical model of disability. There were two keynote highlights. The first was Hans Reinders, a philosopher from Netherlands, who suggested that achievement of citizen is only a first step and will not necessarily lead to social inclusion for people with intellectual disability. The second was passionate address of Len Barton on exclusion which being scheduled at 8.45 on the last day was only heard by a few die-hards.

I spent most of my time at one or other of the two streams on ageing, which were superbly organised by Matt Janicki. These came complete with an easy to read ageing program, a dedicated space and a three course ageing dinner of salmon and other assorted seafood. Thus for me the conference was essentially about ageing, covering diverse topics including grief and loss, older carers, mortality, service adaptations, preparation for later life and issues of diagnosis. The standard of papers was consistently good with one or two that really stood out.

"Growing older: What do people with intellectual disabilities say?" was presented by David Thompson from the UK. After surveying 150 older people he suggests that many of their concerns are similar to those of younger people and we should take care not make people "old before their time". The paper presented by Hezilda Lifshitz, from Israel, on the implementation of a later life planning curriculum found zero scores on choice making for older people with intellectual disability. This is indicative of the life experiences of the current cohort who is ageing and the complexities in translating values into action. Another fascinating study was that presented by Mahon and Mactavish from Canada who undertook participatory action research with a small group of older people to identify critical elements in later life planning. These included, retirement, work, recreation, decision making, money, support, friends, health concerns and educational opportunities, all of which point to notions of active rather than passive ageing by this group.

The most interesting session, for those not completely steeped in ageing, was undoubtedly the presentation of the series of papers prepared by ageing special interest group in conjunction with the World Health Organisation, "Improving Longevity and Promoting Healthy Ageing". These are an important resource and can be downloaded from


The other important event was the presentation of the ageing special interest group's first research award to Matt Janicki for his outstanding contribution to the field of ageing and intellectual disability. As Davidson remarked, although Matt's career has been as a policy worker, he has a publication record that would make any longstanding academic envious.

Two new books on ageing, both published by Brookes that were launched at conference. 'Community support for seniors with lifelong disabilities' is a substantial volume edited by Matt Janicki and Ed Ansello, detailing the

continued next page
Where do ASSID members work?

Tasmanian ASSID is a very active, energetic and enthusiastic branch, one which ‘mainlanders’ might well emulate (their activity list is sometimes almost frightening - the ed). One of the members of that group is Virginia Downton, who co-ordinates BlueLine Employment in Hobart.

BlueLine - an Open Employment Service

BlueLine Employment is a service which negotiates open employment for people with disabilities - and it is showing some pretty impressive successes. Recently work has been gained for individuals in work places as diverse as the Display Department of the Tasmanian Museum, a local Spanish restaurant and Jackson’s Security. Employment that has been taken on by the consumers of BlueLine Employment include jobs as a support worker, gardener’s offsider and a clerk.

Virginia Downton has been an active participant on ASSID-L in recent months and also contributed to the Tasmanian ASSID State Conference held a few weeks ago. At this conference she presented a paper entitled ‘Maximising Opportunities Through Open Employment’ which summarised some of her thoughts and experiences as co-ordinator of BlueLine. In this paper Virginia focussed on the importance of networking, co-ordination and accredited training as integral to maximising opportunities in both supported and open employment. Of open employment she says:

‘While open employment may not be appropriate or accessible to all, it does offer the opportunity to maximise integration into the broader community through the workplace.’

‘People with disabilities who choose to register with a disability-specific employment agency are able to access pre-vocational and workplace training, which on the surface may seem to be similar to the training offered in the supported workplace - the difference being that the training in this instance is directed towards the workplaces of the broader community. Training in this way maximises the opportunity to integrate more appropriately.’

‘Both Day Support and Supported Employment also offer opportunities that may be considered as “stepping stones” to the goal of integration. The opportunities to achieve this goal are further maximised by open employment, which may be viewed as a further progression towards full integration.’

‘Open Employment maximises opportunities by:
• Discussing client’s work expectations with them, to assess needs and skills, to then match them with employment which is both enjoyable and meaningful.
• Accessing accredited training (and providing support during that training) to help develop a career, rather than just a “job”.
• Providing workplace support for both the client and others within the workplace during the “settling in” period.
• Offering the opportunity to secure and keep employment.
• Developing a wider social network within the broader community through the workplace.’

Report back IASSID continued

diverse community initiatives that have occurred to support continued community living for older people. The second is titled ‘Moving on Without Parents’, written by Christine Bigby, with a foreword by Matt and is an examination of the planning, transitions and sources of support for middle aged and older people with intellectual disabilities. Both are available from the Sydney based publishers MacLennan and Petty.

The conference was a welcome break from the rigours of a Melbourne winter and second semester teaching, energising me for the rest of the year. By the time the next conference comes around we will all have aged four years and what better place to contemplate ageing than Montpellier in the south of France in June. See you there.

References


What's going on - Research

In the March edition of Intellectual Disability, Australia, we included an outline of the following project, 'Day Support Options for Older People with a Lifelong Disability'. This is a nationwide project, which seeks to address questions with regard to day programs for people as they age. Raising and addressing issues around people with disability who might, for example, want to 'retire' from their day support is critical in an era in which the population of older people, with and without disability, is increasing rapidly while awareness of their needs is largely left to be both anecdotal and unfunded. In this edition, we report on the progress of this important piece of research.

Day Support Options for Older People with a Lifelong Disability

Progress to date

- Questionnaires have been sent to all CSDA funded day and leisure programs. There has been a significant response. Contact the project team (details below) if you have not received a questionnaire for your day program.
- Responses to questionnaires to community and aged care day programs in two regions of Victoria suggest few people with lifelong disabilities may be participating in these types of programs.
- Consultations have been held in each state and territory, in areas representing issues for metropolitan, regional and rural, and remote localities. There have been meetings for people with disabilities, carers, advocacy organisations, service providers and government representatives.
- Not everyone can get to a meeting! The project team has received dozens of emails, faxes, telephone calls and written submissions - sometimes with the important issues for one family, a support group or a service provider or locality. We're keen to receive more ideas and feedback up until 15th September.
- A demographic analysis, considering the CSDA, AIHW and ABS data national bases, as well as individual state and territory figures, is nearing completion.

Issues emerging

- There has been much debate about when age is important. Some people nominate an age range, or personal abilities - other people emphasise planning throughout a person's life. Everyone talks about treating people as individuals.
- How people spend their time during the day, on weekends and in the evenings is part of the analysis of day support options.
- The barriers identified to effective day support range from very local issues (such as lack of cooperation between key agencies) to system-wide issues such as eligibility for, and interfaces between HACC and state/territory disability programs.

Next Stages

- Comments are very welcome until September 15th - see the contact details below.
- Updates about the project can be found on the website: hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/org_research#old

Project Team

Researchers from La Trobe University's School of Social Work and Social Policy have been engaged by the Disability Services Division of the Victorian Department of Human Services, on behalf of the National Disability Services Sub-Committee. The project funding comes from the Commonwealth State Disability Agreement National Research Fund.

Any queries about the project can be directed to:

Dr Chris Fyffe, Project Manager
47 Fadersons Lane, Mandurang, Victoria 3551
Tel: 03 5439 5305
Fax: 03 5439 3334
E-mail: mcfyffe@ozemail.com.au

Information Exchange

Angus Capie asks:

Can anyone recommend some good readable material on activities for this group of neglected people (that is, adults with severe/profound disabilities in day programs)? I can't find much that is contemporary and Age Appropriate. A title or two would be appreciated.

Contact: Angus Capie Director, Standards and Monitoring Services, P.O.Box 11-252, Wellington, New Zealand.
ph +64-384-7010
fax+64-4-384-7669,
Email: angusc@actrix.gen.nz
Self-Determination: Examples of Good Australasian Practice

Dear Colleagues,

I am writing a book on ways in which children and adults with an intellectual disability can be more self-determining. My aim is to write something that is sufficiently practical to allow anyone wishing to implement ‘self-determination principles’ to do so. While the book will also cover the background to, and principles of, self determination, international experience and implementation strategies, a major aim is to describe practical examples of self-determination across the life-span in the Australasian context.

I aim to feature approaches that successfully foster friendships that support inclusion, decision-making and choice. I also want to highlight practices that provide genuine opportunities for control, (including financial control), focus service provision on the achievement of individuals’ aspirations, and/or assist people to be responsible and participating citizens.

If you know of any practices that I should have a closer look at - with a view to describing them in the book - would you contact me at one of the following addresses:

tonys@education.canberra.edu.au

Tony Shaddock
Special Education Program
University of Canberra
ACT AUSTRALIA 2601

All suggestions are welcome. I appreciate your assistance very much.

Many thanks,

Tony Shaddock