

INTELLECTUAL DISABILITY

Australia

Relationships in focus



This is not the 'Women's Weekly' but we would like to announce the wedding of Roy and Katie which took place at the picturesque St Peter's Church in Richmond, NSW on October 7th, 2000. Read more inside.....

Also inside:

- **Beyond Business as Usual: the conference for community**
- **The About Us Quilt**
- **Families: New developments internationally**
- **Sorry, I'm a Support Worker not your Friend**
- **Vision and Values in Practice**
- **Current Research**
- **Living Safer Sexual Lives**
- **What is informal support & why it's so important**

and more...



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Editorial

Welcome to the special issue of *Intellectual Disability, Australia*. The idea for this issue came about months ago when Jenny Smith in Queensland posted information about a seminar by Tom Doody ('Supporting the Development of Freely Given Relationships', held in Brisbane earlier this year) on ASSID-L. Jenny's posting created considerable interest and a number of people became involved in the discussion. Thoughts and references were exchanged: it was a great demonstration of how the list serve, **ASSID-L**, can inspire and support membership interests, it was also a demonstration of the importance placed on questions – and actualities – of relationships by people working with and supporting people living with intellectual disability.

The articles in this special edition of *IDA*, refer and are a testament to the growing research and policy acknowledgment of the importance of relationships. Keith McVilly's article: 'Sorry, I'm a Support Worker and not your friend?' raising questions as well as providing information on research results and policy statements (p6). The staff at the Illawarra Disability Trust show how one service, at least, has tackled the ethics of staff/consumer relationships in day to day practice (p8), Chris Bigby discusses informal support (p16) and Gwynnyth Llewlyn reports on developments nationally and internationally (pp5,9,15). Issues of sexuality within relationships are not forgotten – see 'Living Safer Sexual Lives,' (p12).

The centrality of relationships was also highlighted at the very successful joint ASSID/NCID conference held recently in Fremantle. All too often, it seems, friendships, instances of contact, moments of shared joy and pain among people with intellectual disability are left out of the 'big picture'; people with intellectual disability are encouraged to make friendships 'in the community' as if 'community' necessarily does not include them already. The 'About Us' strand at the conference tackled this problem, not only because it was a demonstration of the strength and effectiveness of relationships among people with disability (p3), but also because it indirectly ensured that, this time, people without disability had to come to people with disability, and not the other way around. Katie and Roy McAlpine, newly weds, attended the conference at the end of their honeymoon – their real life story is here, too (p4).

Relationships, as Keith McVilly points out, are at the very core of 'quality of life', irrespective of where one fits in the complex society we inhabit today. The articles we have here are only a tiny beginning but, we hope, a useful one. It is clear that there is a diversity of approaches, thoughts and philosophies which underpin study and practice around relationships. This diversity is a strength, a strength that should be constantly recalled and called upon, to avoid the narrowness and inflexibility which so often constrains the lives of people with disability.

My thanks to Chris Bigby, who has acted as Associate Editor for this issue. Chris has been a terrific contributor throughout 2000 and has been a great support for this novice editor. Thanks Chris. Thanks also to all the contributors, for this edition and throughout 2000. Your dedication and enthusiasm have been invaluable.

Don't forget to read the President's report (p19) and catch up on State Updates (p10) and the success of ASSID members (p17). And, to all members of ASSID, enjoy this issue, don't forget to send us some feedback and have a fun-filled but safe festive season.

Ann Penhallurick.

Beyond Business as Usual: the conference for community

'I'd like to have a boyfriend and do something together. I'd like to share feelings with him. I'd like to find a caring, loving sort of man.'

These are the words of one of the twenty five people (with disabilities) who contributed to the research and practice of Living Safer Sexual Lives (see page 12 of this magazine). The words themselves and the sentiment they express are remarkable both for their honesty and for their familiarity – this is what so many girls have said to their friends at high school, what many others might have thought to themselves late at night. People with intellectual disability, however, face greater barriers than most when it comes to finding that 'caring, loving' partner. Barriers of attitude and prejudice must be faced, and the immense practical issues that Roy and Katie are aware of (see p4 of this issue) are often only the tip of the iceberg. Just to meet someone many people must surmount the geographic isolation of their suburban group home, the issues of limited recreational facilities, as well as government policies which promote relationships with people outside the home but do not encourage any within the home (or employment setting, or day program etc).

The Fremantle ASSID/NCID conference was, as well as the venue for presentation of research and study, a demonstration of the extraordinary strength of relationship, understanding and co-operation among people with disability. PWID (people with intellectual disability) accepted the presence of PWOID (people without intellectual disability), they shared jokes and lunch time conversation, but the strong bonds among the PWID themselves were always evident as groups of self advocates sat together, laughed together, organised and discussed together. This co-ordination among people with disability produced the 'About Us' strand which ran throughout the conference. Full day discussions were held about issues (including relationships). The only real problem reported was that the room was too small – as there were so many enthusiastic delegates. One of the outcomes of this was the 'quilt project' (see page 4 of this issue), which will serve, as it travels the country, not only to showcase artwork and to educate but also to trace a strong thread of connection among people with and without disability throughout Australia.



Self advocacy is in itself a call for the whole community (which does include people with and without intellectual disability) to acknowledge that PWID want to band together, just as other 'minority' groups have found strength in working for a common cause. Self advocates do not work alone or just for themselves; but have strong ties, networks and beliefs in common goals. Self advocacy organisations have arisen or are developing in every state of Australia and they are becoming more vocal all the time. They do not need to integrate into 'the community'; but are a community which is already part of – and essential to – the whole community.

One person who is trying to take the self advocacy movement even further is Roy McAlpine. Roy would like to see the development of a National Self Advocacy Movement. There is strength, as

he sees it, in numbers, communication and co-ordination. If you or anyone you know is interested in furthering something along the lines of a National Self-Advocacy Network, you can contact

Roy McAlpine

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BLACKTOWN, 2148

*Much, much more from the conference
in the next issue of
Intellectual Disability, Australia.*

**In the meantime congratulations
and thanks to the hardworking team
of ASSID Western Australia. I'm
sure that all who attended the
Fremantle conference in October
will remember it as a stimulating,
thoughtful, and inspiring event.**

The "ABOUT US" Quilt: 'The fabric of people's lives'

The "About Us" Quilt had its origins at the 8th National Joint Conference of the National Council on Intellectual Disability (NCID) and the Australian Society for the Study of Intellectual Disability (ASSID) in Fremantle October 2000.

The Quilt was created by delegates in the "About Us" stream of this conference which was designed for and by people experiencing a disability. With inclusiveness and human rights featuring as major themes throughout the conference, delegates contributed their personal perspectives and ideas about these subjects, in the form of colourful and imaginative patches.

From the moment the first patches of the Quilt were sewn together, feelings and experiences people had expressed throughout the conference interconnected with each other in a breathtaking visual form. The effect was quite wonderful with the Quilt taking on a life of its own - symbolising the interwoven and relational quality of the **fabric of people's lives**.



For while it reflects the uniqueness and individuality of each person's viewpoint, the "About Us" Quilt also connects us all to the larger picture of our shared humanity.

The "About Us" Quilt is now at the beginning of a long journey to enable contributions to be made by as many people as possible, culminating in its display and re-presentation at the X111 World Conference of Inclusion International Melbourne, September 2002.

To find out about your next opportunity to contribute a patch to the quilt, please contact Ruth Keszia Whiteside, Chairperson, "About Us" at the People 1st Programme on 08 9227 6414. ◆

A show of strength

Katie and Roy McAlpine married just two weeks before October's ASSID/NCID joint conference in Fremantle. In fact, their wedding photos were included as part of a presentation at the conference. Showing themselves to be truly dedicated, they had their honeymoon in Fremantle, touring Perth in the first week and attending just about every session of the four day conference in the second. Fortunately the cocktail party provided an opportunity for some of us to toast the newly weds.

Roy and Katie are both self advocates from New South Wales. Roy is active in NSW Council for Intellectual Disability and is president of Self Advocacy - he's a frightening well-organised and determined person. Katie left home as an adolescent and despite her continuing strong family ties is a woman with a strong, independent spirit. They are both people with a lot to offer the world.

Despite all their skills and personal strengths, however, they both know that they have a lot to face in making a future together. When I spoke to Katie and Roy at the conference and again since returning, they both expressed a clear awareness of the fact that they were 'adjusting a new lifestyle' as Roy put it. The usual settling in period

requires more negotiation than is often the case, however. Needless to say Katie and Roy both have a long history of service involvement - often of services wanting to be involved with them, rather than they seeking support, it might be added. They have moved into Katie's flat but this brings them both under the auspices of a service provider who has a level of control over their lives that few of us have to deal with. Currently they are looking around for somewhere else to live - that's another hurdle with the bar raised a little higher than usual. In fact, raised a lot higher when real estate attitudes, bureaucratic waiting lists, transport issues and costs are all taken into account.

Like most newlyweds, Roy and Katie are not particularly well off and know that they have to work hard to get money to do the things that they want to do in life. But it is more difficult for them than it is for most people to find work. Currently Katie is employed in a workshop situation - and we all know how well that pays! Katie would like to find another and better paid job but there aren't that many around. Roy spends a huge amount of his time doing voluntary work and trying to get national self-advocacy groups off the ground.

Advice from here, there and everywhere is complicating

The recent ASSID/NCID conference in Fremantle, which was so well attended by self advocates and families as well as the usual 'suspects', the researchers, teachers, professionals and direct care workers, was a timely reminder of the inalienable importance of family support for, and interaction with, all that occurs in the 'disability field'. **Gwynnyth Llewellyn** is extremely well known for her work with families; she reports below on two initiatives in the area of family study and support that came out of another conference, the IASSID conference in Seattle this year.

Families: New developments internationally

Two exciting initiatives developed from meetings held at the IASSID conference in Seattle in August this year. These are the beginnings of two new IASSID Special Interest Research Groups (SIRG's).

The first is a SIRG on Families. Twenty-three enthusiastic people met one afternoon of the conference and resolved to get a SIRG on Families up and running. Professor Jan Blacher from the University of California at Riverside is leading this development as temporary Chairperson. As with any SIRG of IASSID 10 financial members are needed to be recognized as an official SIRG. This group has great plans for focusing on issues such as theory regarding family study, measurement in family research, collaborative research (for example, with other SIRG's or outside organizations) and life span and life course issues. Chris Hatton, Jan Blacher and myself are working hard to

Katie and Roy's lives. They both say that some advice is helpful but sometimes there is just too much. Too many different voices with two many conflicting ideas about what they should do. They want to work out what to do themselves, much of the time. But this is the very thing that has perhaps been most neglected in their education – how to negotiate the often rocky territory of a new marriage!

Katie and Roy are energetic people with ambition. Roy has a strong vision for the future and Katie is one of those people whose enjoyment of life shines from her. They 'deserve' to have the opportunity of a successful relationship. The odds are tough, but if anyone can do it, they can! In the meantime they're showing the world what a couple with a bit of grit and determination can do.

**- Ann Penhallurick with
Roy and Katie McAlpine ♦**

get a special issue of the *Journal of Intellectual Disability Research* up and running so watch this space and others for news of this special issue and a call for contributions. Anyone interested in family research and particularly those who are already members of IASSID please contact kelli.dulan@ucr.edu to get on the mailing list. Alternatively, if you would like further information please contact Gwynnyth Llewellyn on g.llewellyn@cchs.usyd.edu.au.

The second SIRG initiative is in the area of parents with intellectual disability. This group came about by several researchers saying, 'wouldn't this be a good idea' – from this came a hosted drinks reception one evening at IASSID, with the University of Minnesota generously providing the refreshments. Lynda Anderson from this university has already established a listserv, we have all contributed our ideas on the main aims of the group and we are currently calling for nominations for a group of enthusiastic people to lead us into formal recognition by IASSID. Again, please call in and join us if you have an interest in parenting. We are particularly looking for people who are either already or planning in the near future to be members of IASSID and we anticipate lots of exciting events in the near future. We have ambitious aims, including; to work to ensure that public policies and professional practices aim at parents with intellectual disability are informed by the results of research; to organize local, national and international conferences, seminars and events under the auspices of IASSID on the subject of parenting by people with intellectual disability; and to encourage, promote, and facilitate the development of research into parenting by people with intellectual disability. We are starting with a special issue of the *Journal of Applied Research in Intellectual Disabilities* (JARID) with a call for papers already issued by Maurice Feldman and Glynis Murphy.

Those interested in joining this emerging SIRG please email Lynda Anderson at ander447@tc.umn.edu. Again, for further information please contact Gwynnyth on g.llewellyn@cchs.usyd.edu.au.

Gwynnyth Llewellyn ♦

The following article is an edited version of a longer presentation made at the recent ASSID/NCID conference in Fremantle. The article is also part of the discussion that gave rise to this special issue on relationships. This discussion arose on ASSID-L and provoked some lively comments. It is fitting, then, that the extensive reference list for this article will be published on ASSID-L a week after IDA. It's a great reference list – don't forget to download. And IDA's thanks to **Keith McVilly** for supplying it.

Sorry, I'm a Support Worker not your Friend?

- Keith R. McVilly

The Importance of Relationships

It has been well argued that of all the possible factors influencing a person's QoL, the existence of stable interpersonal relationships is possibly the single most important; "Our relationships define who we are as individuals" (Kennedy & Itkonen, 1993). Indeed, a review of the literature suggests that interpersonal relationships provide, among other things, material aid, physical support, access to information, assistance with decision making, emotional support and access to opportunities to broaden existing support networks (Hughes, 1999). Research findings consistently suggest that the support of friends, neighbours and relatives act as an important safeguard against occupational stress, psychological illness and unhappy life events (Duck, 1991). Furthermore, the literature documents specific mental and physical health benefits associated with the development, maintenance and expansion of interpersonal networks, including lower instances of common ailments such as colds and flu, decreased risk of ulcers, heart disease and cancer, etc (Flynn, 1989). Also, there is some sobering research findings that clearly establish 'lonely people' in fact die younger (Bloom, et al 1978; Lynch 1977).

Those responsible for the development and delivery of services designed to safeguard and enhance the health and well-being of people with developmental disability need to be conscious that, for many people with developmental disability, significant interpersonal relationships are rare and frequently non-existent (Fleming & Stenfort-Kroese, 1990; Rapley & Beyer, 1996), but that they remain an issue of significant importance to consumers (McVilly, 1995), their families and advocates (Strully & Strully, 1985); "They (parents) rank having friends more important to happiness and quality of life than being competent at toileting, dressing, grocery shopping, bus riding and even competitive employment (Stainback & Stainback, 1987; p. 18).

In a recent study by Froese, Richardson, Romer & Swank (1999) a number of significant issues pertaining to interpersonal relationships were identified. These included: 81% of participants reported that they would like to have more friends and 35% specifically requested more contact with a family member; 65% of participants reported

wanting to have a 'boyfriend' or 'girlfriend', with 9% of participants explicating indicating a desire to marry.

However, the expressed needs of consumers were not always reflected in the opinion of those supporting them. For example, only 19% of "significant others" believed that their client wished to pursue a significant, exclusive interpersonal relationship (i.e., to have a 'boyfriend' or 'girlfriend') and only 4% expressed the view that their client may wish to pursue marriage.

Literature documenting the experience, perspective and needs of people with specifically intellectual disability is limited. The majority of work focuses on the experience of children in the school system. However, there are a few studies reported concerning the experience of adults with ID. For example, Krauss, Seltzer, & Goodman (1992) report on the support networks of adults with ID who live at home. Over a 5 year period, they examined the experience 418 adults with ID living with their parents. They found that, on average people had 7.1 consistent supportive network members, but that 75% of these were 'family members'. The authors report that 80% of their respondents' networks were embedded in their mother's network and only 25% reported having friends totally independent of their family. Most disturbingly, 42.3% of people had no friends outside of their immediate family.

Barber & Hupp (1993) report on the experience of 2271 residents of 236 facilities of varying sizes. Their findings suggest that people living in smaller groups had a greater number of people effectively forming their active social network ($M = 15.3$) than those living in larger institutional settings ($M = 5.6$), and that the experience of people living in smaller group settings was comparable with the experience of a comparison group drawn from the general population ($M = 17.4$).

This brief review of the literature raises a number of critical questions for future research: how do people with developmental disability conceptualise 'friendship'; what are they looking for; where and with whom are they going to realise their aspirations?

We also need to ask: how are services to effectively and appropriately support their clients to explore, develop and

sustain personal relationships that are meaningful for them; and what is the role of Support Staff in this process?

Addressing the Issues and Encountering the Dilemmas

In an effort to address some of these issues, 41 people working in the disability sector recently met and discussed "dual relationships": where a 'personal friendship' co-exists with a 'professional / client' relationship.

Questions discussed included: are support workers 'paid friends'; are they to 'model' friendship and if so how do we assist clients to differentiate between 'models' and 'real' friendship; are workers only to 'facilitate' friendship; and what do you do if you and a client develop a particular liking for each other?

From the discussion it was evident that there are characteristics in common between 'friends' and those in the 'helping professions', but there are some that are distinct, and possibly mutually exclusive. It is when such roles become blurred that "ethical dilemmas" emerge.

Professionals are the people most often involved in the lives of people with ID, often providing very intimate support. They frequently offer the most accessible opportunities for people with ID to form personal relationships. However, while the benefits to clients are potentially great, so too are the risks for clients, workers and organisations.

As with the development of any relationship, the parties involved need to ask questions such as 'are the objectives and expectations of the two parties mutually compatible?'. In the case of Support Staff forming relationships with their clients the question of the 'power imbalance' in the relationship needs to be thoroughly explored. Also, there is a need to consider how the friendship could effect the worker's relationships with other clients, colleagues and their employer.

With all the best intentions in the world, there seems to be no escaping that where a person is paid in a professional. And as Newton & Horner (1993) conclude: "Only when people with disability have lives that include enduring friendships with people in addition to the dedicated staff who are paid to provide them with support are they likely to experience the kinds of social relationships that are so valuable to all members of society" (p.44).

But what are we to do? Do we ignore the issue and hope it will go away? Do we simply tell clients "Sorry, I'm a Support Worker, not your friend"? Do we acknowledge the importance of the issue and actively seek solutions to the problem of *dual relationships* and the ethical dilemmas?

In Tasmania, the Department of Health and Human Services (Disability Services Programme) has provided guidance to staff in a number of policy statements.

In the policy entitled "Interpersonal Relationships" (December, 1998), it is clearly stated that: "Staff have a responsibility to broaden client's social networks and to increase the opportunity for people to meet and do things together".

However, in a separate policy statement entitled "Social contact and visits between staff and clients" (December, 1998), it is clearly stated that:

"Staff should not encourage social contact between themselves and clients with whom they work, outside working situations. This is to ensure that the working relationship between clients and staff does not become confused. Some people have difficulty in separating the two relationships, and may develop expectations of one another, which cannot be met at work. Similarly, work expectations should not be transferred to social situations."

"If staff wish to develop a social relationship with their clients, it is advisable that they cease working with the people concerned, so that the kind of relationship which develops is unambiguous in the minds of both parties."

Similarly, a non-government agency, LEVEDA Inc, following extensive consultation with clients, support staff and external professionals, has developed comprehensive guidelines:

Friendships often develop between consumers and staff. It is important for staff to consider carefully the implications of their behaviour.

Staff are to: (1) avoid any emotional involvement which clouds their judgement, creates a conflict of interest or gives a consumer mixed messages; and (2) discuss any concerns regarding their relationships with a consumer with their Co-ordinator.

If a consumer and staff member establish a close friendship/relationship, it is important for the staff member to inform their Co-ordinator or Supervisor as it may be more appropriate for that staff member to support different consumers. In doing so, a conflict of interest may be avoided, and ensures that the staff member is not accused of bias or manipulation.

Furthermore, if we are to support the development of friendship networks for people with ID and effectively evaluate our efforts from the perspective of people themselves, we need to know what people themselves want. As Haring and Breen (1992) conclude, "It is no longer

continued on page 19

Vision and Values in Practice

The Illawarra Disability Trust has recently undertaken a valuable process in recognising that all too often the values that inform mission statements and vision statements are not clearly identified and are not necessarily commonly agreed on among staff. The Trust recognised that to best meet the needs of people with disabilities, the organisation itself should have a clear statement of values and guidelines for how these articulated with day to day practice. Relationships among and between staff and clients are central issues in identifying and working with in-practice values.

As the staff at The Illawarra Disability Trust put it themselves:

'The intention of the staff values statement is to quantify how our vision and values actually link with our behaviours and workplace practices. The values statement aims to express how our organisational 'ethics' are conveyed in the day to day interactions we have with each other, with management and with clients. The values statement differs from a Code of Conduct in that it is not an imposed set of behavioural imperatives that staff must comply with, but rather a set of principles that are collectively developed and collectively owned by the staff of the organisation.'

A Values Statement

The success of the Illawarra Disability Trust has resulted from a shared commitment to offering the best possible services to people with disabilities and from our strong 'rights based' ideology. The Trust has a range of written documents that support our fundamental values with respect to clients and staff. These values are enshrined in the Trust's Vision Statement, objectives and in client rights and staffing policies.

So, why did we develop a Values Statement?

One of the Trust's strengths lies in maintaining our awareness of how each of the diverse services and activities that come under the Trust furthers the Trust's mission. By being mindful of our values base we knew we were more likely to offer both a more committed approach to the needs/issues of people with disabilities and a more dynamic workplace for our employees. The process of developing a staff values statement is another way of keeping us alert with respect to ethical issues.

Furthermore, sometimes the nexus between values, our workplace activities, and personal actions is not clear. We aimed to define our mutual expectations in a way that makes it easier to know how to consider our behaviour in a constantly changing dynamic setting.

Whilst the entire document focuses on our interactions with our consumers, one particular component looked at our relationships and contacts. Staff felt that it was important that the guidelines in no way suggested that we shouldn't relate to our clients in a warm and friendly manner whilst working with them. In fact it was acknowledged that this is an important aspect of our service provision. However, it was also important to establish our boundaries and guidelines for some of the issues that may arise in a healthy, dynamic human service.

The Process

- A discussion paper was developed by the Manager and distributed to all staff.
- A brainstorming session occurred at a designated staff meeting. This was documented and again distributed to all staff to allow further development of ideas, issues and values.
- A planning day with a facilitator was held. (It was interesting that on this day there were issues identified that were more appropriately addressed through our Policy and Procedures, and this was an outcome we had not anticipated, but was very valuable).
- A number of Values Statements from other organisations (none of which were disability organisations) were gathered to look for formatting ideas that would suit our needs.
- A draft was circulated.
- Proposed changes were discussed and finalised at another staff meeting, prior to the final draft being completed. The draft was circulated and upon approval from all staff was then forwarded to our Board of Directors for approval.
- We identified values which underpin the entire document, a statement of principles, personal and professional conduct, accountability, relationships and contact with clients, conflict of interest, utilisation of resources, working with each other and values that will improve our service.

One of the major challenges we faced in the development of the document was accommodating the very diverse service types within our organisation, and our diverse consumer base. Services are provided to people with all types of disabilities, in a variety of settings, who often have very different needs and expectations. We have staff who work in people's homes, a post school options service meeting the needs of people with challenging behaviour, administration staff, an advocacy and information service, and staff providing a recreation service in the community, to look at just a few. This issue generated enormous

Current Research

With funding from the National Health and Medical Research Council, **Gwynnyth Llewellyn, Lindsay Gething, Hal Kendig, and Rosemary Cant** are conducting a two-year study exploring the service pathways used by older parents of adult sons or daughters with intellectual disability. The overall aim of this study is to investigate the pathways that lead to or prevent older parents of adults with intellectual disability accessing services.

The study has three components. In the first, in-depth interviews will be conducted with a sample of older parents to explore their experiences of parenting and caregiving. In addition, service providers will participate in focus groups to examine their perceptions and expectations of services for older parents. The perspectives of older parents and service personnel will then be compared and contrasted. The study is concerned to explore some of the issues related to caring over a lifetime such as older parents may become disabled themselves; mothers may become widowed and left without spouse support, and adult sons and daughters with intellectual disability are living longer and they are likely to experience the early onset of additional, age related disabilities.

The objectives of the study are:

1. To identify ways in which caring relationships are influenced by major life events, health status, support networks and attitudes towards and willingness to engage with health services.
2. To document reasons why older parents do or do not use services currently, their views on their service needs in the future, and reasons why parent caregiving comes to an end.

Vision and Values *Continued from previous page*

discussion and presented many dilemmas the majority of which we were able to resolve.

The entire process took almost a year to complete, and has been considered positive by all staff. It was an excellent team building exercise, it improved awareness amongst staff of many issues, and part of the end result is that staff are confident about and proud of the final document. By making a conscious attempt to build and strengthen our organisational ethos and common sense of purpose we feel that we are more likely to achieve our goal of offering a committed and dynamic approach to the needs/issues of people with disabilities.

- Staff of the Illawarra Disability Trust ◆

3. To identify service providers' perceptions of reasons why older parents do or do not use services and to contrast their perspectives with those of the parent caregiver.
4. To formulate a conceptual model of the processes of caregiving relationships between older parents and their adult sons and daughters with intellectual disability.

The study is being conducted in the Northern Sydney Area Health region and interviews are already underway. The plan is to interview around 100 older parents over the next 12-18 months and we would be very pleased to hear from anyone with an interest in this area. The expected outcomes of the study include:

- Identification of the influences on older parents' use of health and community services.
- Recommendations for the provision of health and community services to reflect older parents' perceptions and motivations to undertake preventative measures and/or receive supportive or therapeutic services.
- Development of a multi-dimensional health and community services strategy to be trialed with a group of caregivers prior to developing recommendations for well-informed multi-systems level policy and practice.

Please contact Gwynnyth on
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if you would like further information. ◆

**Never forget
that you are invited
to contribute to this
newsletter.**

Send your news, views, letters,
remarks, notes on research,
reports on best practice to

penhall@bigpond.net.au

Alternatively you can
post, fax or phone
(see page 2 for details)

Queensland

Hi from everyone up here in Qld,

Just a few words from ASSID QLD at this time. The committee is currently very busy completing our planning for next year. We are hosting a "planning day" where the committee members sit down and review the year that has past and the year to come....we will try to work out what has worked for ASSID Qld in the last year and what will be repeated or changed for the coming year. So that means that we will have some very interesting information and plans that you will read here in the next edition of IDA...so stay tuned.

One final matter...Just a reminder that we still have copies of the publication: "Some Observations on Several Enduring and Decisive Leadership Challenges in the Field of Disability" that was originally delivered at the Queensland State Conference by Michael Kendrick in July 1999 (See p15 of this issue for details) Michael Kendrick, a Canadian, has had a great deal of experience working and lecturing on issues of leadership and the quality of public and community services and community life for persons with disabilities. He has worked extensively with organisations in Canada, the United States, Australia, New Zealand, the United Kingdom and Norway on matters related to the quality of community life for people with disabilities.

Well that is it for me for the at the moment and I will keep you posted on the plans for next year for ASSID QLD as they come to hand.

Tasmania

Cheers Madonna ♦

We have held our AGM and, given the size of the state branch, had a very good turn up. I was elected State President and have set about planning for the next twelve months with a focus of developing a state branch which people want to belong to (making the actions and programs of the state committee so attractive people will wish to join). To kick this off we held a State Planning Day on the 18th of November examining the following areas: Setting the directions for ASSID Tas for 2000/2001

- Review & development of state strategic plan
- Hot Topic Nights - setting the Calendar
- Regional Interest groups
- State ASSID News Letter
- Increasing ASSID Tas profile and Membership Base
- Developing ASSID Tas Support Worker Network
- Optia application / Research Incentive

Other significant activities that are under way include

NSW

New South Wales recently held a forum (and Christmas drinks) evening which was well attended. (It seemed to be the quality of the speakers that attracted the audience, rather than the wine and cheese as some State Council members were forced to take left-overs home). The forum: "Services for people with intellectual disability who have contact with the criminal justice system: Do we follow the American direction?" was presented by Anne Langford, Co-ordinator of Clinical Services for inmates with intellectual disability for the NSW Department of Corrective Services. Anne had recently visited a range of services in the United States and spoken with people involved in this area at the recent IASSID conference.

Discussants at the forum were Mary Ellen-Burke (well known for her work with people with challenging behaviours) & Georgina Connelly, Principal Solicitor with the Intellectual Disability Rights Service, which is currently at report stage of the Frameworks Project, looking at people with intellectual disability who encounter the criminal justice system.

Differing perspectives were aired (individual rights community protection) and some excellent information about US trends provided. The post-forum discussion was lively and enthusiastic and no doubt encouraged quite a number of the people who stayed long enough to attend the NSW AGM. Luckily the enthusiasm kept bubbling and 14 members committed themselves to being State Councillors for at least the next year. The executive is now: Linda Goddard, State President, Ann Penhallurick, State Vice-President, John Brown, Secretary and Fiona Cameron-Magill, Treasurer.

Discussion had already started for the next state conference; anyone interested in this can contact

Ann on 02 9566 4789 or email: penhall@bigpond.net.au

Other details from Linda Goddard : ph: 02 6051 6875 or email: lgoddard@csu.edu.au ♦

preparation for the celebration of International Day for People with a Disability. In the north of the state there is a significant forum being organized by Northern Residential Support Group to celebrate this day and include having Dr Don Grimes - the 'father of the Disability Services Act' - as guest speaker, and also the national president of NICAN as a speaker. More information is available from David Laugher nrsg@vision.net.au.

Cheers Steve Bristow ♦

St
Up

Victoria

Hello everyone, this update has caught us southerners slap, bang in the middle of carrying out many of the activities that have been planned for during the past year . . . not to mention the speedy approach of Christmas!

To begin with October saw Dr Paul Cambridge from the Tizard Centre, University of Kent at a workshop for carers in Lorne, country Victoria. Paul delivered a workshop that focussed on recognition and responding to sexuality and gender issues when providing personal care for people with an intellectual disability. Patsie Frawley and Kelley Johnson (Australian Research Centre in Sexual Health and Society, LaTrobe University) presented Safer Sexual Lives at the workshop and reported that the day was thoroughly enjoyed by participants and presenters alike.

The national conference was held in late October in sunny Fremantle, Western Australia. The general feeling from those at the conference was that congratulations are in order for W.A.

ASSID, NCID and convenor Mark Rapley for producing an inspiring conference that actively promoted the inclusion of people with disabilities.

To continue the theme of workshops and conferences, a series of two hour workshops for care staff will be held at Moonee Valley on 22 November. Dr Robert Cummins will begin the day with a presentation about Quality of Life followed by workshops on Challenging Behaviour, Ageing and Alzheimer's

Disease, Sexuality, Power Sharing Relationships in Residential Units, Communication, as well as Working with your General Practitioner.

Hot on the heels of the successful national conference in W.A. was the release of first announcement posters and brochures that invite expressions of interest for the 36th Annual Conference of ASSID to be held in Melbourne. The conference, Participation & Citizenship in the Wider World will be held at The University of Melbourne, November 12 - 15, 2001.

Last but not least, was the Annual General Meeting of the Victorian branch that was held in mid October. Dr Paul Cambridge gave a thought provoking presentation about abuse in the disability sector and raised discussion about the definition of abuse and the concept of neglect as a form of abuse. On the more formal side, we would like to thank the outgoing state president, Chris Bigby for all her

West Australia



Congratulations to the WA ASSID team for their exhausting but more than worthwhile work for the 2000 ASSID/NCID conference.

hard work over the past year and welcome the new state president Bob Davis. Patsie Frawley is the new state vice president, Alex Phillips and Daniel Leighton are sharing secretarial tasks and Bill Taylor continues as the state treasurer. We are delighted to welcome new committee members, Liz Alexander, Paula O'Connor, Mike Austin and Carolyn Neville while Chris Bigby, Kelley Johnson, Glen Jose, Kathy Stebbings and Karen Nankervis continue to be active within the state committee. Daniel, Bob, Bill and Karen are state representatives on the national ASSID committee and Karen continues her role as conference convenor for the 2001 conference in Melbourne. We would welcome the involvement of any other interested Victorians and encourage you to attend meetings that are held in Fitzroy at 7:30pm on the first Monday of every month. For more information contact either myself, or Robert.Davis@med.monash.edu.au

Overall the Victorian branch of ASSID has had a successful year with the State Conference, regional workshops and seminars, guest speakers, sponsorship for client attendance at IASSID in America and the monthly Victorian Member News newsletter. With an increase of people on the state committee we aim to build upon the successes of this past year and will no doubt be kept busy organising the annual conference, all of course with our esteemed conference convenor!

From all of us here at the Victorian branch we wish you all a Merry Christmas and a safe, but silly, festive season and we will see you in the New Year!

Alex Phillips

Alex.Phillips@med.monash.edu.au ♦

ate
date

Resources available:

Intellectual Disability Australia, as the 'news voice' of ASSID, is committed to providing membership with up to date information about available resources. Already this year IDA has covered 'Taking Care of Me', a program developed by The Illawarra Disability Trust to promote skills for women with intellectual disability in identifying violence and in seeking supports to deal with the issues. We have also published details of the West Australian Disability Service Commission's 'Feel Safe' program, designed to enable adults with disability develop skills in dealing with potentially abusive situations. Below is the background and the outline of 'Living Safer Sexual Lives', a program of workshops that were the outcome of a project that listened to the stories that people with intellectual disability told about their own lives.

Living Safer Sexual Lives

Kelley Johnson, Patsie Frawley, Lynne Hillier and Lyn Harrison, Australian Research Centre in Sex Health and Society, Latrobe University.

From Research.....

In spite of changes in the way people with intellectual disabilities are perceived in our community, issues of sexuality and relationships remain particularly problematic for them. *Living Safer Sexual Lives* is a three year Victorian Health Promotion Foundation funded action research project which has sought to address how people with intellectual disabilities view these issues. During the first stage of the project twenty five people with intellectual disabilities told their life stories, with a focus on sexuality and human relationships, to experienced qualitative researchers. In the second stage of the project the stories were used to provide people with intellectual disabilities, families and service providers with workshops and resources designed to help people with intellectual disabilities to live safer sexual lives.

Rationale

The project developed from consultations between the researchers and representatives from service provider and advocacy organisations. During these consultations the following concerns were expressed.

- People with intellectual disabilities were perceived as experiencing barriers and problems in leading safe sexual lives.
- There was little opportunity for people with intellectual disabilities to discuss sexuality and relationships.
- There was often little consultation with people with intellectual disabilities in relation to decisions made about their sexuality and human relationships.
- Current research had failed to place sexuality and relationships in the broader context of the lives of people with intellectual disabilities.
- People with intellectual disabilities are vulnerable to sexual abuse or exploitation. Research findings have revealed that women (and to a lesser extent) men are more likely to experience sexual abuse than other

groups in the population and to be vulnerable to sexually transmissible diseases (Brown and Turk, 1992; Carson, 1994; Millard, 1994; Cambridge and Brown, 1997; McCarthy, 1999).

Living Safer Sexual Lives sought to fill some of the gaps in our knowledge of how people with learning disabilities see their own sexual lives and to work with them to find strategies which would assist them in having more fulfilling and safer sexual expression and relationships.

Key findings (from the stories):

- Stories were complex, emotional, passionate, painful and joyful. They were accounts of adults struggling with huge issues around sexuality and relationships. For example Kevin and Hannah live in a special accommodation house where, after a struggle they have been able to share a room. Kevin wants to live more independently but says:

We asked her brother about moving out. He doesn't want us to live in a house. He wants her to live in special accommodation all her life. So I'll spend my life with her there. She's on tablets and that, she gets a bit funny sometimes. And that's probably why he's worried about her.

- Many people led secret sexual lives which sometimes exposed them to abuse and risks. For example Elaine lived at home with her parents and had been involved in several long term sexual relationships. However she had never once been able to have sex at home with any of them. This had led her into situations where she had been both sexually and physically abused.
- Some people led very unsafe sexual lives. Secrecy made it more difficult for people to be safe. Hussein had been sexually abused at the age of 13 and had sex with men on a casual basis. He did not use condoms and was very afraid that his family or worker would find out about his hidden life.
- Many wanted long term relationships. All of the people in the group expressed strong desires for a close long term relationship with someone. For most this was a dream which had been unfulfilled. For example Shaughan says:

I'd like to have a boyfriend and do something together. I'd like to share feelings with him. I'd like to find a caring, loving sort of man.

- Some people were isolated and had experienced repeated rejections by other community members. For example David a young man living alone in the community commented:

I have a few friends but I'm always contacting them, they're not doin' the same, they're not doin' the same to me. Meaning I've got friends, yeah, but it's always: "Give me a phone, give me a phone." It's always on their terms not on mine.

- Almost all of the men and women in the group had been sexually abused at some time. For example Neville had lived for twenty years within an institution. He said that staff at the institution told him that sex was fun and then "jumped into bed with me." However when he tried to form a relationship with a woman living at the institution he was punished and never saw her again.
- People lacked information about sexuality and human relationships. Even when people had been given sexuality education they often found it embarrassing or irrelevant. So Hussein who had an active sexual life comments:

When you have sex with someone, sperm comes out. Whereabouts is it inside your body? I didn't know your body can produce that. Can it?

Conclusion

The stories which people contributed to the project have increased our understanding of the place of sexuality and relationships in the lives of people with intellectual disabilities. In particular the stories reveal how sexuality needs to be seen in the broader context of someone's life. Efforts to protect people by service providers and families in many cases left them vulnerable to sexual abuse or to a denial of their rights to a safe and pleasurable sexual life. The lack of power and information to make informed choices by this group of people reflected their relative powerlessness in other areas of their lives.

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.....To Practice

The life stories contributed by 25 people with intellectual disabilities to the *Living Safer Sexual Lives* Project formed the basis for the development of a range of different resources designed to assist people with intellectual disabilities to live safer sexual lives. The resources consist of:

- A one day workshop for service providers which uses the stories to focus on issues such as values and attitudes, safety and rights has now been developed and trialled with more than 200 service providers across the state. A manual for the workshops is now complete in draft form.
- A four week set of workshops for women with intellectual disabilities has been developed, trialled and evaluated in both city and country areas.
- A family workshop of two hours has been developed and trialled.
- A set of stories has been prepared for publication as plain English booklets for people with intellectual disabilities. These deal with major themes arising in people's lives. Two publishers have indicated interest in publishing the booklets.
- A video of three of the stories has now been produced.

1. Service Provider Workshops

The workshops have now been trialled with more than 200 service providers across Victoria and internationally. Participants have included staff at Supported Employment Services, Adult Training and Support Services, accommodation services, and community visitors. Workshops have been run in both rural and city areas.

The evaluation provides evidence that the workshops challenged service providers to reflect on their values and beliefs through the stories. They then began to use these reflections to set a framework for informed, aware and thoughtful responses to the issues that arise for them when working with people with an intellectual disability around sexuality.

More particularly the workshops assisted staff to respond more appropriately to people with intellectual disabilities by:

- becoming aware of the fact that the sexuality of people with an intellectual disability is more about sexuality than disability and it is not a "behaviour" that has to be managed.

Continued on next page

- recognising that the sexuality of people with intellectual disabilities is not "something different" to that experienced by the rest of the community.
- treating people with intellectual disabilities with respect, privacy and dignity and using this way of working to solve problems which may arise.
- acknowledging that you cannot deny the sexuality of this group.

The workshops provide a unique basis for working with service providers. We believe that from this basis existing courses and modules provided by other agencies, for example, sexual assault or sexual abuse may be added depending upon the needs of particular groups and agencies.

2. Family Workshops

Four workshops have been run for families with 42 people attending them. Two workshops were carried out in Melbourne and two in a country area.

These workshops were developed slowly over the six months. They proved more difficult to shape than those for service providers and required much more reflection about content and process. More substantial changes were made to them over time. However, it is clear from the questionnaire responses to the last workshop that families found the workshops even in shortened form a challenging and useful process. The need for workshops that can assist families to face their fears and anxieties and to become more proactive in helping family members with disabilities to learn positively about sexuality, relationships and sexual rights and safety has been shown repeatedly through these workshops.

3. People with Intellectual Disabilities Workshops

Eight workshops have been run with women with intellectual disabilities. Thirty eight women have been participants. The workshops for women with intellectual

disabilities have revealed very positive and energetic responses to the stories and activities. The evaluation has shown that the sessions seem true to the life experiences of the women. Further they offer a space and opportunity for women to be treated as adult learners who bring their own experience and skills to address issues which are important to them. Providing the workshops over time allows for a climate of trust and equality to be developed. However it is also apparent from the evaluation that the facilitators of these workshops require considerable skills in working with people with intellectual disability, confidence to respond flexibly to diverse needs and sensitivity in dealing with intimate experiences. In these workshops there is an adult exchange of questions, queries, replies, thoughts and feelings. They are not contrived.

Conclusion

The experience of running the workshops over time has been both challenging and exciting. On the basis of this experience we believe that they offer a new way of working with people on sexuality and relationship issues. In particular the workshops offer an opportunity for organisations to provide education to families, service providers and people with intellectual disabilities simultaneously and within a common framework. This offers real possibilities for change. We are currently developing the workshops further and they are now available to organisations and groups working with people with intellectual disabilities.

If you would like further information contact:

Anne Mitchell, Australian Research Centre in Sex Health and Society, Latrobe University,
215 Franklin St Melbourne 3000.
Ph (03) 92855382
Email: a.mitchell@latrobe.edu.au



March Edition of IDA

to include:

- ★ Details of the 2000 conference
- ★ Controversy over reports
- ★ Review of 'Moving On without Parents'
- ★ Pics of ASSID members enjoying themselves (yes, the evidence exists)

AND MORE....

Changing your address?

Let Wendy at the Secretariat know!

Contact: **Wendy Grant**

ASSID Secretariat
University of Newcastle Union
PO Box 18,
University of Newcastle, Callaghan NSW 2308
Phone: 1800 644 741 Fax: 02 4921 7151
Email: scwbg@alinga.newcastle.edu.au

Wendy will update the database and you will continue to receive all the benefits of ASSID membership.

Publications and Reports Available

Parents with a disability in the NSW Children's Court.

This report found that almost one quarter of all cases before the NSW Children's Court in care and protection matters were parents with a disability. Furthermore care and protection workers typically put parents with a disability into the "too hard" basket. Concerns of workers were more about potential for harm than alleged or substantiated abuse.

The Court's reliance on expert opinion further disadvantages these parents, who are assessed by diagnosis rather than parenting performance. The majority of children of parents with intellectual disability were made state wards. The absence of suitable support services results in more invasive actions than would be the case if assistance was available to parents in the community.

The report is available from David McConnell or Gwynnyth Llewellyn at the Family Support and Service Project, Faculty of Health Sciences, University of Sydney, PO Box 170, Lidcombe NSW 1825
G.Llewellyn@cchs.usyd.edu.au or
D.Mcconnell@cchs.usyd.edu.au

(Thanks to Gwynnyth Llewellyn)

Making a Statement: Barriers Facing Women with Intellectual Disabilities when Making a Statement about Sexual Assault to the Police.

This report, by the Intellectual Disability Rights Service in NSW, is the product of an study involving in-depth interviews with police officers and sexual assault workers in the greater Sydney area. *Making a Statement* gives further weight to evidence that women with intellectual disability face enormous barriers in completing a victim statement that has forensic value. The report concluded with recommendations as to how these barriers might be diminished. The study and report were supported by funding from the Dept of Corrective Services, Victims of Violent Crime Grants Program.

Copies of the report available from IDRDR,
Level 1, 128 Chalmers St, Surry Hills, 2010.
Phone: 02 9318 0144,
Fax: 02 9318 2887 or
Freecall: 1800 66 66 115

Victorian Department of Human Services: Management of Services for People with an Intellectual disability.

The Victorian Auditor-General tabled a report in Parliament recently on a performance audit examining the Department of Human Services' management of services for people with an intellectual disability, including:

- resource allocation processes
- safeguards to protect the rights of people with an intellectual disability
- quality of services provided
- adequacy of monitoring arrangements and accountability mechanisms.

The audit focused particularly on case management, day programs and shared supported accommodation.

Copies of the report are available from the Victorian Auditor-General's Office on 03 8601 7000 or www.audit.vic.gov.au or Information Victoria 03 1300 366 356.

(Thanks to Anita Tang) ◆

New Publication

Some Observations on Several Enduring and Decisive Leadership Challenges In the Field of Disability

Michael J. Kendrick PhD

The Queensland branch of ASSID is proud to announce the publication of a new monograph.

Some Observations on Several Enduring and Decisive leadership Challenges in the Field of Disability was originally delivered at the Queensland State Conference by Michael Kendrick in July 1999.

Kendrick discusses such topics as:

- Establishing Shared Vision, Values and Moral Purposes
- Strengthening the Voice and Influence of Persons with Disabilities
- The Work of Improving the Quality of Life for People with Disabilities within Communities"
- Challenging and Transforming the Relevance of Already Established Services
- Strategic Investments in the Renewal and Evolution of the Field

ASSID (Qld) is proud to make this publication available for the price of \$5.00 per copy.

Enquiries should be addressed to:

The Secretary ASSID (Qld) Inc PO Box 12062
BRISBANE ELIZABETH STREET QLD 4002

What is informal support and why is it so important?

Dr Christine Bigby, Senior Lecturer, School of Social Work and Social Policy, LaTrobe University.

This brief article considers why informal social relationships are so important and thus *argues that* finding ways to create, support and nurture these for people with intellectual disabilities should be a central part of the formal service system.

Unlike formal services, informal support is provided on the basis of personal ties between individuals as individuals. These stem from kinship ties between family members, personal affinity between friends or geographic proximity in the case of neighbours. Informal support is multi-dimensional and conceptualised in various ways. One of the most common is in terms of "caring about" and "caring for" (Dalley, 1988), where the latter involves a more direct hands on day to day caring role. Horowitz divides informal support into four components, emotional support, direct instrumental support, financial assistance, and management of relationships with formal organisations (1985). Refining this further, ten distinct types of instrumental support for older people with intellectual disabilities are identified: (a) decision making; (b) financial management; (c) adoption of formal or legal roles; (d) mediating, negotiating and advocating with service systems; (e) monitoring service quality; (f) provision of primary care; (g) supervision of medical needs; (h) coordinating support from other network members (i) provision of backup or short term replacement of other members; and (j) skills development (Bigby, 2000).

Different members of informal networks may fulfil different functions. The various relational ties people have bring different limitations and strengths to an informal network. Litwak's (1985) theory of task specificity argues that, family, friends and neighbors have different characteristics that differentiate the type of support they are best able to provide. For example, neighbors are characterised by close proximity, but loose or non affective ties, and thus are well suited to support that requires low commitment but either speedy response or proximity such as emergency assistance, monitoring an empty house or feeding the cat. In contrast relationships with spouses or other close family members are characterised by proximity, face to face contact on a daily basis and high degree of commitment. They are often the only ones in a network in a position to provide support with primary care tasks, which require these characteristics. Other family members may not be geographically close but still have a strong commitment and be suited to tasks that don't require frequent day to day contact such as administration of financial affairs, advocacy or negotiation with formal organisations. Friends are characterised by

affective ties but often not proximity or long-term commitment and may be better suited to tasks such as emotional support or shared activities that require intermittent contact with a low level of commitment.

Clearly, this delineation of characteristics of primary groups is based on ideal types. Both relationships and the tasks fulfilled by informal network members are mediated by factors such as gender, social context, individual resources, personal histories and negotiated commitments. Nevertheless, Litwak's ideas provide a basis for considering the varied tasks undertaken by informal support and can provide indications of which functions may not be well performed by a person's network. In addition, this perspective can help ensure that tasks are not expected from network members that do not match their characteristics, which may therefore place too great a strain on the relationship or may be impossible to fulfill.

The current paradigm of community membership and participation places great emphasis on the importance of relationships - individual connections between people with intellectual disabilities and others in the community (Bradley, 1996). Yet a dominant theme that emerges from research on deinstitutionalisation and community living is that while far more people now have a physical presence in the community, few who live in shared supported accommodation have built relationships with members of the community (Mansell & Ericsson, 1996). People may visit or use community facilities but their interactions with others remain at an anonymous or impersonal level rather than being part of the rich social relationships found within the numerous voluntary, cultural or sporting organisations that make up the fabric of civic society (Walker, 1995). Indeed, the recent Victorian Auditor General's performance audit of intellectual disability services states, "Overall we conclude that service sites we visited had a satisfactory level of basic care, but beyond that there were wide variations in the extent to which the legislative principles and standards were met in relation to the provision of developmental opportunities and integration into the community" (2000, p. 68).

Yet, effective informal support networks not only provide substantial direct care to people and reduce the demand for formal services but are associated with psychological and physical wellbeing, "in sum social support for (older) people appears to be related to higher morale, less loneliness and worry, feelings of usefulness, a sense of individual respect within the community and a zest for life" (Hooyman, 1993, p 139). Litwak also suggests that formal

organisations cannot replace all the tasks performed by informal networks as they cannot take into account idiosyncratic needs and find it hard to perform non-routine tasks. Nor can they adequately fulfill tasks that require long term commitment, advocacy or an affective relationship, such as emotional support, financial or personal affairs management and monitoring and negotiation of service quality.

My research has found that, in middle-age and beyond, formal services tend to replace parents as primary carers providing direct "care for" people with intellectual disability but informal support continues to fulfil the "caring about" tasks, providing affective support, managing and mediating relations with formal services and providing significant advocacy. These latter functions are crucial to the quality of life, particularly for people who live in shared supported accommodation and are those not easily replicated by formal services. In Victoria, services such as case management, statutory guardianship and the Public Advocate's Office only undertake fragments of tasks such as these and then only for limited periods. Formal services cannot provide a continuing comprehensive oversight of an individual's well being (Bigby, 2000).

The inability of formal services to substitute for roles fulfilled by informal network members emphasises the vulnerability of those people who lack strong networks and suggests the importance of actively acknowledging and supporting the maintenance of informal supportive

ties and finding ways to foster the development of informal sources of support.

C.Bigby@latrobe.edu.au

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Sorry, I'm a Support Worker not your Friend? *continued from page 7*

sufficient to teach people to engage in three or four conversational scripts with one or two non-disabled peers and call our job done. We must look at the contexts in which those conversational scripts are being used and their contributions to the relationships between a target and his or her non-disabled peers" (p.331).

To this end, there are a number of models and methodologies that may prove useful (Amado, 1993; O'Brien & O'Brien, 1992), once we have established the perspective and aspirations of people with ID.

For example, the 'Citizen Advocacy Relationships', in which a person with an ID and a person without an ID develop a long term relationship involving support and advocacy (Widrick, Hasazi & Hasazi, 1990). Another example of an effective model would be the 'Circle of Support' concept (Mount, Beeman & Ducharme, 1988).

One useful model that has been empirically validated is that reported by Newton & Horner, 1993. The authors propose the use of a 'Social Guide' model which they demonstrate can give rise to an increase in gross network size, the number of new people in a person's network and

an increase in the range of activities to which people are exposed, even for persons with severe ID.

'Social Guide' model addresses some of the issues identified by Newton, Olson, & Horner, 1995 that may impede the development of meaningful friendships for people with ID. These include such barriers as:

- Organisational procedures (and the underlying belief systems) that make it difficult for a person receiving support to spend time with potential friends;
- Personal schedules that are not conducive to the pursuit of pleasurable recreation in the company of like-minded people;
- Individual skill deficits that effect the person with ID's capacity to participate in activities, communicate with potential friends and foster the relationship through reciprocation.

Conclusions and Future Directions

It is evident that issues and questions relating to the formation and development of interpersonal relationships for people with ID remain controversial. So too, the role

Continued on Page 18

ASSID AWARDS

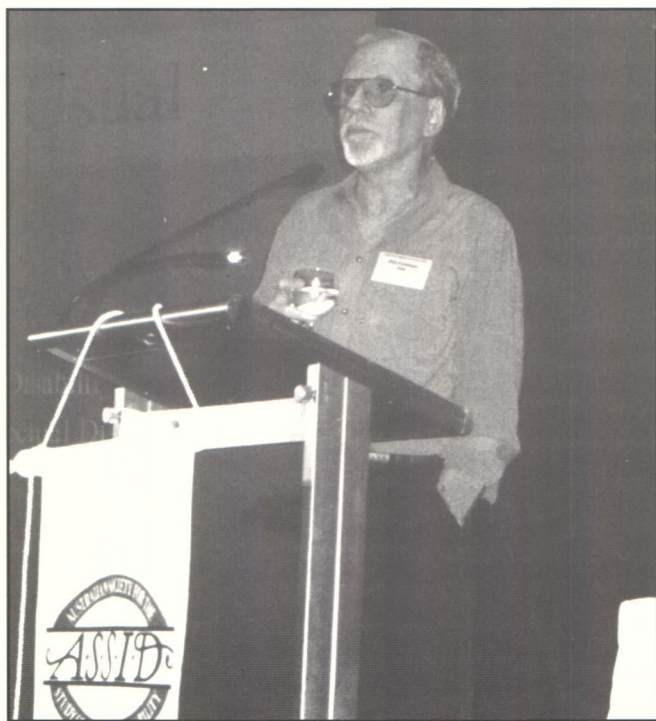
Jeff Sigafoos reports that ASSID members have been recognised as major world researchers.

A recent article published in the USA-based journal *Research in Developmental Disabilities* has sought to identify the top researchers in the field of applied research in mental retardation/developmental disability.

Among the top 25 researchers are 2 Australians – both ASSID members (Robert Cummins and myself). We are tied for the 21st spot.'

'Among the top 50 institutions are six Australian Universities. I think this is a pretty impressive showing!'

(Thanks Jeff and Congratuations – the Ed.)

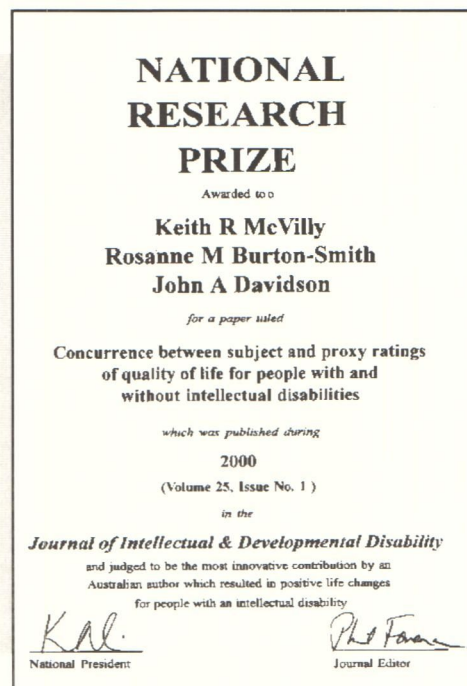


Professor Phil Foreman, editor of the *Journal of Intellectual & Developmental Disability*, presenting this year's journal award for excellence.

Sorry, I'm a Support Worker not your Friend? continued from page 17

and involvement of Support Staff in the lives of their clients, especially in terms of the potential development of dual relationships, remains an issue that should be of major concern to employees and employers alike.

At this stage, the majority of our considerations in the area of interpersonal relationships for adults with ID are based, rightly or wrongly, on normative models developed out of research in the wider population that have been 'assumed' to apply to people with ID, solely on the argument of *Normalisation*, the seemingly arbitrary application of which has itself recently been questioned by its chief



Distinguished Service Awards

Each year ASSID National calls for nominations for **Distinguished Service Citations**. State Councils put forward the name(s) of members who have been active, dedicated, involved, forward thinking and just plain hard working. Of course there are many of these, but never enough - so the ASSID members below who received Distinguished Service Citations in 2000 more than deserve their acknowledgment for the many hours and many years they have dedicated to this organisation. This years awards have gone to:

Paul Grevell, from Queensland

Clare Dwyer, Victoria

John Annison, Victoria

Alan Hudson, Victoria

CONGRATULATIONS and sincere thanks for all your work to each of these members. ◆

proponent, Wolfensberger (Wolfensberger, 2000). For this reason, priority needs to be given to establishing the perspective of people with ID. This is a task that can and will be taken up by researchers currently working in the field.

For further information contact:

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E-Mail: mcvillyk@mpx.com.au ◆

President's Report

The highly successful National conference in Fremantle was the venue for the final ASSID National Council for 1999/2000 and the first meeting and election of national office bearers for 2000/2001. Details of National Councillors and State Presidents are below. Councillors play a critical role in the operation of ASSID and are thanked for their dedication and commitment to activities and membership. It was announced at this meeting that myself and Bill Taylor, the National Registrar, would not be seeking another term after the final Council meeting for 2000/2001. With this announcement in advance, there is time for Bill to play a mentoring role for any ASSID member who would like to take up the National Registrar's role. If you are interested you are encouraged to contact Bill on (03) 9459 6719.

With the season of jollity, good cheer and a touch of madness upon us, I won't start to delve into business that requires serious thought. Instead I will outline the major business of the National Council meetings and flag some of the activities and considerations for ASSID in the coming year.

Membership

The fees collected through its membership fund ASSID's activities and a constant aim of National Council is to maintain and extend the membership so that the organisation remains viable. Recruitment and retainment of members is achieved through the provision of the journal, magazine, conferences and other events. It is important that non-members are made aware of the value of being an ASSID member through marketing and publicity. Also, it seems that there are a number of people who want to continue to be ASSID members but are unaware that their membership has lapsed.

The marketing committee of National Council has developed a marketing plan, with strategies aimed at attracting and maintaining members of ASSID. Apart from

recruitment strategies, a number of initiatives are to be put into place to help existing members renew their membership next year. These include a 10% discount and protection from any price increases for members paying 3 years in advance and the provision for continuing authority for membership renewal. It was also decided that there would be no increase in membership fees for 2000/2001.

The Disability Foundation of Australia

The National Council on Intellectual Disability and ASSID are working together to establish a Foundation that would attract sponsorship from non-traditional sources of funding. This Foundation would initiate and manage research projects that are critical to the live of people with disabilities.

While still in the early stages, this collaboration will continue and represents an ideal project where ASSID and NCID can join forces, maximising the strengths of both organisations.

Review of the Constitution

This year saw the adoption of a new mission for ASSID. With the accompanying aims and objectives, the new mission is now inconsistent with the existing Constitution of ASSID. There has also been some work done towards the inclusion of New Zealand as branch in ASSID.

Both of these developments mean that it is the ideal time to review the ASSID Constitution. A working party has been established to undertake this work. The working party consists of myself (Karen Nankervis), Sue Peden, Paul Grevell and Keith McVilly. National Council also invites any other ASSID member who is interested in this project to contact us.

On behalf of the National Council of ASSID, I wish a happy and safe Christmas to you and your families.

Karen Nankervis *National President, ASSID* ♦

ASSID National Executive

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Magazine Editor	Ms Ann Penhallurick	02 9566 4789	penhall@bigpond.net.au

ASSID National Councillors

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QLD	Ms Madonna Tucker	07 3840 1983	m.tucker@mailbox.uq.edu.au
SA	Ms Jennifer Blackwood	08 8266 8513	idaainc@senet.com.au
WA	Dr Mark Rapley	08 9360 2861	mrapple@socs.murdoch.edu.au
Tas	Ms Mr Steve Bristow	03 6336 4306	bristows@tafe.tas.edu.au

Upcoming Events . . .

Sydney, 15th Feb 2001

Reproductive Health of Women with Disabilities National Forum,

Women With Disabilities Australia (WADA)
PO Box 229 Dickson 2602 ACT
Ph: 02 6242 1310 Fax: 02 6242 1314 Mobile: 0407 301 746
Email: mmda@ozemail.com.au
Website: www.daorg.au
Contact: Carolyn Frohmader, Executive Director

16-17 Feb 2001

Disability Conference

The forum is being run in association with the conference *Disability With Attitude: Critical Issues 20 years After IYDP*,
For information about the conference contact:
Social Relations of Disability Research Network,
School of Social Work, Level 15 Matthews Building,
University of New South Wales, Sydney NSW 2052
Tel: 02 9385 1870 Fax: 02 9662 8991
Email: dwaconf@unswedu.au
Website: www.arts.unsw.edu.au/socialwork/disability.html

4-7 March 2001


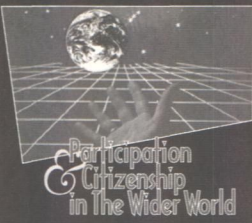
6th National Rural Health Conference Canberra

Contact PO Box 280 Deakin West ACT 2600
Phone: 02 6285 4560 Fax: 02 6285 4670
Email: conference@ruralhealth.org.au or
Website: www.ruralhealth.org.au

22-28 April 2001

First International Conference of the Specific Learning Difficulties Association (SA) Inc. Dyslexia - What's New?

Adelaide Contact SPELD (SA) Inc. PO Box 83 Glenside SA 5065
Phone: 08 8431 1635
Fax: 08 8364 5751
Email: info@speld-sa.org.au or
Website: www.speld.sa.org.au



36th Annual Conference
of the
Australian Society for the Study of Intellectual Disability
Copland Theatre,
University of Melbourne
November 12th-15th, 2001

Further information:
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Fax: (03) 9925 7303
Email: karen.nankervis@rmit.edu.au
Website: <http://www.rmit.edu.au/departments/ps/assid/>

ADHD IN THE THIRD MILLENNIUM - PERSPECTIVES FOR AUSTRALIA.

March 16, 17 & 18, 2001,
CHERI sixth annual Conference.
Westmead Hospital, Sydney.

Keynote speakers will be

- **Russell Barkley**, Professor of Psychiatry and Neurology, Uni of Massachusetts Medical School and
- **Rosemary Tannock**, Senior Scientist, The Hospital for Sick Children, Toronto.

For further information please contact **Leslee Edwards** on

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