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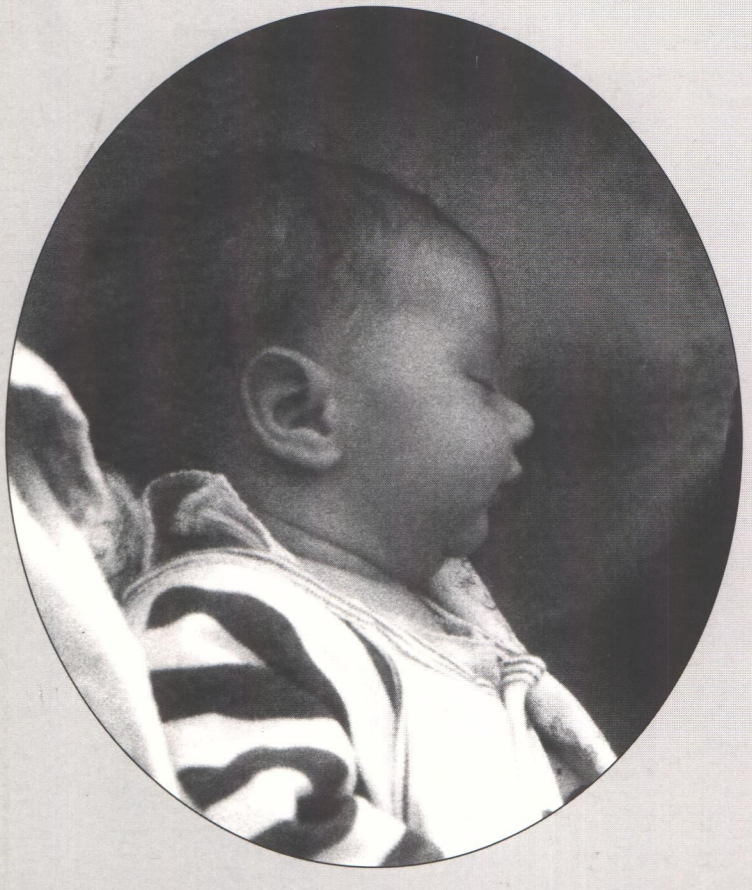

Sleep Disorders Report

from Amanda Richdale, RMIT

Inside:

Magazine of the Australasian Society for the Study of Intellectual Disability

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Contents

Editorial


Deb Keen

There are probably times when all of us have felt deprived of sleep and have experienced the many effects on our mental and physical health and well being. Individuals with intellectual disability are far more likely to have difficulties with sleep, whether temporarily or over an extended period of time. Of course, inability to sleep or disrupted sleep patterns can and do impact on family and others that come into contact with the individual who is experiencing these difficulties. In many of the biographical accounts of autism written by parents, there are often moving accounts of the consequences of sleep deprivation, as their child's activities in the small hours of the morning mean little sleep for family members. In this edition of IDA, Amanda Richdale provides us with a succinct overview of the issues associated with sleep disturbance and current views on the best ways of managing this problem. Our June edition of IDA also provides some interesting reading about the way disability is portrayed in print with an article written by Chris Kilham from the University of Canberra. A book review on literacy for individuals with intellectual disability and updates on ASSID in Australia and New Zealand complete this edition. You will also find out about our new secretariat as we introduce you to the staff from Parfett.

Our next two editions of IDA will focus on special topics and there is still an opportunity to make a contribution to these editions. In September, the special topic will be challenging behaviour. Book reviews and articles will examine this topic, providing up to date information on current research and practice in this area. The December edition will focus on the health and well being of individuals with an intellectual disability. This will include consideration of general health, mental health, and quality of life and will again include articles and book reviews to provide information on current practices in this area. If you would like to contribute, or get in touch with me about these special editions, please email me deb.keen@uq.edu.au.

Deb Keen
IDA Editor

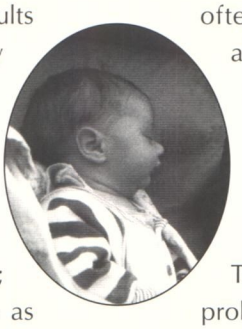
Never forget
you are
invited to
contribute!
Send your news, views, letters, reports on best practice to
deb.keen@uq.edu.au

Sleep Difficulties in Children with an Intellectual Disability

Amanda Richdale
Psychology & Disability Studies, School of Health Sciences, RMIT University, Bundoora, Victoria.

The Sleeping Difficulties

Childhood sleep difficulties are common and can be associated with other problems such as poor attention and concentration, difficult behaviour, and anxiety in children, and maternal depression and family stress and discord. Children with an intellectual (or developmental) disability are more prone to sleep difficulties than typically developing children. The prevalence of sleep problems in children with an intellectual disability averages from under 20% to over 80% of children surveyed. In many cases parents report that sleep problems are chronic, lasting on average 6 to 7 years. As sleep problems are also common in adults with an intellectual disability it is likely that they become a life-long problem for some children with an intellectual disability. The wide variation in prevalence rates occurs for a number of reasons including the age of the children studied; the degree of intellectual disability, the presence of specific developmental disorders like autism; the presence of other medical conditions such as asthma or epilepsy; the definition of sleep problems used by the researchers; and the way participants are recruited.



There are three broad groups of sleep disorders:
(1) Difficulty falling asleep, staying asleep or excessive daytime sleepiness, that may be caused by intrinsic (biological), extrinsic (environmental), or circadian (timing of sleep within the day) factors. These are referred to as dyssomnias.
(2) Problems such as nightmares, night terrors, sleep walking, or teeth grinding that is, sleep disorders that intrude on sleep. These are referred to as parasomnias.
(3) Sleep disorders that are secondary to another mental or medical condition. Extrinsic sleep disorders are particularly common in children, including children with an intellectual disability.

While shortened night sleep occurs in some children with an intellectual disability, there is currently no reason to suppose that children with an intellectual disability generally require more or less sleep than other children. Children's sleep length decreases with age and there is also considerable variability within any age group. Average sleep requirements over the 24 hour day vary: At one year of age children sleep around 15 hours (some of this being taken as a daytime nap or naps), by age 4 this has reduced to 11-12 hours (some children may still have a daytime nap); while by middle childhood, children average 8 – 10 hours sleep, dropping to 7 – 8 hours towards the end of adolescence.

Parents of children with an intellectual disability typically report that their child has difficulty settling to sleep, co-sleeps [sleeps with their parent(s)], wakes frequently and disturbs others, wakes too early, or sleeps too little: These problems are reported more frequently than for other similar age children. Parasomnias such as sleep walking, nightmares, or night terrors do not seem to occur more often in children with an intellectual disability, although there is not much research about parasomnias in these children. Bedwetting is associated with sleep disturbance, and most probably occurs more frequently due to the delays and difficulties that often occur with toilet training children with an intellectual disability. There is little research about the impact of sleep problems in children with an intellectual disability. However, the presence of sleep problems is associated with more difficult child behaviour problems, and increased family stress. There is also some evidence that treating the sleep problems results in some improvements in daytime functioning or behaviour.

Treatment

Given that sleep difficulties are common, long term, and are associated with behaviour problems and family stress it is surprising that investigations of treatment options are uncommon for children with an intellectual disability and sleep problems. There are several important treatment issues including the small number of studies on which recommendations about intervention are based; few randomised medication or behavioural trials or other well controlled studies involving children with an intellectual disability; and little attention to the potential impact of child and family factors on assessment and treatment choice.

Parental perception of a sleep problem is important, especially given the negative impact sleeping difficulties can have. Nevertheless, other things such as the frequency, duration and severity of the problems reported are also very important. It is those parents who

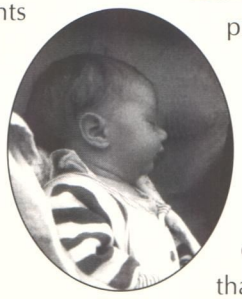
continued page 4

Sleep Disorders

continued from page 3

believe that their child has a sleep problem who are most likely to seek treatment. Some parents do not seek treatment for their child's sleep problem even when they believe one is present. When parents do seek treatment, a range of treatments are offered, including medications for which there may be little evidence of effectiveness, a behavioural intervention that may be poorly implemented and monitored, or a combination of both. Parents also use a variety of alternative treatments, which generally appear to be ineffective. As well, some parents report that the sleep problem is viewed as part of the child's disability that must be put up with, rather than as a problem that can respond to treatment.

Before beginning any treatment, it is important to take a thorough history of the child's sleep problem, and any other behavioural or medical concerns. Current information about the child's sleep should also be collected, and this is best done by the parents keeping a child sleep diary for two weeks. Armed with this information the clinician is in a position to thoroughly evaluate the problem, decide whether further investigations (e.g., polysomnography for sleep apnoea) are needed, and along with the family determine the most suitable treatment approach.



Medications with sleep-inducing effects are reported as useful, and are usually prescribed by a doctor. However, despite this, research supporting these medications is generally lacking and recommendations appear to be disability who are already likely to be on medication because of other factors associated with their disorder, and who in some cases (e.g., autism) may experience unexpected drug effects, the use of medication can also cause additional worries. Nevertheless as a form of short-term relief medications may be useful; research with young, typically developing children suggests that medications are also helpful in calming the child while a behavioural intervention for the sleep problem is begun. There is some evidence that melatonin (a hormone involved in regulating the sleep / wake cycle) is useful for treating sleep problems in children with an intellectual disability, particularly for difficult cases, but it should only be used with medical supervision; while no side effects are reported, research is still limited.

For sleep problems such as settling, co-sleeping and night waking where the child disturbs other members of the family, an appropriate bedtime routine and the use behavioural approaches to treatment are likely to work. These sleep problems are frequently associated with inappropriate bedtime routines, an inability to self-soothe when night waking occurs, or the association of settling to sleep and staying asleep with parental presence or the presence of other comforter items (e.g., a bottle). That is they are extrinsic problems and sleep is under the control of inappropriate stimuli (e.g., the bottle), or is inappropriately rewarded (e.g., by getting a parent's attention). Some parents may also have unrealistic expectations about the amount of sleep their child requires.

Good sleep hygiene is important. Children should have a regular bedtime routine and be put to bed and woken at an appropriate time for their age, average sleep needs and daily routine. For some children, using appropriate sleep hygiene practices may be sufficient to treat the sleep problem.

Standard extinction (where the child is put to bed and ignored) is currently the best supported treatment for settling and co-sleeping as well as some night waking problems in children with an intellectual disability. However some practitioners believe that it is too stressful for the family and child because of the likelihood of an extinction burst where behaviour becomes temporarily worse before it improves. Nevertheless it is fast (usually working in a few days) and there are now several studies showing that when parents are provided with appropriate training and support extinction is acceptable and can be used successfully. It is not recommended if children are ill or have serious medical conditions.

If standard extinction is not suitable a range of other, more gradual behavioural approaches may be effective, for example, graduated extinction, bedtime fading, fading with parental presence, and bedtime scheduling. However these approaches can take from a few weeks to a few months to work completely. Again parent training and support is important, though a recent study suggests that many parents will do well with good written advice. Information about the various behavioural approaches for treating sleep problems can be found in the references at the end of this paper. Their choice depends on the presenting problems and child and family characteristics.

Sleep problems can also be associated with psychological disorders such as anxiety or depression. In these cases it obviously important to get appropriate clinical help to treat the underlying psychological disorder, and the sleep problem may improve with this treatment. Sleep problems can be associated with epilepsy, which is more common in children with an intellectual disability, and this may need to be excluded in some children with night waking problems. Asthma is also associated with sleep

continued page 5

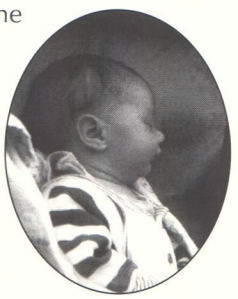
Sleep Disorders

continued from page 4

disturbances and may need to be considered. Finally children with disorders associated with intellectual disability, such as cerebral palsy have a high rate of sleep problems. While research is lacking, it is likely that medical problems associated with their disorder and night-time discomfort experienced by these children cause them to wake and disturb others. Research is needed on the best way to treat sleep problems in these children.

Conclusion

Thus, sleep problems, especially settling, co-sleeping and night waking, are common and often long-lasting in children with an intellectual disability. While there may be many causes, these more common sleep difficulties are likely to respond to a behavioural intervention. A number of issues remain largely unanswered, including why sleep problems are so frequent, the impact of these sleep problems on the family and child, and appropriate and effective approaches to treatment.



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*This book is useful for parents as well as professionals.

CALL FOR CONTRIBUTIONS

INTELLECTUAL DISABILITY Australasia

*will focus on **special topics** in the next two editions.*

Book reviews and articles will provide up to date information on current research and practice in these areas.

September's special topic is **CHALLENGING BEHAVIOUR.**

December's edition will focus on **HEALTH AND WELL BEING.**

If you would like to contribute, or get in touch with me about these special editions, please email deb.keen@uq.edu.au.

"Who Cares for the Carers"

- some brief comments

by Rowanne Janes samsrj@actrix.co.nz
& Angus Capie angus@actrix.co.nz

In New Zealand the vast majority of people with an intellectual disability live with their own families, despite the significant increase in residential providers in the last decade. The National Health Committee report "To have an Ordinary Life" released in early September 2003 received a reasonable amount of coverage in the national media. (available at www.nhc.govt.nz, along with a significant number of reviews of service issues undertaken by the Donald Beasley Institute)

The project looked at the lives of adults with an intellectual disability and noted many issues that need to be addressed. It was interesting that most of the media coverage focused on medication issues, and little notice was paid to what many of us consider just as important - the need to make major changes to the way people's lives are controlled by service providers. The report acknowledges that "family/whanau[1] play a critical role in the long term support of adults with an intellectual disability" and recommends that families and whanau are adequately supported. Over the last four years the Standards and Monitoring Services (SAMS) has run a series of 45 workshops across New Zealand with a group of family members who described themselves as unpaid carers.

Some of the findings.

The workshops were held over 1 or 2 days depending on location, and 680 unpaid carers participated. There was no charge to participants as all costs were met with funds supplied by the Ministry of Health. The age range of participants was from 17 to 80 years.

One of the more alarming findings was that in this sample, around 13% of the carers were over 64 years of age and were still caring for an adult with a disability at home. Grant et al. (1998) point out that carers do not necessarily perceive themselves as being "stressed" and emphasize the rewards and satisfactions of caring more frequently than the stresses. However with the increasing longevity of people with disabilities many are going to outlive their carers.

Are we addressing this need? The answer in short is no. Despite the recent steps to improve communications, most carers report that it is exceedingly difficult to get information about services they could access. They regularly identify fragmented service delivery as a major obstacle. Many report that service providers can rarely give them comprehensive information about services in their area. They also repeatedly point out (as does the National Health Committee's Report) that the services that are available are often based on a model that is unacceptable to them.

A prime, widely accepted need that carers have is to receive quality respite care. It is therefore disappointing to find that practically right across the country families find appropriate respite care out of home exceedingly hard to

[1] Whanau is a Maori word that is now widely used in NZ English to describe the extended family.

continued page 7

"Who Cares for the Carers"

continued from page 6

	Strategy	Comments workshops and NHC
15.1	Needs Assessment to be holistic.	Current process not working well. (National Health Commission Report)
15.2	Improve Support and Choice.	Too Limited - SAMS and National Health Commission models.
15.3	Provide Education and Information	Some progress but need one information base.
15.4	Family/Whanau Input	Still inadequate.
15.5	Develop Resource Kit for Professionals	Dissatisfaction with professionals' approach common.
15.6	Work with Families in Policy Development	Ministry of Health, and National Health Committee report promoting different models
15.7	Debate on Caring and payment	Office of Disability Issues is undertaking a study.
15.8	Provide accessible information for families and others who support people with disabilities	Weka Website but still no one stop shop. Many carers say web searches too time consuming.

access, and often find it a nightmare to recruit anyone to provide in-home respite care.

For a variety of reasons many carers who participated in the workshops did not use services, and were largely outside any Disability Support system. (In a small study of carers, Janes (2001) showed that 47% of those caring for people over the age of 25 years reported they did not receive support from any formal support services, and 52% of carers caring for people under the age of 25 years reported they did not receive support from any formal service.) We know from UK figures (Horne, 1989) that both epidemiological data and empirical evidence clearly indicate the existence of a hidden population.

The New Zealand Disability Strategy selects eight areas in Objective 15 that particularly relate to families. A simple examination shows that much remains to be done before carers needs are met.

In Conclusion

We believe that the programmes run for carers partially satisfied an unmet need. However it is also clear that much still needs to be done for this group of citizens before they are fully recognized. Indeed we believe that the time is ripe to replicate the excellent studies completed as part of the National Health Committee's report, and focus on obtaining a National Strategy to address the unmet needs of this large and neglected group of citizens. It is clear from the comments of carers that professionals could do better. We all need to reflect on this.

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New Zealand

Since the last IDA, NZASSID has organised two very successful meetings with Professor Tony Holland. Tony, who has a chair in Learning Disability at Cambridge University and is well known to many ASSID members, gave a public lecture at the Christchuch Medical school to over 50 people.

In Auckland more than 40 people attended a seminar he conducted. The topic covered at both meetings was "Understanding the links between genetic syndromes associated with intellectual disabilities and behavioural and psychiatric disorders". Both presentations were warmly received. Tony was in NZ as a keynote speaker at the International Prader Willi conference and was kind enough to make his services available to NZASSID. The meetings were also used to promote NZASSID and upcoming conferences in Christchurch, Adelaide, and next year in Auckland.

Planning for the 2004 NZASSID conference is in hand with a call for papers going out in 2-3 weeks time. The conference will be held on 30th September to 1st October at the Holiday Inn in Christchurch. The conference theme is 'Journeys' and keynote speakers include Stephnie Roberts, Bob Davis, and Glynnis Murphy. There will also be a self advocacy stream. For further details contact OWebb@richmond.org.nz

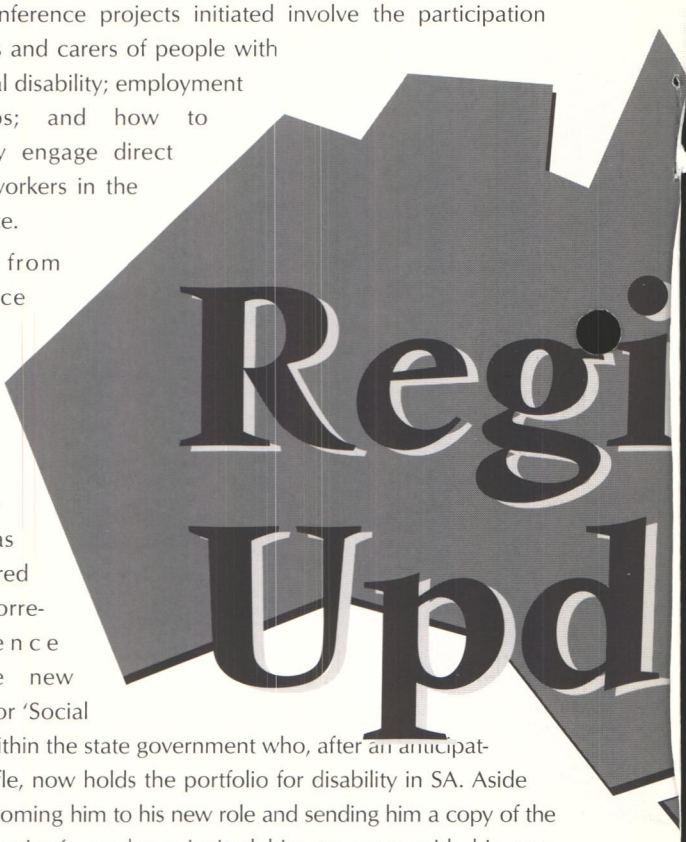
Both the NZ conference planning group for Christchurch and the Australasian Conference planning group, have met to discuss the 2005 Australasian conference. A progress report on our planning for the conference will be given at the ASSID mid year meeting in Melbourne.

Angus Capie

South Australia

The South Australian Branch has been primarily focussed on preparations for the annual Australasian conference in November 2004. Our advance publicity campaign is on track with a 'postcard' and initial call for papers having been distributed widely in hardcopy and electronic versions. (Printing and distribution of the registration brochure is imminent).The conference programme committee has been meeting on a monthly basis with a core committee and a number of 'corresponding members' contributing. A number of exciting projects have been initiated though the work of this group. One of the aspects that the SA organising and programme committee is focussed on is 'self advocacy'. To this end, the conference convenor has addressed meetings of CEOs and managers of both the non-government and public sector agencies inviting them to consider who amongst their clients they should be considering supporting to prepare presentations for the upcoming conference. We have also approached agencies that may be able to assist in these matters and are anticipating input from the "Our Voice" committee of NCID. In reference to the self advocacy stream, we are asking people to think broadly about the type of presentation they may want to support their clients /sons and daughters to undertake. We suggest that agencies, staff, carers, and clients from interstate also give some consideration to this opportunity. In an effort to provide some practical assistance for this idea, we have submitted an application to the Commonwealth Department of Family and Community Service Disability Conference Funding Program to support the participation of people with disabilities at the national conferences. We are optimistic that we have a real opportunity to significantly increase the participation of people with an intellectual disability in the 2004 conference. For further updates visit the website (See the events section on the ASSID website).

Other conference projects initiated involve the participation of parents and carers of people with intellectual disability; employment workshops; and how to effectively engage direct support workers in the conference.



Aside from conference preparations, the ASSID (SA) committee has also entered into correspondence with the new minister for 'Social Justice' within the state government who, after an anticipated reshuffle, now holds the portfolio for disability in SA. Aside from welcoming him to his new role and sending him a copy of the SA communiqué, we have invited him to meet with his constituency over a meal (breakfast or dinner), seeking to repeat the previous successful 'Meal with the Minster' event involving the previous minister. If the Minster takes up our invitation we shall circulate flyers to the SA and NT membership and our usual mailing lists.

Richard O'Loughlin

Queensland

The Queensland branch is looking forward to hosting a dinner with the State Minister for Disability Services, Communities and Ageing, The Honorable Warren Pitt on Tuesday 4 May. Mr Pitt is a relatively new minister (some two months in the job) and has been asked to provide with information about his view of the issues currently facing disability services in Queensland.

The Branch also has a hot topic night planned sometime soon in Toowoomba around the topic of dual diagnosis. Apart from that we are gearing up for the annual Sharing the Road conferences in July (Brisbane) and August (Cairns). The State conference will happen on July 18. More on that in the next edition.

Chris Montgomery

New South Wales

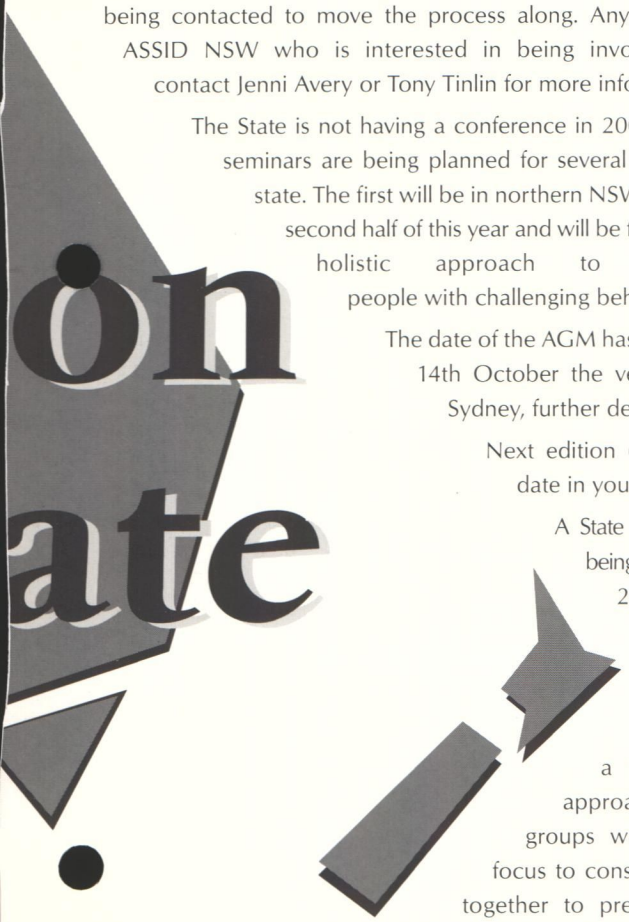
A note to ACT members. The committee will endeavour to ensure that ACT is included as part of our title. I will raise the matter at the next national council meeting to see what has to happen to officially include ACT in our title, making our Association the NSW & ACT Association.

Planning for this year has taken place, and regular meetings of the committee are being held. An outcome of the 2003 conference in Albury was that ASSID NSW would develop a position statement on Health. Those people who expressed an interest are being contacted to move the process along. Any member of ASSID NSW who is interested in being involved please contact Jenni Avery or Tony Tinlin for more information.

The State is not having a conference in 2004, however, seminars are being planned for several areas in the state. The first will be in northern NSW early in the second half of this year and will be focusing on a holistic approach to supporting people with challenging behaviour.

The date of the AGM has been set for 14th October the venue will be Sydney, further details

Next edition (but put this date in your diary).



A State conference is being planned for 2005 and will be held in Sydney. The early thoughts are around approaching other groups with a similar focus to consider working together to present a very interesting conference. If you are interested in being involved or have suggestion please contact a member of the State committee.

2006 is NSW turn to host the national conference. It has been decided that the Conference will be held in Canberra.

Tony Tinlin

Victoria

The last few months have been characterised by change as some Victorian members have settled into new council roles and we have been reassessing the resources and supports available to us. It has been interesting and somewhat challenging at times to reconcile the sometimes unstable nature of employment with the need to provide consistent contact details of event organisers to members. For example, does a council member provide their home or mobile telephone number to address queries about an event they are organising when their working week is divided between two services, and a direct telephone line is only available at one service but diverts to the secretary when they are not there? Such questions have recently been raised during the course of event development and have lead council to investigate alternate options. In line with the theme of change, the monthly Victorian Newsletter has unfortunately fallen by the wayside. We anticipate this to be temporary because council members agree that it is an important means of contact with the wider membership and we are reassessing the format and considering electronic distribution.

During April Mr Bill Taylor and Dr Karen Nankervis were officially each presented with a Distinguished Service Citation at a well attended dinner in a restaurant that continues to be popular for regional events such as these. Many thanks go to Dr John Annison who recalled working with Karen and Bill amongst others, on ASSID over the years, and who presented them with their awards. Thanks also to Dr Chris Fyffe who relayed very pertinent results from a research project about community living.

Any mention of Bill and Karen's dinner would be incomplete without acknowledging the ongoing involvement (since birth) of the "children of ASSID", Amelia and Henry Taylor. Although the dinner celebrated significant contributions made to ASSID by Bill and Karen, it equally signified, to the delight of Amelia and Henry, a minimised responsibility to attend meetings, conferences and of course, stuffing all those bloody envelopes! The Victorian branch thanks Amelia and Henry for their work, good company and sense of fun over the years and wishes them too, a happy retirement.

Alex Phillips

Tasmania

The last few months have been quiet for Tassie with all committee member having very bust lives outside of ASSID. We have decided to forego a regional conference this year and instead we are focusing on sponsoring a couple of workshops with a view to holding them in each region in Tassie. This will mean some pretty heavy work from now into the later part of the year with trying to organise the right speakers with the time frame and small budget ASSID has.

The committee is also working on its own award for student working in the disability sector. In the past we have sponsored TAFE students with ASSID awards however being the climate of traineeships and many recognised training authorities (RTO) to choose from we have decided to expand the eligibility to an ASSID student award with our committee making the decision rather than another organization. More information to come on this later in the year.

The other big thing we will focus on this year is an induction manual for new ASSID committee members. We are hopeful that the national committee member handbook will be very helpful in this project as a lot of hard work has been put into the handbook to date and it is obviously best for our members if "we don't reinvent the wheel".

Darryleen Wiggins

Depictions of Disability: A Way with Words

by Chris Kilham, University of Canberra

This paper traces our developing understanding of children with additional needs between 1960 and the year 2000, and is based on text in the Australian Journal of Early Childhood (AJEC) and the Australian Preschool Quarterly.

LANGUAGE

The terms used to describe people with disabilities can be a litmus test of attitudes towards them. In keeping with historical developments, the language in the disability field has evolved over the years. Perhaps the most transparent indicators of change are "people first" expressions.

People First

When scanning the articles I was prepared for the earlier items to refer to people by their disability category. For example "the post-polios"; "a diabetic"; "young Downs". It was rather more confronting to read that a child was referred to as "a feeding problem" and "a low grade mongol" or that a new mother was counselled by her doctor not to take it home, because it will never do anything (where "it" referred to her baby with Down syndrome). Today, these seem very impersonal referents, emphasising people's deficits. However, the backdrop of the day was where normalisation - giving people with disabilities the choice to live more like mainstream society - was just beginning.

A less extreme but persistent form consists of describing the disability before the person as seen in "the brain-injured child"; "deaf/blind child"; and "handicapped child".

It was rather more confronting to read that a child was referred to as "a feeding problem"...

Such language is not recommended today. This is mainly because such terms suggest that people with the same disability form an homogeneous group. By obscuring the uniqueness that typifies all human beings, it is in effect depersonalising them. Instead, "people first" language is considered best practice. For example, "child with acquired brain injury" replaces "the brain-injured child" and "children with additional needs" is used in preference to "special needs children". This type of language was first noted in AJEC in 1976, but people first terminology was not consistently evident until the 1990s.

There are several sporadic objections to this view, some of which have been voiced by people with disabilities themselves. For example, Vaughan (1999), himself blind, states that being blind is an important part of his self concept. If anything needs to be changed, it is the connotations of disability, not the terms themselves. For these reasons, vestiges of non people-first language remain today. Usually this occurs because of a reaction to political correctness and frustration with the more cumbersome language that it requires. It is much quicker to write "the ADHD child" rather than "the child who has been diagnosed with ADHD".

The ultimate test is of course to ask people with additional needs how they wish to be designated.

DEPICTIONS OF DISABILITY

Closely related to the question of language is how children with special needs have been portrayed.

Disability as deficit.

There was a tendency in the 1960s and 1970s to envisage people with special needs largely in terms of their permanent deficits. For example "deafness imposes a severe handicap on a child due to the loss of his most important biological sensory modality, the lack of social contacts and the consequent retardation in language development" (Nall, 1962, p 19)

One of the biggest antidotes to the view that disability was a permanent deficit was the emergence of early intervention, which focuses more on what the child can do. Authors using this theme in the 1980s and 1990s were more likely to assume the potential for improvement. For example: "children with special needs might benefit from the day care environment (eg opportunities for language learning)" (Schneider, 1986, p 43).

Another outcome of rejecting the "deficit in the child" view, was that programs became multi-faceted. Programs supported not just the individual child, but their wider environment, including the whole family unit. This approach has become known as "ecological" approach.

How can this more holistic way of thinking be transferred into practice? Some pointers can be found in the process of Individual Education Planning. Many practitioners insert explicit questions relating to the child's

continued page 11

Depictions of Disability

continued from page 10

strengths and interests into proformas which are then distributed to relevant parties for a considered response. Collaboration with all stakeholders is then encouraged to formulate a realistic set of long-term and short term goals that will have value and significance for individual children. Affirming questions such as "What is your dream for your child?" are becoming more customary. Overall, we need a planful approach with explicit reminders to think comprehensively.

They deserve our pity

Before the 1980s, articles were much more likely to contain phrases such as "suffering from" "burdened with multiple handicaps"; "confined to the hospital"; "bed-ridden child". These are all highly charged terms that emphasize the downside of having special needs. They segregate and dis-empower these children and their families, by suggesting that they are different from us and deserve our pity.

> "The parent has been right in many instances and the teachers and psychologists may well have been wrong" (Rees, 1976, p 31)

In relation to early childhood practices, positive depictions of– and even better, contact with – people with disabilities is a recommended way to combat negative attitudes. The Paralympics has proved timely in helping celebrate the achievements of people with disabilities, and positive role models can be found in many other walks of life. Newspaper clippings, TV and movie excerpts, and even "Barbie doll in a wheelchair" can provide fertile ground for discussion. Finally, why not encourage contact with relevant visitors with disabilities, who typically can deal with children's unexpected questions with such aplomb, humour and realism?

Normal vs non-disabled

Use of the word "normal" has also changed over the years. In the 1960s, virtually every article used the "n" word like an antonym, to mean "a child without disability / special needs". In the next decade, there were some modifications: articles about children with sensory disabilities (in vision and hearing) usually used the contrasts "sighted children" or "hearing children". Beginning in the 1980s the terminology evolved to statements such as "Placing disabled non-disabled children together". This latter form is accepted usage today.

Are there any lessons from practitioners from this analysis? I believe so. The earlier convention of contrasting a child with special needs with a "normal" child accentuates the divide between them. It suggests they are not one of us, so implicitly excludes them. More recent linguistic conventions are less divisive, and we should take note of them and use them with colleagues, parents and children. If we are to welcome diversity in our society, we need to ensure that our words as well as our actions reflecting an inclusive philosophy, not an exclusive one.

Experts know best

Early articles reflect an "us and them" approach. At times this was downright combative. One author, a psychiatrist wrote: "After having made every effort to keep the child attending, the parent or parents have successfully sabotaged our attempts to do so" (Partiger, 1963 p 18). The pervasive medical approach was not unconditionally accepted however, and paved the way for portraying parents as important though subservient partners. It was not long before the admission came that "The parent has been right in many instances and the teachers and psychologists may well have been wrong" (Rees, 1976, p 31). Again, the stage was set for emerging parent involvement. Parents who advocate for their child will give them a good start on the road to self-determination.

Nevertheless, there is no room for complacency. Critics still warn us of the danger of ascribing too much power to the professionals who claim to know what is needed by people with disabilities. There is a growing movement for self-advocacy and self-determination for people with disabilities, and for family involvement. Many are still fighting for quality assurance, as they perceive that users of disability facilities don't have the clout to buy or reject the service, so feelings of powerlessness remain. Vigilance and sensitivity on the part of today's practitioners remain as crucial as ever.

CONCLUSIONS

Much has been made of changes in terminology in this paper. Yet even when language was used that was politically incorrect by today's standards, there was still a sense of cherishing the child. Indeed, the sentiment that "the child with a disability is first and foremost a child" was reiterated several times throughout the sixties (Eg Nall, 1962, p 20). The sticking point is that some people first learn about children with special needs not through direct experience, nor interacting with them, but by reading about them. The danger in using such language seems that it too easily provides the scaffolding for negative stereotypes, even though they may not have been in the mind of the writer. As one author put it: "The child who is

continued page 12

Book Review:

Literacy for Living Book 1.

Author: Vize, A, 2003

Melbourne: Phoenix Education

Review by: Karen B. Moni,
The School of Education,
University of Queensland

One of the challenges for researchers and educators involved in literacy education for adolescents with special needs is the limited availability of resources that are age and interest appropriate, and yet which also meet the literacy needs of adolescent learners. *Literacy for Living Book 1* written by special education teacher Anne Vize, is a welcome addition to the field.

The book is aimed at Years 7, 8 and 9, however the cover illustrations, some of the themes and suggested activities indicate that the resource would also be suitable for older adolescents. Some of the minor inconsistencies in the materials (e.g. Sally aged 14 earns $88.00 a week from a casual job) suggest that the original audience for some of the materials may have been older.

The book is organised into four units based around short stories. The units are sequenced in the same way beginning with activities that prepare the readers to engage with the text through accessing prior knowledge and relating ideas from the stories to their own experiences. These activities are useful in introducing learners to the concepts and ideas in the stories and the author provides suggestions incorporating a range of oral, writing and visual literacy activities that cater to different learning styles.

The stories are written in a similar informal style and in different genres. *Riley's Party* is first person narrative, *Meeting Zenmaster* is third person narrative with the inclusion of some on-line chat, Barry's diary is a journal, while Facing the music is third person narrative. All of the stories apart from *Barry's Diary* are written in present tense which adds to their immediacy. Each story develops themes that include friendship and families, bullying, tolerance and acceptance of difference and also provides opportunities for learners to focus on practical living skills such as buying tickets for events, dealing with difficult situations, personal safety and taking responsibility for actions. The story in Unit 1 is squarely aimed at adolescents in the middle years, with a story based on a fancy dress party. However, the more mature content of the stories in units 2-4 with topics related to on-line predation, sexuality and shoplifting suggest that teachers should read each unit carefully before using this resource in order to consider its appropriateness for individuals and groups of students. For example, two stories contain material that over-dramatises already difficult situations for the main characters, and which may be both confronting and confusing for some learners. In *Barry's Diary*, Barry not only has to deal with being bullied and coming to terms with his own homosexuality but also with his mother's drinking, while in *Meeting Zenmaster* it is not enough that the Zenmaster is an older man who wants to take 'naughty' (sic) photos of young girls, he has also been taking photos of women in toilets.

Overall, however, the integration of multiple multimedia, oral and print genres, the topicality of the stories and the engaging 'risk-taking' characters ensure that these stories reflect both contemporary understandings of literacy and the diverse range of texts currently studied in English classrooms. This suggests that this resource would be useful for teachers wishing to develop modified units for

Depictions of Disability

continued from page 11

different ...may be handicapped as much by attitudes towards his handicap as by the handicap itself" (Woodroffe, 1970 p 4).

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Book Review:

Literacy for Living Book 1

continued from page 12

students with special needs who are included in regular classrooms, and also for teachers developing alternative programs in mainstream environments.

Following each story are worksheets and activities loosely grouped under the headings of activities for beginning readers, word skills, writing skills, speaking and listening, and research and extension. The strengths of these worksheets and activities lies in the integration of all aspects of literacy and in the choice available to teachers and to learners. For example, included in *Activities for Beginning Readers* are suggestions for community and classroom-based activities that focus on practical as well as literacy skills. Activities in the *Writing Skills* section range from re-arranging sentences, composing sentences, analysing characters, making storyboards and writing action plans or developing flow charts. Activities in all sections cater for different levels of independence and literacy skills. For example, dictionary activities are included in the *Word Skills* section which assume independent word search skills while other activities require learners to circle appropriate words, place words in alphabetical order, and identify word patterns. The worksheets are photocopiable and are clearly presented. Each worksheet is one page in length which makes for easy copying and use, and is organised in the same way with instructions for completing the tasks at the top of each sheet. However, some worksheets may appear crowded and have too small a font or working space for some learners.

This is a useful resource with a wide range of applications. As well as providing four units of work that could be used in modified English, life skills, and community-based programs, the worksheets and activities provide models for developing a similar range of activities around other resources. The content of some of the stories and thus the focus of some activities suggest that as a stand alone resource, the materials may be more relevant to older learners with special needs particularly those with intellectual disabilities, rather than learners in Years 7 – 9.

The 39th Australasian Society for the Study of Intellectual Disability Inc Conference: Visions and Realities is to be held at the Adelaide Hilton, South Australia in 2004.

Visions and Realities - The way things are and the way things should be.
Empowering people with intellectual disability and supporting their families in the 21st century.

Abstracts are to be submitted by 30 June. If you have missed the deadline and still want to submit, please contact Richard O'Loughlin on rolstmarys@esc.net.au ASAP.

Early Bird registration is applicable up until 1 September. Save money, register now. There is a registration brochure with more details inserted in this issue of IDA.

New Zealand members and overseas applicants please note: All costs quoted in registration brochure are in Australian dollars (including membership application details). Payment using a credit card enables automatic-conversion without complication.

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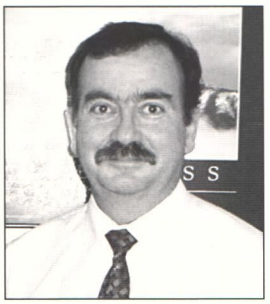
Meet the New ASSID Secretariat

IDA would like to introduce readers to ASSIDs new secretariat. Although they have been involved with ASSID for some four years, Ross Parfett and Margaret Wilson have now expanded their role from accounting to looking after membership issues and a range of other matters that fall to the secretariat. Ross and Margaret have given us a little information about themselves and I must say I'm impressed to find fellow AFL supporters but am surprised to find Margaret owning up to supporting the Bulldogs.

Ross Parfett



My wife, Robyn, and I have two children, Emily 15 and Mark 20 and we have lived in Rosanna and been involved in the local community for 20 years.

I enjoy most sports, a hacker at golf, love cricket and follow Essendon (is there any other team) in the AFL.

Started my private practice 20 years ago after working in a suburban practice for 10 years. Our clients are mainly small businesses enterprises and we enjoy the face-to-face nature of meeting with such clients rather than large organizations.

We have been looking after the accounting requirements of ASSID National for the past 4 years and have recently taken over the secretariat role. Whilst still coming to grips with the particular quirks of the Data base and directing members enquiries to the appropriate ASSID personal, Margaret is working hard to master the system and her always friendly disposition will provide an efficient, cheery first point of call for members.

Margaret Wilson

I have worked for Ross for 15 years (my how time flies when you are having fun!) starting off on a part time basis when my two girls were at primary school.

I was introduced to Ross through his wife Robyn when we were on the local Kindergarten committee together. He's a great fellow to work for and has a particularly good sense of humour, even if he is an accountant! We try to keep our office lighthearted as the work is constant and there are always deadlines.

In my spare time I enjoy painting (watercolour) and going to the football (Aussie Rules) to see the Western Bulldogs (I must be mad as we are always losing). I am a keen genealogist and am increasingly amazed at what we are able to discover about our ancestors and their lives. I never have enough time to pursue this interest.

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Upcoming Events

. . . continued from back page

9/11/2004 - 12/11/2004
39th ASSID Annual Conference
Place: Adelaide, SA
See page 14 for more details

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

Just email ***assid.national@bigpond.com*** *and put* ***'IDA:upcoming events'*** *in the subject line and it will be passed to the IDA editor to go into the next available edition.*

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

Upcoming Events . . .

21/7/2004 - 24/7/2004

One World: Many Childhoods
- Strengthening Early Childhood International Links

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

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

25/7/2004 - 27/7/2004

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

Place: Melbourne, Vic

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

16/7/2004

Helping Young People Grow
Understanding Emotional and Behavioural Problems in Young People:
Modern Approaches to Assessment

Place: Bayview Conference Centre
1 - 19 Hayview Ave,Clayton, Vic 3168
Contact: Mrs Mary Tidey
Phone: (03) 9594 1301
Email: mary.tidey@med.monash.edu.au

The Monash University Centre for Developmental Psychiatry & Psychology, whose mandate is to provide research and teaching in the field of developmental psychiatry with a particular focus on child, adolescent and family mental health is hosting this one day conference.

28/10/2004 - 29/10/2004

Medical Conference "Well Beyond 2004"

Place: Bardon Centre -Brisbane QLD
Contact: Jude McPhee
Phone: (07) 3840 2496
Email: j.mcphee@sph.uq.edu.au

The Australian Association of Developmental Disability Medicine (AADDM) in association with Qld Centre for Intellectual & Developmental Disability (QCIDD) is holding a two-day national medical conference for all specialist and generalist medical practitioners and allied health professionals with an interest in child and adult developmental disability. Keynote speakers include Prof Nick Martin (genetics and behaviour); Prof. Frank Bowling (metabolic disorders); Prof Bruce Tong (ASD); and international keynote speaker Dr Steve Moss (Psychiatric Assessment).The topics covered will include: mental disorders, gastro-enterology, metabolic disorders, ADHD, severe behavioural problems, epilepsy and autism spectrum disorders.

continued page 15