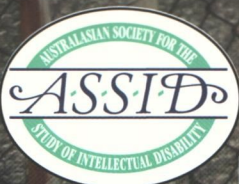


Volume 28, Issue 1 March 2007

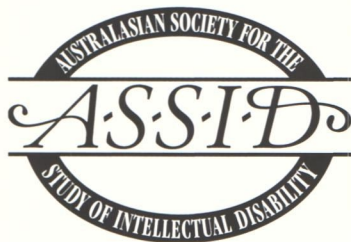
# IDA

ISSN 1446-9987  
Intellectual Disability Australasia

## problem behaviours: getting in early



Magazine of the Australasian Society for the Study of Intellectual Disability



*Intellectual Disability Australasia* is produced and distributed by the Australasian Society for the Study of Intellectual Disability.

The views expressed in this newsletter are not necessarily those of the Australasian Society for the Study of Intellectual Disability.

**Editor:** Deb Keen

**Phone:** (07) 3735 5643

**Email:** d.keen@griffith.edu.au

**Editorial Assistant:**

Ross Tudman

**Advertisers:**

Rates are available, on inquiry, from the editorial assistant at [krvt@optusnet.com.au](mailto:krvt@optusnet.com.au)

**Editorial Address:**

78A Cheltenham Rd,  
Croydon, NSW, 2132

**Membership and Subscription Information:**

Margaret Wilson  
ASSID Secretariat  
PO Box 84  
Rosanna VIC 3084  
1800 644 741  
[assid.national@bigpond.com](mailto:assid.national@bigpond.com)

**Artwork:**

krvt DESIGN  
[krvt@optusnet.com.au](mailto:krvt@optusnet.com.au)

**Printed by:**

Bloxham & Chambers Printers

## Contents

Getting in Early .....	3
Region Update .....	8
Community use of Intra Nasal Midazolam .....	10
Book Review The Dancing Dialogue .....	11
Book Review Going to College .....	12
Upcoming Events .....	15

**Front Cover:**

Photo courtesy of Zak & MC VT

# Editorial



**W**elcome to the first issue of IDA for 2007. Our feature article for this issue was written by Richard O'Loughlin from South Australia and it examines risk and prevention factors associated with challenging behaviour. Richard leaves us with many questions that help to frame a context for on-going research in this area to improve outcomes for individuals who have, or are at risk of, challenging behaviour.

Sheridan Foster provides us with a plain English version of an article written by Margaret Kyrkou, Michael Harbord, Nicole Kyrkou, Debra Kay and Kingsley Coulthard for the ASSID Journal of Intellectual and Development Disability (JIDD) on the use of Intra Nasal Midazolam for managing prolonged seizures. This article, which presents the potentially life-changing research of these authors, won the JIDD Australasian Research Prize in 2006.

Usual features such as the regional reports from around Australia and New Zealand can be found in this issue together with two book reviews. We continue to have a number of books available for review and would welcome contact from readers interested in undertaking a book review for IDA. Send an email with information about your particular areas of interest to [d.keen@griffith.edu.au](mailto:d.keen@griffith.edu.au). Details of books that may be of interest to you can then be sent and you may choose to accept or reject the offer to review.

Starting below, photos from the Disability Support Workers Conference and the Disability Support Professional Ethics Workshop are spread throughout giving us glimpses of the good work done there. See the regional report from Victoria for details.

**Deb Keen**



# Getting in Early

## Risk Factors and a Preventative Approach to Challenging Behaviour: Towards a Research Agenda

*Richard O'Loughlin*

Senior Psychologist  
Intensive Intervention Team  
Disability Services

SA Department for Families and Communities



Disability Services (SA)'s "Intensive Intervention" team provides support to families who have children with challenging behaviour and are at risk of breakdown. The team doesn't keep a waiting list but advertises vacancies when the team has capacity to take on new clients. The selection criteria used to judge whether a family or individual 'gets a guernsey' is generally expressed in terms of severity of behaviour and risk of family breakdown. Team members often feel that what they are able to provide is too little, too late. The challenging behaviour and associated patterns of interaction between family member and the individual are entrenched. The family is exhausted.

Could the team have made a greater difference if they had been able to intervene earlier? The classic difficulty is that at the time when the team might've been able to more effectively intervene, the behaviour was not of sufficient severity such that the family would have been able to access our service.

This is the bind.

Despite the intervention and behaviour management literature making a strong case for early intervention (eg Murphy, Hall, Oliver & Kissi-Debra 1999; Sloper & Turner 1993; Russell & Harris 1993) access to supports – whether it be specialist programmes, or discretionary funds administered by community teams, tend to be based on severity of behaviour and imminent risk. This paper proposes that we introduce another dimension to our thinking: "The capacity to benefit" (Baker 1995).

This forms a need matrix:

Low severity challenging behaviour	Low severity challenging behaviour
Low capacity to benefit	High capacity to benefit
High severity challenging behaviour	High severity challenging behaviour
Low capacity to benefit	High capacity to benefit

To enable us to utilize this dimension requires that we identify those clients and/or circumstances where challenging behaviour is likely to develop in the future. The other key issue to consider is how we might identify and assess: 'capacity to benefit'.

So, the questions to address:

- i) Can we identify those factors that characterise clients with an intellectual disability who are likely to display challenging behaviour in the future?
- ii) Can we identify those carers and family factors that are associated with challenging behaviour, or are indicators of increasing or reducing carers' capacity to benefit; capacity to cope, (or 'family resilience')?

### Risk factors and vulnerability

Examining the characteristics of those that have intellectual disability and display challenging behaviour enables the identification of consistent patterns that can be described as 'risk factors' (Sigafos, Arthur & O'Reilly, 2003). The presence of such factors corresponds with increased probability of displaying challenging behaviour.

Incidence of challenging behaviour is two to three times higher amongst people with a developmental disability than it is when compared to the rest of the population (Enfield and Tonge, 1996; Parmenter, Einfeld, Tonge, Dempster, 1998). However, as Sigafos et al (2003) note "the majority of people surveyed in prevalence studies are not identified as having challenging behaviour. Challenging behaviour cannot therefore be attributed to the fact that the person has a developmental disability" (p25).

### Degree of disability

Although various studies have found that prevalence of challenging behaviour increases with severity of disability, (e.g. Borthwick-Duffy, 1994; Kiernan and Kiernan, 1994; Qureshi, 1994, Oliver, Murphy, & Corbett, 1987), the relationship is not straightforward. While there may be a higher rate of challenging behaviour amongst people with a severe intellectual disability, when compared to people with mild to moderate levels of disability, there tends to be a decline amongst those with a profound intellectual disability. This may be related to the fact that many people with a profound intellectual disability have associated conditions resulting in multiple disabilities, such as physical disabilities that make it difficult for them to display some types of challenging behaviour.

*continued page 4*

# Getting in Early

## ... a Preventative Approach ...

*continued from page 3*

Similarly, there are different types of challenging behaviours that are more common amongst those that have a mild to moderate intellectual disability. For example, verbal aggression is more common amongst people with mild to moderate intellectual disability (due to the fact that people with moderate to severe intellectual disability are less likely to be able to speak). Similarly, Einfeld (1992) found that the type of challenging behaviour most likely to be displayed depended on the level of intellectual disability, e.g. aggression and destructive behaviours are more likely to be found amongst people who have a mild to moderate level of intellectual disability whereas self injurious and stereotypical behaviours are more likely to be found amongst those with a severe level of intellectual disability. People with more severe levels of intellectual disability are also more likely to display multiple forms of challenging behaviour (Borthwick-Duffy, 1994; Oliver et al., 1987) whereas those with a lesser degree of intellectual disability are more likely to be 'specialists', displaying particular behavioural topographies.

### Adaptive behaviour

The risk of challenging behaviour is associated with deficits in a range of adaptive skills (Borthwick-Duffy, 1994; Kiernan and Qureshi, 1993). Emerson, Kiernan, Alborz, Reeves, Mason, Swarbrick, (2001) found that those people who showed more demanding challenging behaviour required greater levels of assistance in a range of skills such as eating and dressing, tended to be more likely to be incontinent, and had more restricted receptive and expressive communication.

Amongst people with an intellectual disability, a higher rate of aggressive behaviour is associated with deficits in skills such as communication skills, social skills and independent living skills (Allen 2000).

### Gender

Emerson (1995), states that males are more likely than females to be identified as having a challenging behaviour. This relationship is stronger for aggression and property destruction compared to self injury (Oliver et al 1987; Borthwick-Duffy 1994). However females are more likely than males to display 'multiple topographies' of challenging behaviour (Maurice & Trudel 1982).

Emerson et al (2001) found in their 1995 prevalence study that two thirds of the sample identified as having challenging behaviours were boys or men. In contrast, Sigafos et al (2003) reports that, "gender does not appear to be a major risk factor for challenging behaviour" (p29). Sigafos et al notes that, although the HARC prevalence surveys found a higher proportion of males identified as having a challenging behaviour, this did not take into account the proportion of males to females in the population of people with an intellectual disability.

### Age

Studies suggest that the incidence of challenging behaviours tends to increase initially with age, emerging during pre school years and then escalating through childhood into adolescence until it peaks during young adulthood and then declines (Borthwick-Duffy, 1994; Kiernan and Kiernan, 1994). The 'peak age range' where challenging behaviour is most likely to occur is 15-34 years of age with a particular over representation amongst people with challenging behaviour in the in the age range of 15-24 ( Kiernan and Qureshi, 1993). Emerson et al., (2001) found a higher incidence (two-thirds) of challenging behaviour amongst adolescents and young adults, with the effect of physical development in terms of height, weight and strength having an influence on the extent to which the behaviour displayed was experienced as challenging. The incidence of specific topographies of challenging behaviour vary with age, e.g amongst those who display self injurious behaviour (SIB), head punching and finger chewing have higher incidence in younger people, while skin picking and cutting is more likely to occur amongst those who are older ( Oliver et al 1987).

### Co-occurring conditions

There is a higher incidence of challenging behaviour amongst people with an intellectual ability and conditions such as epilepsy (Gedye, 1989) and amongst children with intellectual disability and autism. (Tomanik, Harris and Hawkins, 2004). The presence of sensory impairments also corresponds with increased probability of challenging behaviour (Borthwick-Duffy, 1994; Kiernan and Kiernan, 1994).

### Particular conditions

Some forms of challenging behaviour have a reliably higher incidence rate associated with specific syndromes. Some conditions have such a consistent incidence of a particular type of behaviour, that it is possible to describe a 'behavioural phenotypes': eg

- In people with Lesch Nyhan syndrome there tends to be self injurious behaviour involving hand and lip biting (Lesch and Nyhan, 1964; Murphy, 1994).
- In people with Prader Willi syndrome there is always a range of issues associated with appetite and eating and an increased probability of behavioural difficulties (Murphy, 1994).

In other syndromes and conditions there is an increased probability of particular behaviours occurring:

- With people with Cri du Chat syndrome, stereotyped behaviours, self injurious behaviour and aggressive behaviour are reported as occurring in high percentages of the group (Ross Collins & Cornish, 2002).

- There is a higher incidence of aggression, self injurious behaviour and disruptive behaviour in Fragile X and Cornelia de Lange syndromes (Murphy 1994, Hyman and Oliver, 2001).
- In Rett syndrome there is high incidence of self injurious hand wringing (Emerson, 1995).

Einfeld, Tonge, Turner, Parmenter and Smith (1999) in a longitudinal study, compared levels of behavioural and emotional disturbance between four groups of children and adolescents with different syndromes over 4 years. People with Down syndrome had less behaviour problems when compared to those young people with Prader Willi and Williams syndrome, who displayed more challenging behaviour. They found that “genetic cause(s) of intellectual disability (had a) strong influence on the severity of behaviour problems” (p349)

### Setting Events

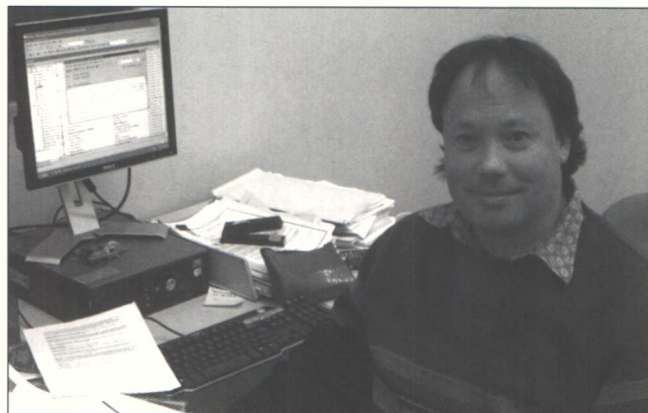
The presence of factors such as pain, infection or illness (Gunsett, Mulick, Fernald, & Martin, 1989) influence of hormonal cycles eg menstrual cycles and PMT (Carr, Smith Giacin, Whelkan & Pancari, 2003) sleep disturbance (Brylewski & Wiggs, 1999; Didden, Korzilius, van Aperlo, Overloop & deVries, 2002) and other ‘biological setting events’ are associated with higher rates of challenging behaviour. Other factors such as bereavement ( MacHale and Carey, 2002) are also associated with increased levels of emotional disorders and challenging behaviour.

The type of environment in which one is surveying populations also has a significant influence on prevalence rates of challenging behaviour. For example, there is a higher rate of challenging behaviour amongst those who are resident in more restrictive settings, although the causal direction for this correlation must be questioned. (Borthwick-Duffy 1994; Griffin, Ricketts and Williams, 1987; Holloway and Sigafos 1999).

Other environmental factors include the presence of environmentally challenging conditions such as excessive heat, noise or overcrowding. In institutional service settings, dimensions such as staff turnover, inappropriate interaction styles, and lack of structured activity and presence of aggressive models can all be associated with increases in rates of challenging behaviour (Allen 2000).

### In Summary

McLintoock, Hall and Oliver (2003), conducted a ‘meta-analysis’ of prevalence and cohort studies in order to identify ‘risk markers’ associated with challenging behaviour in people with intellectual disabilities. They found that males were more likely than females to show aggression; that individuals with severe/profound levels of intellectual disability were more likely show self injury



and stereotypical behaviour than individuals with mild or moderate levels of intellectual disability; individuals with autism were more likely to display self injury aggression and disruptive behaviour; and that individual with receptive or expressive communication deficits were more likely to display self injurious behaviour.

Risk factors include biological factors that influence the likelihood of whether a behaviour manifests or not, such as the presence of specific syndromes, level of intellectual disability, health issues and a range of other conditions such as epilepsy or autism. There are also factors that are a function of both the physical and social environment such as different physical aspects of settings, interactional styles, and contingencies that serve to maintain the behaviour. Given that aspects of the social environment have an impact on the manifestation of challenging behaviour, what family factors should be considered in predicting whether challenging behaviour will occur?

### Family Resilience

What factors influence the likelihood that a family will continue to support a person with an intellectual disability? What variables influence their ability to successfully manage challenging behaviour? What factors does the research identify?

Allen (1999) in a review of ‘Mediator analysis and challenging behaviour’ notes that the association between a child’s behaviour problems and increased family stress is well established.

Parents have enormous influence in shaping and maintaining particular interactions with children (Altman and Mira 1983). It has been demonstrated that parents can maximise learning through the application of behavioural procedures across a variety of settings ( Egel & Powers 1989).

Parents in families supporting a child with an intellectual disability report significant stress and difficulties in maintaining healthy interactions across a range of family life areas (Turnball & Reuf 1996). Looking at a family’s capacity to adjust to the demands of a child with a disability, Bristol, Gallagher & Schopler (1988) showed that the strongest predictor of adjustment was marital harmony.

There is a demonstrated relationship between the severity of a child’s challenging behaviour and parents’ experience of stress in reference to not only the child with a disability, but also with regard to dealing with

*continued page 6*

# Getting in Early

## ... a Preventative Approach ...

*continued from page 5*

others both within and outside the family environment (Dyson 1997).

Research suggests that carer stress is a factor in predicting family breakdown: (Bromley and Blacher 1991; Tausig 1985). Single parent status has also been identified as a factor (Black et al., 1985).

(Kelly, McEntee, Clark and Dench, 1995) identified predictors of 'out of home placement' of children with an intellectual disability. Children were considered to be at high risk of placement if parents had considered making a request for long term alternative placement within the next 12 months. Child and family characteristics from this group were contrasted with a control group. The study found a range of distinguishing factors. Six of these factors were features of the family (rather than aspects of the child.)

Out of home placement was more likely if there were:

- i) fewer number of children biologically related to carer
- ii) higher levels of discord in family relationships
- iii) employment /job related problems,
- iv) financial problems
- v) problems with other children
- vi) 'other' family problems including issues such as conflict with extended family.

Availability of social support was also identified as a factor (Kelly et al 1995). Stoneman and Crapps (1988) found that social support mediated family stress, perception of competence and depression.

So how do we build the capacity of families to support their children with intellectual disability?

Effective coping is more likely to be found amongst families who demonstrate a high level of 'family cohesion' and 'hardiness'; Family members accept responsibility and believe they are capable of meeting family needs and engage in creative problem solving to mediate stress; Parents in coping families have generally healthy marital relationships characterised by an internal locus of control and a positive appraisal of circumstances. External variables that characterise coping families are access to resources both within and outside of the family (Scorgie et al 1998).

Anstey (2001) suggested that family resilience should not be viewed as a fixed trait but rather as a resource that can be developed and enhanced. Given well targeted and timely support, resilience can be developed and strengthened. Anstey advocated specific assessment of vulnerable families and targeted strategies to work with the family to strengthen their capacity to provide support to their child with intellectual disability. Anstey recognised motivation and capacity (available time and energy), as issues that would further influence targeting of services to those who had the capacity to benefit from such supports.

Gavidia-Payne and Hudson (2002) in a review of behavioural supports to parents of children with an intellectual disability and challenging behaviour suggest the key components of effective support include: providing parent training in positive programming and applied behaviour support approaches; adjunctive supports that enable the implementation of programmes ( addressing treatment adherence, side effects and generalisation across settings) and enhance the effect of parent training strategies; 'behavioural marital therapy' and problem solving training.

### Early Identification and Intervention

Sloper and Turner (1993) suggest that, in order to improve a families' capacity to support children with disabilities, there is a need for early identification of problem behaviours and critical family factors; the provision of supports to parents to deal with behaviour with a focus on maintaining a positive parent-child relationship; awareness of the impact of health issues; and an awareness of the spiraling effects of family factors with the incidence of challenging behaviour.

Early forms of self injurious behaviour (SIB) have been found to be present in young children but tend not to be reported as SIB as the behaviour had not resulted in actual injury (Murphy, Hall, Oliver, Kissi Decra, 1999). Murphy et al note that interventions to address chronic and severe self injurious behaviour generally require high levels of professional input, are stressful to run and with no guarantee of success. They suggest that a better use of specialist expertise may be in early intervention with "those beginning to show SIB in childhood" (p.31).

In reference to the development of aggressive behaviour, Russell and Harris (1993) make the point that aggressive behaviour often starts early in life (although serious issues are not apparent at this early stage). Aggressive behaviour becomes unmanageable as the individual matures and develops a greater physical capacity to inflict damage. The behaviour tends to continue into adulthood. Could early identification prevent such behaviour from developing to the point where it becomes a problem?

However, there is little published research on the development and prevention of challenging behaviours in children with intellectual disabilities (Green, O'Reilly, Itchon and Sigafos, 2003). "Very few studies have examined the course of challenging behaviour over time" (Emerson, 1995, p. 29). As Green et al, (2003) notes:

It is possible that that a better understanding of the early development and longitudinal course of aberrant behaviours in young children with developmental disabilities may lead to improved prevention efforts (p. 48).

## Longitudinal Studies

Although there is substantial research that identifies 'risk factors' associated with challenging behaviour, these studies tend to be cross sectional in nature (Murphy Beadle-Brown, Wing, Gould, Shah and Holmes, 2005).

Einfeld and Tonge (1996; 2000) tracked a group of 582 Australian young people with intellectual disabilities (age ranging from 4 to 19 years) from 1991 to 1996, researching prevalence rates of psychiatric and behavioural problems and how patterns of psychiatric disorders change from childhood to adolescence. Prevalence rates of 40% were found for emotional or behavioural disorders with high levels of persistence over time.

Sloper and Turner (1993) conducted a longitudinal study examining the prevalence of behaviour problems in a sample of 49 children with Down syndrome ranging in age from 7 to 14 years. Over a two year period they considered both child and family factors and found that those most strongly associated with the persistence of behaviour problems were child factors (low self sufficiency and health problems). Factors related to family functioning (low family cohesion and poor parent child relationship) were also found to be significant.

Longitudinal studies that have specifically examined the development of challenging behaviour over time include Murphy, Hall, Oliver and Kissi-Debra, (1999). They considered the identification of self injurious behaviour (SIB) in young children with an intellectual disability who were observed at 3 monthly intervals over an 18 month period. They found that increases in SIB were predicted by teacher concern with no other predictive variable identified. Murphy et al. noted that "no other studies have examined the changes in children's early SIB over time" (p.43). Green, O'Reilly, Itchon and Sigafos (2003) examined the development and persistence of emerging challenging behaviour in 13 preschool children with 'developmental disabilities' over a 3 year period and found that 9 of the 13 children demonstrated persistence of high levels of challenging behaviour that were measured at the beginning of the study. She concluded that "prevention would therefore, seem to require home-based interventions that begin before 4 years of age" (p.47). Murphy et al. (2005) followed up 141 adults with severe intellectual disabilities and/or autism that had been assessed 12 years previously when they were less than 15 years old. The principle finding was that the presence of 'abnormal behaviour' at follow up was predicted by the presence of abnormal behaviour at the time of the first assessment (1971). Murphy et al noted the uniqueness of the data set (a longitudinal study that utilised epidemiological data that had not initially selected subjects on the basis of the presence of abnormal behaviour). Early intervention was not available to these children at the time of the initial study (Wing, 1971). Murphy et al speculated regarding the difference such intervention might make to future cohorts.



## Conclusions and further research questions

Allocation of resources to maximise benefit to families, staff and the community in general is dependent on having information that can inform decisions about the interaction of need versus benefit. The literature makes a case for the provision of early intervention to maximise efficacy of interventions by building family resilience. However, given the limited availability of longitudinal research data, early intervention with people who may manifest challenging behaviour is problematic in terms of identifying those most likely to manifest significant challenging behaviour in the future.

Given that there is substantial cross sectional data available from prevalence studies on the 'risk factors' associated with the probability of manifestation of challenging behaviour, can this research be effectively utilised to project the likely course of various types of behaviour? What type of assessment process can assist in identifying how to ensure that a family will benefit from intervention? What types of resources or service options would most effectively build resilience? Can the impact of challenging behaviour be ameliorated if it is identified at an earlier stage in an 'emergent' or 'latent' form?

Is it probable that manifestations of challenging behaviour correspond with particular social and developmental challenges? Is challenging behaviour more likely to occur in circumstances of stress or transition, eg beginning at school, leaving school to commence other activities, developing adult relationships and leaving home? Does the incidence of challenging behaviour cluster around particular times associated with these life challenges?

Further investigation of these issues will assist in identifying people who would benefit from early proactive intervention. ♦

Please note that due to space restrictions, a list of references cited in this paper has not been included but is available from the author on request at [richardoloughlin@bigpond.com](mailto:richardoloughlin@bigpond.com)

## Tasmania

by Darryleen Wiggins

Our Planning Day is scheduled for February 28th 2007 to discuss upcoming events for this year and start planning the 2009 Australasian conference.

Having held the last National conference in 2002 (prior to New Zealand joining ASSID) we know only too well how much preparation needs to go into a major conference such as this. The committee would like to begin discussing potential themes and keynote speakers as early as possible. Anyone with a genuine interest in assisting Tasmania with the big task is welcome to come along to meetings or to contact an ASSID Tas committee member to pass on your ideas.

Donna Venn has stepped down from The ASSID Committee after a 3 year term, the past 2 as President. The Tasmanian ASSID committee thanks Donna for her hard work and commitment and wishes her all the best. Vice president, Darryleen Wiggins has stepped up as acting President until the next AGM and Craig Jones will commence as Acting Vice President. Craig is currently the third member of the Australasian board for the Tasmanian branch and has been with the committee for the past year.

## Victoria

by Daniel Pennefather

The 6th Annual Conference for Disability Support Workers, held 16 & 17 November 2006 was once again very successful. This year, with attendance near maximum and a large number of registrations received from outside Victoria, the conference provided a great opportunity to network with colleagues from across Australia and New Zealand.

Some of the most popular sessions were Wendy Lawson's workshops on Autism Spectrum Disorder and sexuality, Dr Keith McVilly's discussions on the ethics and nature of the supporting relationships between workers and clients, and Amy Hewitt discussing credentialing Disability Support Workers in the U.S. However, it's clear from the feedback received that many delegates (and indeed many of the presenters) found the smaller workshops just as valuable as the keynotes. Hearing about successful practice and being inspired to try new, evidence-based methods in ones own workplace is a goal of the conference that delegates say was achieved again this year.

The 2006 Disability Support Worker Awards Ceremony was also hosted at the conference. The awards, an initia-

tive of the Department of Human Services, recognise people who have demonstrated outstanding achievement in direct support work. ASSID Victoria heartily congratulates this year's recipients Luke Gervalla, David Hall, Bob Tasic, Andrew Peachey, and ASSID Victoria's own Sam Murray.

ASSID Victoria would like to thank the events major sponsors, DHS, RMIT University Worksafe HACSU and HASA, as well as the minor sponsors and exhibitors.

Directly following on from the energy of the Disability Support Workers Conference, Keith McVilly facilitated a very active writing session for Disability Support Professionals Code of Ethics project. Over 40 people from Victoria and interstate participated in this workshop, attempting to begin a draft of code of ethics for Disability Support Professionals. Dr Christopher Newell, prominent Tasmania Ethicist, and Amy Hewitt, contributed to the day with their knowledge of ethics and issues pertaining to Disability Support Professionals.

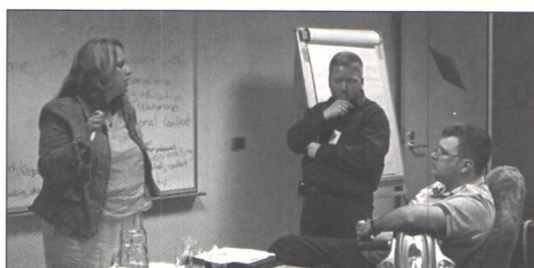
The final event for the year was a workshop on evidence-based practice in the field of intellectual disability. The workshop was facilitated by Dr Pammi Raghavendra, from Novita Children's Service (SA). The group of over 20 people was challenged to think about the evidence base for the work that they do. The need for evidence-based approaches to ensure quality service provision for people with an intellectual disability was highlighted. ASSID Victoria thanks Sheridan Forster for her work in organising the workshop.

After a very busy end of 2006, the ASSID Victoria committee has enjoyed a break during January, and will meet again in early February.

## New Zealand

by Martyn Matthews

The NZ region held its annual conference on the 2nd and 3rd of November, with 109 people enjoying an excellent range of speakers. A great feature of the conference was the number of collaborative presentations involving people with intellectual disability and their support people or family members. We had a fantastic reception to Dr Mark Barber, who in addition to an outstanding keynote



presentation, also ran a workshop on Intensive Interaction which generated lots of interest.

Planning is already underway for our next annual conference which will be in Wellington, during September 2007.

The theme of conference will be Best practice for progress: How do we show it? How do we know it, how do we do it?

We will also be hosting Steve Moss in late August or early September who will be running PAS-ADD workshops. Dates and locations will be confirmed soon.

During the conference we also held our AGM & council elections with several new members elected. Office holders for 2007 are:

ASSID President: Olive Webb

NZ President: Sharon Brandford

Vice-President: Adrian Higgins

Secretary/Treasurer: Martyn Matthews

A face to face planning day for the new council was held on 30th January 2007 in order to set key goals/tasks for 2007, in addition to the major task of organising the conference, these are:

- PAS-ADD workshops
- Risk Assessment Workshop
- Increasing individual and student membership
- Financial Planning & increasing income.

## Western Australia

by Chris Coopes

With Christmas, New Year and school holidays this quarter has been fairly quiet and we did not have our state council meeting in January.

The third and final ID Network forum for 2006 was held on the 21st November, the forum title being Family, Friends and Networks: At the Heart of the Matter. There were three speakers from different backgrounds who discussed various aspects of the relationship between people with intellectual disability and their family, friends and networks. Members of the audience asked questions and made comments and the successful evening finished with network mingling over light refreshments.

ASSID (WA) is planning an evening forum in March to discuss issues arising out of the recently publicised situ-

ation in the USA concerning a nine year old girl named Ashley who is severely intellectually and physically disabled. She will remain small and undeveloped as a result of surgery and hormone supplements which were requested by Ashley's parents. Panel members will be a medical practitioner, a relative, a service provider and a lecturer in ethics.

As most people are aware from advance publicity, the 2007 ASSID National Conference organising committee has been very active and is having its first meeting for the year on 6th February.

A major focus for our February meeting will be the development of an ASSID (WA) Plan which will be based on the ASSID Strategic and Operational plan. There has already been some preliminary discussion on this at our December meeting.

## South Australia

by Richard O'Loughlin

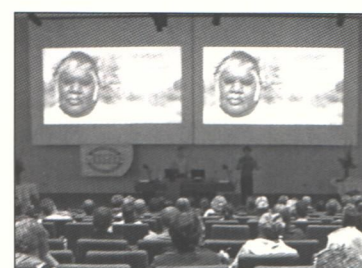
The ASSID (SA) committee have made a positive start to 2007. In collaboration with Leveda - a South Australian NGO that provides accommodation and community support to people with intellectual disability, we are hosting an introductory workshop on "Active Support" on the 8th February. The workshop facilitator is well known to ASSID people - Dr Keith McVilly - a lecturer and researcher at the school of Health Sciences at RMIT. We look forward to catching up with Keith and anticipate a stimulating workshop along with an opportunity to catch up with old friends while consolidating professional networks.

We are also currently planning a forum on isolation in March, with the intention that some form of document will be produced - such as a discussion paper - which we plan to circulate amongst decision makers in SA.

After further discussion with academic staff at the University of SA at the end of 2006, we anticipate running a research showcase at the University of SA later in the year.

Other matters that are keeping the ASSID (SA) committee busy is our intention to respond to various position papers that are being circulated for the purposes of consultation by Disability SA, the public sector agency that has taken on the role of providing and organising services for people with disability as part of the ongoing process of change and reform in the disability sector in SA.

As always, we are interested in the views of our membership and invite their contributions. Feel free to contact me by email at [richardoloughlin@bigpond.com](mailto:richardoloughlin@bigpond.com) ♦

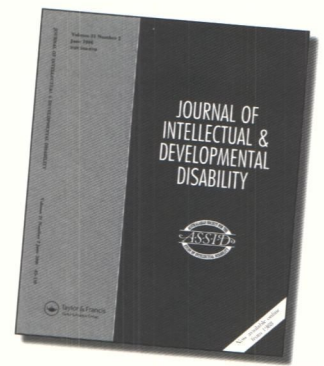


# Community use of Intra Nasal Midazolam for managing prolonged seizures

by Margaret Kyrkou, Michael Harbord, Nicole Kyrkou, Debra Kay and Kingsley Coulthard

from Children, Youth and Women's Health Service; Flinders Medical Centre; Flinders University; and Department of Education and Children's Services, South Australia

*The following article is a Plain English Version of a paper that appeared in the Journal of Intellectual and Developmental Disability and was prepared by Sheridan Foster.*



## Medication for seizures that last a long time

Epilepsy is a problem in the brain that causes seizures. Sometimes seizures are called fits. There are different types of seizures. One type of seizure is when the person's body shakes uncontrollably. Most seizures last a short time, but usually no longer than 2 minutes.

If a seizure lasts more than 5 minutes and the person does not become alert or clear headed, it is called status epilepticus. This can be very dangerous for the person. It is a medical emergency.

There are two types of medication for people to stop status epilepticus seizures: rectal diazepam (valium) (which we will call RD) or Intra Nasal Midazolam (which we will call INM).

Rectal diazepam is a liquid that is put in the person's bottom. It stops the seizure. There are some problems with RD. The problems include:

- the person needs to go to a private place to have RD,
- if the person is in a wheelchair somebody needs to get them out of their wheelchair to give them RD,
- the person's carer needs to be specially trained and allowed to give RD, but some staff are not allowed to give RD, and
- the person may be sleepy for at least a day after they have RD.

INM is a newer type of medication. INM is drops given in the person's nose. Some people think it may be better than RD for a few reasons. Good things about INM include:

- people feel sleepy for only an hour with this medication,
- the drops can be given in public, you don't need a private place,
- the drops make the seizure stop quickly,
- some staff, who are not allowed to give RD, may be allowed to give INM. This means that the person will not have to wait for an ambulance or somebody else with extra special training. But people giving this medication still need training.

The researchers in this study wanted to learn more about using INM for people with disabilities in the community.

The study involved a few steps:

- giving training to people about epilepsy and how to use INM,
- making rules (guidelines) for using the medication,
- giving these people a special yellow folder about their specific medication, and
- following up with people after the training.

The researchers contacted the parents and carers of 131 children and adults who had used INM. They asked a few questions about the medication.

Question 1: Is it practical and safe to give INM?

Answer: Most people found it easy to use INM. Some people had problems using it. The researchers recommended that pharmacists give people pictures of how to use INM. Some people had problems getting the little plastic ampoules of midazolam.

Question 2: Does INM help people who have status epilepticus?

Answer: INM helped nearly everybody in the study.

Question 3: What did parents and carers think about INM?

Answer: Most of the parents and carers liked INM better than RD. They thought the INM worked faster and did not leave the person as sleepy.

Midazolam is a powerful drug. It must be used properly. Anybody giving INM must have special training. INM may be a quicker and more convenient treatment for many people who are affected by status epilepticus. ♦

### Acknowledgements

Approval was given by the authors and original publishers of this paper to prepare and publish this Plain English Version.

Reference for the original paper is:

Kyrkou, M., Harbord, M., Kyrkou, N., Kay, D., & Coulthard, K. (2006). Community use of intra nasal midazolam for managing prolonged seizures. *Journal of Intellectual & Developmental Disability*, 31, 131-138.

The home page for the *Journal of Intellectual and Developmental Disability* is

<http://www.tandf.co.uk/journals/titles/13668250.asp>. This page provides access to instructions for receiving the Journal's table of contents alerts via email.

## book review

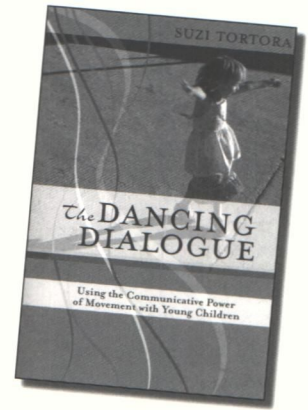
# The DANCING DIALOGUE

## Using the Communicative Power of Movement with Young Children

by Dr Suzi Tortora

Paul H. Brookes Publishing Co, 2006, p 532.

Reviewed by Katy Gerner



I was a little skeptical about teaching children with disabilities to dance, when I first opened this book. My initial thought being that teaching dancing was nice in principle but wouldn't it be more useful to teach them to talk or use the toilet or to walk? However, I soon realised that Dr Tortora's program was teaching something very important – to help a child express themselves.

Dr Suzi Tortora, Ed. D., ADTR, CMA, runs two clinical dance movement psychotherapy practices and designs wellness, preventative and therapeutic mental health programs that incorporate movement and dance-based activities. Her clients include children with Attention Deficit Hyperactivity Disorder, Autism, communication and language delays, issues related to adoption, parent-child attachment issues and sensory integration dysfunction.

Her techniques aim to make clear a child's non verbal cues and for their educators and carers to use these non verbal interactions to connect with the child. The techniques also help the child develop and improve their social interactions.

Dr Tortora writes: "Having an awareness of nonverbal expression supports communication by providing an alternative avenue of contact that is especially useful in reaching infants and children with diverse or delayed communicative, developmental, and learning styles. Adding nonverbal expression to social-emotional, motor, cognitive, and communicative development can greatly support a child's diverse abilities to learn and engage in the environment. Although many assessment, intervention, and educational programs exist to support the growth of children, none emphasize the qualitative nonverbal elements of expression. The enhanced awareness of nonverbal expression can augment the formation of meaningful relationships with young children with special needs and their families." (p 21)

Dr Tortora weaves her stories about her clients, their families and therapists amongst the theoretical sections, which makes the book more interesting and the theory which is quite difficult, easier to follow.

The dance movement therapists are encouraged to pay attention to a child's actions to understand the child's personal movement style and to determine how the child feels about themselves emotionally and how they interact socially and communicate with others. Once the therapist understands the child's movement style they can best support the child's growth in developmental areas. For example a therapist can learn that a child: is a visual

learner, is very anxious, has attachment problems, has a wonderful imagination, loves music, can run or jump, needs to strengthen certain muscles, has a sense of rhythm, is listening and has understood, has difficulties controlling their senses, is trying to control their behaviour, is fonder of their parents that suspected or would just like to be noticed.

This is particularly important when the child cannot talk and needs to express themselves with the people they relate to, such as their parents or educators.

One parent writes: "I think nonverbal expression is an incredible way to communicate. Maybe if I didn't have Nikki, I wouldn't know or see it that much ....I think it's become an integral part of my life because Nikki communicates non-verbally – it's her movements and the way that she stands and the pace that she walks and the way that she bends her body or the way that she bends over that tells me so much about where she is at the moment and what she wants and needs. I'm dependent on that to know my daughter...And she can communicate with us because we're listening to her nonverbal communication. Can you imagine understanding things and having no way to say it – the look on her face when you get it – when you know what she wants – is incredible. Yes, she has her computer and she can sometimes point and tell us when she's hungry. But all those finer things, you know, to be able to know that she's sad because of the way she's sad because of the way she is sitting on a chair or something and to be able to go to her and acknowledge that she's sad – it's so important." (p 54)

Dr Tortora's techniques are often used to build social skills. These methods include: having activities that shift between free individual movement explorations to structured group movement explorations, having each child try the movements of peers and keep the group moving and relating as a group.

Movements which can be used to increase body awareness, sense of self and control, which are particularly important for children with Autism Spectrum Disorder or Pervasive Developmental Disorder, include: using a strong, clear rhythm with moderate tempo that organizes or creates full body or body part coordination, movements that require increased body control and interspersing periods of relaxation, stretching and breath awareness.

The techniques are also used to help children develop physical skills such as using a ball dance to teach crawling and standing.

*continued page 13*

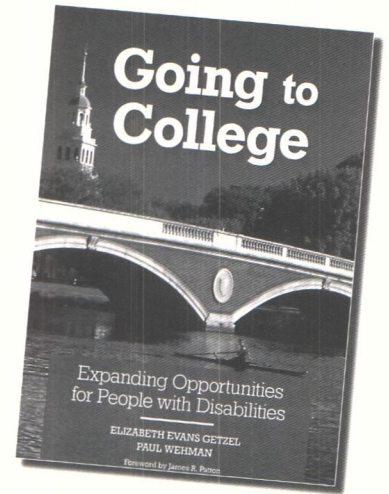
# Going to College

## Expanding Opportunities for People with Disabilities

*Edited by Elizabeth Evans Getzel, MA  
and Paul Wehman Ph D,*

Paul H Brookes Publishing, USA, 314 pages. RRP \$64.00 (Inc GST)

*Reviewed by Katy Gerner*



**G**oing to College is a series of essays on helping adults with disabilities who attend college. The essays are so interesting, I just wish there was an Australian version for helping students at university and TAFE. Fortunately much of the information in these essays can also be useful to university lecturers and TAFE teachers in Australia. As I am a Disability Support Teacher in TAFE in Australia, my review will (selfishly) concentrate on the essays that I found most relevant to teachers in a similar work environment

The book is divided into four sections: College Planning and Admissions, Creating a Welcoming Environment Through Design and Implementation, Applications for Students with Disabilities and Creating Opportunities for Employment.

The essays in section one are:

- The Need and the Challenges Associated with Going to College
- Understanding the Regulatory Environment
- Self Determination and the Transition to Post Secondary Education
- Preparing for College
- The Role of Disability Support Services

Colleen A. Thoma's and Michael L. Wehmeyer's "Self Determination and the Transition to Post Secondary Education" focuses on the skills a student needs to study as independently as possible. The advice given is very sensible, and I know a number of students without disabilities who would benefit from brushing up on these skills.

"Students need to have skills in setting their own goals and in working to attain them, managing their time and rewarding themselves for their efforts. Students also need to understand that what they do affects their world. If they do well on a test, it is because of their hard work and /or prior knowledge (internal locus of control), not because of fate and chance. In addition, students need to increase some academic skills so they will believe that they have the ability to learn the material presented in college courses (positive attributions of efficacy) and that if they use those skills, they will do well (positive attributions of outcome expectancy)." (p 63)

The article also recommends that places of higher education provide:

- Alternative teaching resources to help students with access difficulties including: the use of web based programs for discussion and a place for posting lecture notes, assignments and calendars to keep students organized.
- Workshops in time management and work organisation.
- For the students' needs *before* their course starts, for example do they need training in applying on-line.
- A clear description of the support services they can provide to prospective students as what a campus can provide differs greatly.

The essays in section two are:

- Implementing Universal Design for Instruction to Promote Inclusive College Teaching
- Expanding Support Services on Campus
- Strategies for Students with Hidden Disabilities in Professional School
- The Role of Technology in Preparing for College and Careers
- Training University Faculty and Staff

Shannon McManus's and Lisa Donegan Shoaf's "Strategies for Students with Hidden Disabilities in Professional School" looks at the needs of students with learning disabilities who are unsure about disclosing their needs. In some cases, this may be because they have only recently been diagnosed and may be unaware of ways they can compensate. The article concentrates on preventing difficulties that could arise during work placements.

The author advises the student to:

- Visit the site early and spend time there becoming familiar with the pace, staff, documentation and any special features of the environment.
- Get to know the instructor before hand.
- Ask for an extension of the time of the work placement so that the student can process the amount of information they need. It should be very clear what the student is expected to achieve in any additional time.
- Disclose their disability before placement rather than during, and be very clear what accommodations they will need.

- Be aware of the characteristics of their disability, their strengths and weaknesses and how their disability affects their learning and performance.
- Keep a daily journal where an observing professional and they reflect on the activities of the work placement, the students' strengths and weaknesses and how the student could improve.
- Discuss with the observing professional how often feedback would be provided and in what form.
- Carry a list of words they need to use and / or an electronic speller.
- Study other employees' paper work and use them as a guide.
- Use speech to text software (173)
- Use audiotape or digital recorders to record information quickly for future review.

These useful skills could easily be taught by a tutor a few weeks before work experience begins.

The essays in section three are:

- Students with Psychiatric Disabilities
- Students with Learning Disabilities or Attention-Deficit / Hyperactivity Disorder
- Dual Enrollment as a Postsecondary Education Option for Students with Intellectual Disabilities

I found section three to be the most interesting, and for me, the most helpful part of "Going to College", as it was most relevant to the type of students I work with in TAFE.

Linda S Albrecht's "Students with Psychiatric Disabilities" reports that students with psychiatric disabilities have low completion rates, low employment rates and drop out of study more often than other students with disabilities. She said their needs include: counselling, housing, welfare, transportation and interpersonal support. She reported that the most successful programs to assist students with psychiatric disabilities included:

- The availability of a person such as a case manager or a peer support mentor to build a one to one relationship.
- Vocational assessment and planning.
- Information and help with using campus resources.
- The development of skills such as time management, studying, stress management and interpersonal interaction.

Anecdotes about successful assistance in reducing stress include:

- The use of a personal digital assistant which sends reminders about upcoming events and that it is time to take medicine.

*continued page 14*

## book review

# The DANCING DIALOGUE

*continued from page 11*

"By summer we have begun to add more elements to this ball dance. Now following her own initiative she rolls along her vertical axis, too, while on top of the ball – log rolling from prone to supine and then back again. After a few of these rolls, she decides when to reach back with her arms rolling onto the floor to her knees, and then uses the ball to push up to kneeling. We realize this supports the leg strengthening work she has been doing in physical therapy. She has been working on high kneeling. Next she uses the ball to push into high kneeling, extending our choreography.

"Brianna continues to find ways to creatively and spontaneously incorporate her physical therapy exercises into our dance-play. In the fall, she is practicing standing." (p 278-279)

"The Dancing Dialogue" is divided into three sections: Historical and Theoretical Foundations, Observation and Intervention, and Movement as an Interdisciplinary Tool.

The essays in Historical and Theoretical Foundations are Communication without Words: Early Childhood Development and Interaction; *Ways of Seeing*: Movement Development, Expression and Body Awareness; and The

Language of Movement: From Dysfunction to Creative Expression.

The essays in Observation and Intervention are Elements of Movement Observation, Nonverbal observation in Context, Witnessing, Kinesthetic Seeing and Kinesthetic Empathy, The *Ways of Seeing* Technique, and Movement and Dance-Based Tools.

The essays in Movement as an Interdisciplinary Tool are Working with Parents; Focusing on the Child: From Nonverbal Assessment to Intervention to Educational Programming; and Adding Nonverbal and Movement Awareness to the Classroom.

Dr Tortora also includes checklists, a list of recommended resources which can be used for simple imagery, rhythm play and as imagination builders, and a glossary.

"The Dancing Dialogue" should be read by therapists looking for an alternative and creative approach to helping children with disabilities. ♦

Available direct from Elsevier Australia Customer Service, 1800 263 951 or email [customerserviceau@elsevier.com](mailto:customerserviceau@elsevier.com). ARRP \$61 (inc GST), NZRRP \$72 (inc GST)

## book review

# Going to College

continued from page 13

- Teaching the student to set goals and break a large project into manageable parts.
- Finding a place to exercise.
- Study Skills workshops.
- Support Groups for people with the same disorder.
- Role playing a conversation about their disability before they disclose to staff so they only give the staff pertinent information to their academics.
- Use of a calendar or time line to keep track of and plan due dates of assignments.

Michael F. Hock's "Students with Learning Disabilities or Attention Deficit/Hyperactivity Disorder" observed that there was an increase of students with these disabilities attending college, which would continue to grow. The difficulties these students faced were due "to an enormous gap between the academic skills they possess and the academic demands of the college environment." (p. 233)

Tutoring is essential for these students. They need:

- To develop coping strategies such as using word processing because it has spell check and cut and paste features.
- Learn to work as a team, listen critically and problem solve.
- To advocate for their needs.

The tutoring program that he recommends is the Strategic Tutoring Model which is a four phased instructional sequence for a student who needs help with an assignment. In Phase one, the tutor assesses the student's current approach to the task by asking questions to identify the strategies the student currently uses and to determine the nature of the assignment. The tutor then explains the rationale for learning a more effective strategy and asks the student to commit time and effort to learn it. In Phase two, the tutor and student co-construct a learning strategy, which addresses the student's academic needs and weaves the student's current strategy with a new and more efficient and effective strategy. The tutor explains each step of the new strategy, checking that the student has understood. In Phase three the tutor models the strategy and in Phase four the tutor discusses and plans with the student so that they can transfer the newly acquired strategy to their next assignments.

The essays in section four are:

- Internships and Field Experiences
- Career Planning and Placement

Lori W. Briel's and Paul Wehman's "Career Planning and Placement" write that adults with disabilities have been traditionally unemployed and underemployed because employers:

- Are biased against, uncomfortable with or unfamiliar with people with disabilities
- Believe that people with disabilities cannot cope with the type of work their company needs
- Worry about high costs of meeting the person's needs
- Do not know how to find and use workplace supports for staff with disabilities

The authors recommend that students with disabilities who are looking for work need to:

- Be comfortable with their disability
- Be confident
- Learn about their disability and how it will impact on their work environment
- Become familiar with compensatory strategies and assistive technology
- Learn about protections afforded and responsibilities under the Disabilities Act
- Acquire self-disclosure skills and the ability to request accommodations
- Obtain work placement supports through community resources
- Learn how to manage insensitive employer comments and attitudes
- Gaining traditional employment experiences.

"Going to College" is a very useful book for adult educators, full of sensible advice and excellent teaching strategies that could be put into immediate practice. ♦

Available direct from Elsevier Australia Customer Service, 1800 263 951 or email [customerserviceau@elsevier.com](mailto:customerserviceau@elsevier.com).

Special Offer: Readers of IDA will receive a 10% discount and free delivery when ordering direct from Elsevier. Just mention this review.



## upcoming events

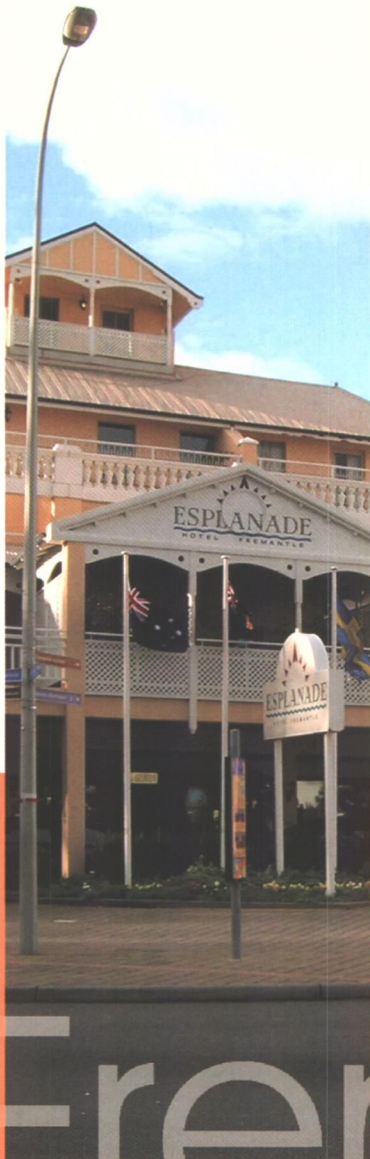
<p>2 - 3 April 2007</p>	<p><b>ACROD Ageing and Disability Conference:</b> <i>Between two worlds: Growing older with a disability</i> to be held in Adelaide, South Australia. Further information <a href="http://www.acrod.org.au/conferences/a&amp;d2007/home.htm">http://www.acrod.org.au/conferences/a&amp;d2007/home.htm</a></p>
<p>2 - 5 May 2007</p>	<p><b>International Meeting for Autism Research (IMFAR)</b> To be held in Seattle, Washington. Further information <a href="http://www.cevs.ucdavis.edu/Cofred/Public/Aca/WebSec.cfm?confid=238&amp;webid=1326">http://www.cevs.ucdavis.edu/Cofred/Public/Aca/WebSec.cfm?confid=238&amp;webid=1326</a></p>
<p>27 - 31 May 2007</p>	<p><b>Speech Pathology National Conference.</b> To be held at Darling Harbour, Sydney. <a href="http://www.speechpathologyaustralia.org.au/Content.aspx?p=62">http://www.speechpathologyaustralia.org.au/Content.aspx?p=62</a></p>
<p>16 - 19 June 2007</p>	<p><b>Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT)</b> To be held Toronto, Ontario, Canada. Brings together 5 international conferences related to disability and to aging. Further information <a href="http://www.ficcdat.ca/TheFestival/default.aspx?lang=en-US">http://www.ficcdat.ca/TheFestival/default.aspx?lang=en-US</a></p>
<p>9 -13 July 2007</p>	<p><b>5th Asia Pacific Conference on Speech, Language and Hearing.</b> To be held in Brisbane. Further information <a href="http://www.shrs.uq.edu.au/apconference/index.html">http://www.shrs.uq.edu.au/apconference/index.html</a></p>
<p>25 - 30 Sept 2007</p>	<p><b>14th Deafblind International World Conference</b> to be held in Perth. Further information <a href="http://www.dbiconference2007.asn.au/">http://www.dbiconference2007.asn.au/</a></p>
<p>5 - 8 Nov 2007</p>	<p><b>Australasian Society for the Study of Intellectual Disability (ASSID) 42nd Annual Conference.</b> To be held Fremantle, West Australia. (see back cover)</p>
<p>25 - 30 August 2008</p>	<p><b>International Association for the Scientific Study of Intellectual Disabilities (IASSID)</b> <i>will be holding its 13th World Congress</i> in Cape Town, South Africa. Information available from <a href="http://www.iassid.org">www.iassid.org</a>.</p>
<p>3 - 6 October 2008</p>	<p><b>Early Childhood Australia Biennial Conference</b> To be held in Canberra. Further information <a href="http://www.eacaconference.com.au/">http://www.eacaconference.com.au/</a></p>





# 42nd Australasian ASSID Conference

November 5 - 8 2007



## *In Tune*

42nd Australasian ASSID Conference



Active Citizenship . Community Engagement

## ACTIVE CITIZENSHIP AND COMMUNITY ENGAGEMENT

Esplanade Hotel, Fremantle

Western Australia

For further information please contact:

Dr Angus Buchanan

[angusb@dsc.wa.gov.au](mailto:angusb@dsc.wa.gov.au)

61 8 9426 9371

Professor Daniela Stehlik

[d.stehlik@curtin.edu.au](mailto:d.stehlik@curtin.edu.au)

61 8 9266 3248

<http://www.strongercommunities.curtin.edu.au/assid2007>