

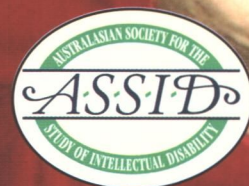
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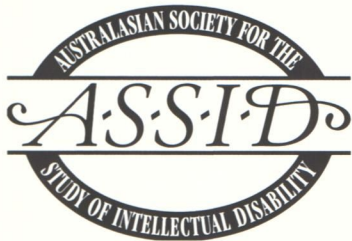
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Intellectual Disability Australasia



Nourishing Connections



Magazine of the Australasian Society for the Study of Intellectual Disability



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Front Cover:

Nourishing Connections in Saskatoon.
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Editorial

Nourishing Connections

The articles and reviews in this issue of IDA either directly or indirectly consider connections - connections between individuals with disabilities and their family, friends, members of their communities and those involved with their education. As we approach the Christmas period, it seems a good time to stop and reflect on how connected individuals with intellectual disabilities are within the school, work, and residential communities to which they belong. Clearly, connectedness isn't just about being 'in the community'. We have seen significant changes in the past 20 years, with individuals with disabilities moving from segregated settings such as residential institutions and special schools to more inclusive settings. However, we also know from the research concerning the effectiveness of these initiatives in improving the quality of life of those involved, that we need to do more than just change the physical location of where people live or go to school. Changing where someone lives, works, or goes to school doesn't automatically ensure connections within the community.

Understanding how people are connected and how connections can be facilitated is complex. We gain some insight into what underlies connections through some of the articles in this issue of IDA. In reviewing the book *Breaking Bread*, Bob Perske states that the book "rises and shines as it draws its meaning from the evolving standards of decency that mark the growing understanding and respect for persons with disabilities" (p6). We are also told that the *Our Voice SA* video/DVD concludes with the following comment: "Nothing about us should be decided without us. If we are given a chance and treated with respect, we will speak up" (p10). Connectedness is more than respecting each other, but respect is surely a great starting point!

On behalf of the editorial team at IDA, we wish all our readers a wonderful Christmas and look forward to the year ahead culminating in our annual conference for 2006, to be held in Canberra.

Deb Keen, Editor



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Problem Behaviour: Schools Navigating the Iceberg

Alison Gable PhD Candidate, University of Queensland

Schools are frequently overwhelmed by the demands placed on them by students with disabilities who present with problem behaviour. The constraints of 'time', 'resources' and 'expertise' are frequently cited by schools as staff and parents struggle to find adequate solutions resulting in a general sense of disempowerment in the management of these students. Consequently, opportunities to provide useful and powerful learning experiences for the child can be lost in favour of safely containing them for the duration of their school lives. This is not to say that schools do not work tirelessly to support and educate this group of students, rather it suggests that many schools may struggle with the complexities of the issues related to disability and behaviour. This article presents a theoretical perspective that aims to find long-term and sustainable solutions to the difficulties of educating these students.

The theoretical perspective

Theories on problem behaviour give meaning to what we see and how we organise and structure our approach in dealing with any student. In effect, different theoretical perspectives serve as models for interpreting, analysing and intervening in problem behaviour (Ayers, Clarke, & Murray, 2000; Porter, 2000). Many focus on responding only to the individual under the premise that problem behaviour is a direct consequence of some internal mechanism. However one theory removes itself from such an approach, accounting for problem behaviour in terms of the interconnectedness between the child and their environment.

These are systems type perspectives that explain problem behaviour as a product of the interactions between players. The conceptual framework lies within 'systems theory', conceiving of schools and the people within, as a complex mix of dynamically interacting parts. Consequently, changes to any part of 'the mix' are likely to affect other parts of the school. More importantly the theory argues that there is a cyclical chain of actions and reactions between players

within the school (Upton & Cooper, 1990). For example, a student disrupts the class; the adult reacts to correct the behaviour which then 'demands' the student respond to that correction (Porter, 2000) and so on. To intervene and break this cycle, schools must turn to analysing what is going on around the student in order to find meaningful solutions by changing negative interactions.

The value of a systems perspective

The attraction of a systems perspective lies in a shift away from the view that behavioural problems are somehow the consequence of a child's own deficits, towards an understanding of behaviour as an upshot of some dysfunctional mechanism between human systems and social institutions. Significantly, a systems perspective on challenging behaviour draws professionals, practitioners and parents away from a medical model of understanding and intervening in behavioural problems, to one that focuses on multiple and recursive causation. In this respect the approach argues that all participants (students, teachers, administrators, peers and parents) through their interactions, contribute to and therefore have some responsibility for finding solutions to problem behaviour (Ayers et al., 2000).

Understandably, this focus has several significant implications for the management of children with disability and problem behaviour. To a large extent the reformulation of the origins of student problem behaviour requires schools to adopt a different form of action in behaviour management and planning. The approach reconstructs three powerful concepts that ultimately entail extending individual case management, towards a more comprehensive intervention on the school environment.

The first concept is that of blame which is refocused on the interaction patterns of all players (Upton & Cooper, 1990), rather than the child with a disability. Consequently diagnostic labels become irrelevant when the focal point is the interplay between the child and those around them.

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With this in mind, each agent is required to reflect on their own behaviour and the contribution of this to the problem.

Secondly, as everyone contributes in some form or another to the problem, responsibility for finding solutions extends to a wider network of players. Solutions to behavioural problems are not seen to be the sole responsibility of classroom teachers and parents. Rather they are seen as being symptomatic of a stressed or 'dysfunctional' system (Souter, 2001) requiring careful analysis and action towards a more responsive environment for all agents.

Finally, systems perspectives are long term solutions focused with the aim of facilitating meaningful pathways towards more responsive (and ultimately inclusive) schools. Problems are seen to emerge from specific school environments and thus require context specific solutions. The consequences of this are powerful (yet often novel and simple) and sustainable interventions for children with disability.

An institutional systems perspective

The emergence of systems theory in the management of students with disruptive and problem behaviour is securely rooted in family therapy practices where the target of intervention lies within the contexts immediately surrounding the child. In school settings, this is usually achieved through collaborative problem solving amongst a small team of agents (parents, class and specialist teachers). However, schools are of themselves, large and complex systems open to the many and varied influences the external world can impose on them. There are multiple sub-systems within the school (committees, teams, year levels) as well as more physical systemic components (books, technology, resources, student movement patterns, and staffing allocations) all of which are visibly and invisibly interconnected. We must remind ourselves that a collaborating team surrounding an individual student is just one sub-system among many within the school, attempting to find solutions to problem behaviour.

With this in mind, it's possible to take a more institutional view of systems theory and its implications for problem behaviour. This alternate view is expressed by Robert Burden (Burden, 1981) who writes:

"The necessary approach for working within the framework of systems theory is to start from the assumption that schools exist and that children must attend them and will be expected to act in certain ways when they do. Such an approach does not dispute that some problems may well stem from within an individual child or from within an individual teacher, but seeks to understand how the explicit and implicit organisational structure of a school effects the perceptions and behaviour of its pupils in a way

that leads them to be seen as problematical or disruptive by those faced with the task of maintaining that structure." (page 35)

This institutional perspective suggests that a collaborative team must work within a system already imposing its own challenges on the student. This should lead us to question the extent to which agents can effectively work towards planning and implementing behavioural supports for children who test a school system. We must also query the limitations school context may impose on creating sustainable and meaningful interventions for children with disability and problem behaviour.

Burden argues that 'problem behaviour' is something that should be interpreted in light of the school organisation, suggesting that student behavioural outcomes and indeed behavioural improvement only occur as a consequence of internal system analysis and well designed system change. In this light I now turn to another systems theorist, Peter Senge (2000, 1990) who contends that the capacity of schools to improve themselves rests with their understanding of the dynamics at play within the system.

Managing behavioural 'events'

Senge (2000) argues that we are conditioned to see the world in terms of 'events' with the expectation that for each event there is one cause. So a teacher resigning, a house catching fire, a car breaking down, or an empty bank account are all instances of 'events'. Responses to these events are always reactive and necessary, but solutions are invariably short lived. Thus house fires are extinguished, teachers are employed, and money is sourced.

Many schools would hold similar perceptions of behavioural incidents, indeed traditional behaviour management practices have been entrenched in reactive responses to behavioural 'events'. However, whilst most reactive responses are necessary and justified, they can only ever serve to minimise the impact of the 'event' on those involved.

To illustrate we can hypothesise a situation in which a young student with a disability, overwhelmed by the crowd and noise of the school canteen, hits the student behind him in line when the child moves against him. The student may face some sort of punishment (a detention, a withdrawal, a time-out, an exclusion from the canteen) the aim of which is to communicate to the child that aggressive behaviour will not be tolerated whilst simultaneously re-establishing the canteen lines as safe places for all children. These are valid and justified responses on behalf of the school, but will not provide any meaningful lesson for the student with a disability and therefore the solution is short lived. The child will still be overwhelmed by crowds, noise and the close proximity of pushing children.

Managing behaviour by recognising patterns

Senge (2000) maintains that to describe reality we need to think of an iceberg, and critical events as being at its tip (see diagram). As a systems theorist he proposes that there are no single cause and effect models of events, rather there are any number of contributing factors leading to any one event. Indeed there may be a familiar history of similar behavioural events and what emerges from this history are systemic patterns. Senge (2000) contends that these are not human behavioural patterns; rather they are the behaviour of the school system responding to any number of variables. Consequently they lie below the event water-line and point to important trends and changes within the school over time.

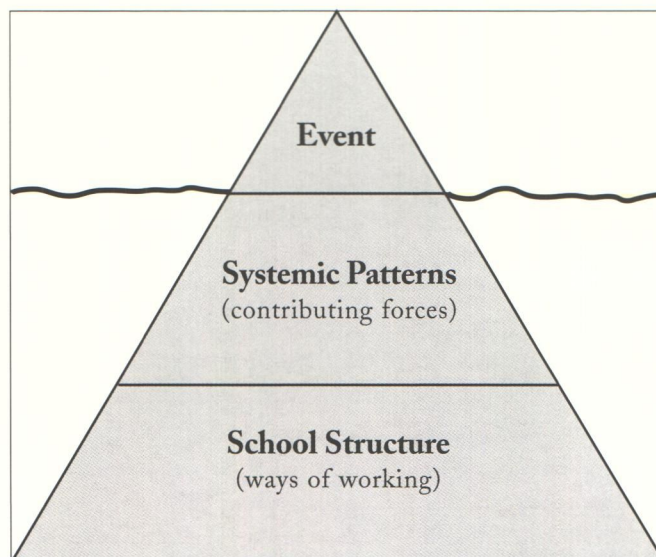
Returning to our hypothetical student, the school might come to realise that the cacophony of noise accompanying the lunchtime canteen student crush contributes to heightened anxiety levels ultimately leading to the student's physical aggression. The distress this student experiences may in fact be evident in other, seemingly unrelated behavioural incidents in the classroom, or in the library. But floating below the waterline might be several key systems variables; perhaps student numbers have been on the increase creating pressures on the canteen and library. Perhaps the priority for professional development has been towards curriculum reform rather than student behavioural management (especially of children with special needs). Perhaps there has been an unfortunate turnover of teachers in the child's classroom.

Recognising patterns of behaviour that underlie on-going and repeated incidents provides the school with some degree of leverage (Senge, 1990) in effecting change. However often the forces seem impenetrable, so piecemeal solutions are found to account for and intervene in, less than ideal contexts. In the case of our hypothetical student, the school may justifiably respond with measures to minimise the child's exposure to anxiety stimulating situations. Perhaps they would allow him to go to the canteen earlier than the rest of the student body; perhaps he is given access to a quiet room during recess and lunch. Perhaps more teacher aide time is allocated to the classroom when his teacher is absent.

While pattern responses are often necessary and justified they are nevertheless limited to the ability of schools and individuals within those schools to anticipate, plan, adapt and forecast. Schools need to question whether or not they have provided the student with skills necessary to equip them for life or are they dependent on key individuals to buffer the effects of the school context on the child.

Managing behaviour by changing systems

Once a school can recognise trends that underlie events, they move one step closer to understanding the systemic



school structures driving that pattern. This is the deepest level of the ice-berg, holding the greatest point of leverage for creating real and meaningful improvements (Senge, 2000) to the system.

To overly simplify this level, we can think of it as 'the way of working' within the school organisation. These are the decisions that are made and how perceptions, goals and norms are translated into actions (Senge, 1990). Embedded within this way of working, are the values, attitudes and beliefs of the school that shapes the way the community perceives and takes action.

In some situations there are schools with practices, working climates and attitudes that have remained unchallenged for many years, leading to habitual approaches to chronic problems (Senge, 2000). This maybe better explained through the hypothetical case study where deeper reflection within the school might reveal some fairly entrenched beliefs and ways of working. Perhaps the staff believe responsibility for students with disability lie with 'the experts', or the class teacher and not with themselves. Perhaps there is a culture that believes teachers have no role in orchestrating playground activities, influencing student friendship patterns or developing social skills. Perhaps the administration does not provide opportunities for staff to collaborate on behaviour management issues. Perhaps the staff views behaviour management as a discipline issue for administration, and not as a teaching concern. Whilst there may be any number of structural issues at play in this scenario, each would have powerful implications for any attempt to design and implement behavioural supports for the student. However, they also provide the school starting points for more meaningful and sustainable intervention into problem behaviour.

By identifying the structural elements at play, schools can begin to access pathways towards more effective management of disability and problem behaviour. This change comes at the organisational level and often a re-evaluation of the mindsets that have served to

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Book Review:

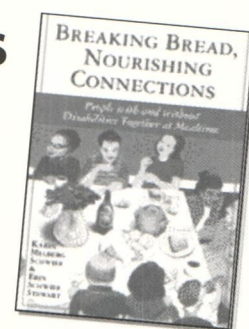
BREAKING BREAD, NOURISHING CONNECTIONS

– People with and without Disabilities Together at Mealtime

by **Karin Melberg Schwier and Erin Schwier Stewart**

Baltimore: Paul H Brookes Publishing Company, 2005

Review by: **Robert Perske**



There are many mealtime books for persons with disabilities, but none as warm, instructive and expansive as this one. It contains a magnificent concatenation of mealtime stories, tips, actions, attitudes and even some down-to-earth recipes. They come from the United States, Canada, New Zealand, Sudan, Ireland, Italy and Australia. They focus tightly on persons with all kinds of disabilities and persons without such obvious limits. Over 50 contributors shared what they did to make such mealtimes more rich, joyous, mutually valuing of one another and sometimes holy.

To quickly catch the book's spirit, one only needs to thumb through the pages and view the 56 photographs. After I did it, my mind fixed immediately on close Italian neighbors who are forever saying to me, "Come over and eat with us. We have *abundanza!*" This book is awash with that kind of welcoming and heartwarming abundance.

The book is obviously the brainchild of an extended family called Schwier. Karin Schwier is a journalist and editor of an award-winning newsmagazine, *Dialect*, as well as an author of a string of books – all aimed at giving assistance and dignity to persons with intellectual disabilities. Stepdaughter, Dr. Erin Schwier Stewart, is an occupational therapist who supplies a rich technical understanding of what can go on during mealtimes with persons having disabilities. J. Spencer Schwier, a professional folk art-

ist, produced "Gathering" for the cover. In the spirit of Grandma Moses, he painted 15 diverse persons feasting together around a large table. Karin's husband Richard, an ever-present fixture in the Schwier kitchen, serves as an advisor. Jim Schwier, the son of Richard and stepson of Karin, serves as the in-kitchen spark plug for many of these remarkable family gatherings. His likeable face can be easily recognized in 11 of the book's photographs. After considering the vast number of shared international mealtime experiences, it is clear that another book of this magnitude will not be written for a long, long time.

Brookes Publishing Company should be commended for printing this timely book. The company published an earlier one, *Mealtimes for Persons with Severe Handicaps*, that came to them via Random House and University Park Press in 1986. It is out of print now. As the team leader of that earlier book, I can honestly say the old one needed to die and this new one needed to come alive. The earlier book attempted to rescue persons with disabilities from awful mealtime practices that were first generated in crowded institutional wards, oversize group homes and nervous families. It included numerous warnings about rapid feeding, "bird feeding," unnecessary tube feeding, wrong-positioned feeding while lying on the back—often taking place in noxious, foul-smelling, noise-filled atmospheres. Karen Green McGowan, the

Problem Behaviour: Schools Navigating the Iceberg

continued from page 5

support the system in the past. When schools are able to question their ways of working in relation to students with disability and problem behaviour, they begin to effectively navigate their way around the iceberg.

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Front Cover:

Jim Schwier provides a course on the proper use of chopsticks on a bowl of chicken sate' for an aged friend in a Vietnamese restaurant in Saskatoon. Unfortunately, the friend flunked the course. Then he sheepishly asked for a fork.



team's registered nurse, described these hurry-up-and-be-done-with-it practices as "the quiet little murders" of the spirit and the body of persons who could not even begin to protect themselves from the thrusts of spoons held by unfeeling hands.

The new book rises and shines as it draws its meaning from the evolving standards of decency that mark the growing understanding and respect for persons with disabilities. The new book talks more about enriching mealtimes, instead of perfunctory feeding. The authors even spelled out their own manifesto:

So what do we mean by mealtimes for the purposes of this book? As authors intimately connected to family and friends with disabilities, we propose an expanded definition. We are looking at mealtime opportunities for people of all ages, cultures and living situations; for people with friends and without; and for people whose disabilities are profoundly challenging as well as for those who can, with a little support, participate easily. To us, no disability precludes the sharing of an enjoyable mealtime experience. These opportunities for intimate one-to-one interactions we collectively call mealtimes—including planning, shopping, selecting, preparing, and eating—can involve all sorts of skills, talents, information gathering, community presence, social value, sensory experiences, and human involvement.

At first, readers may wonder how to quickly digest everything on this gigantic smorgasbord table of experiences and ideas. Some may choose to approach it like many of us did when *The Whole Earth Catalog* was published some years ago. It, like this mealtime book, needed to be read in bits and pieces. For example, one might start by merely browsing the photographs, as mentioned earlier.

Next, readers might skip-through the book again by reading only the "Tidbits." There are 102 tiny bits of information that appear as sidebars throughout the book and in an appendix. These Tidbits fall into five categories: Good Ideas (e.g., "Turn off the cell phone and television at mealtimes"); Food for Thought ("Never talk past a person

you are eating with. Talk to that person"); Positioning ("One's mouth and hands work better when one's trunk and shoulders have a firm base of support"); Gadgets ("If adapted utensils are needed, respect the person's age. A Winnie The Pooh tippy cup is fine for a 3-year-old, but what does that say about a 30-year old?"); Safety and Health ("Taking a CPR and first aid course is never a waste of time"). These items and many more help readers to suddenly pay special attention to things that can so easily be overlooked.

After that, readers may choose to browse the recipes in the back of the book. Two of them ("Skinny Fries" and "Skinny Man Chili") caught my eye. Both were instantly recognized as fun things that friends might cook together.

It is expected that many readers will tackle the numerous short and long stories in the main body of the book in segments—like one might read daily reflections. Many will become memorable. A few of the many that stick in my mind: Al Etmanski's tender story, "Diana and Joan--The Gift of Communion;" Raffath Sayeed explaining why in his culture one must "Never Lead With the Left [Hand];" Jean Vanier's reflection on "Community and Growth;" Dick Sobsey's "Pass the Understanding, Please," describing his son's agonizing situation that cleared out a Burger King in one minute; Goomblar Wylo's "Consider the Source," offering a blessing for the animal that gave its life to feed others. Then there is Darlene Leister's "I Wish Mom Coulda Seen Me Make a Cupcake."

Persons who sincerely want to make their mealtimes more than they presently are now will profit immensely from the reading of this book. Be prepared to come away from it with new techniques and memories that will be hard to forget.

Robert Perske,
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NZ

by Marleen Verhoeven

The recent ASSID conference in Auckland was a great success. The presentations were of high standard and the air was buzzing. It was wonderful to see such a vibrant group of self-advocates contributing to this event. The theme "Out of the ordinary? Creativity, co-operation, collaboration" was explored from different angles by the keynote speakers. The conference had a distinct New Zealand flavour, based on our cultural and professional identity / identities. The Powhiri (welcome ceremony) was warm. The dinner was a great occasion with Pacific dancing and drumming, and the reception by the Governor General well received. After the conference I received feedback from an overseas guest. She had never attended a conference before where intellectual disability was explored from so many different angles. The conference was attended by self-advocates, parents, policy makers, clinicians, educators, caregivers, managers and others all working in cooperation, which was in true parallel with the theme. I trust the conference has facilitated inspiration and creativity to achieve further collaboration.

The conference was followed by a two day workshop by Glynis Murphy and Neil Sinclair, University of Lancaster, Cognitive-behavioural treatment for men with ID at risk of sexual offending (SOTSEC-ID). Next year's NZASID conference will be held in Wellington. The NZASID AGM was well attended and we have a big committee. The executive has changed with Angus Capie's resignation and Olive Webb's promotion to the ASSID presidency. Sharon Branford is our new president and Adrian Higgins the new vice-president. Marleen Verhoeven continues as the secretary / treasurer.

Victoria

by Daniel Pennefather

With the Victorian AGM finally set for 8 November, and the DSW conference on the 24th and 25th, it's definitely the business end of the year. Outcomes from the AGM will be reported in the next ASSID Vic newsletter, and in the next issue of IDA. Any members who would like to be active on the ASSID Victorian committee, or would simply like to come along to a meeting and have a look, would be more than welcome. The committee meets at 6:30pm on the first Tuesday of every month, at Milparinka ATU, 138 Lord St, Richmond.

By the time you read this, the Disability Support Worker Conference will have been held at the University of Melbourne on November 24th and 25th, 2005 including



Region Update

the Disability Support Worker Awards on the Thursday night, from 5.30-8.30pm. The program this year is full and varied with international keynote speakers and popular interstate and Victorian presenters. For more detailed information visit the website below.

<http://www.courses.as.rmit.edu.au/psychology/dsw05/index.htm>, or email the conference coordinator, Sue Mason, at dswconference@rmit.edu.au.

To contribute to next month's electronic newsletter, or if you would like to be added to the email list, send an email to assid.vic.news@optusnet.com.au.

SA

by Richard O'Loughlin

SA held its AGM on 27 September. Our guest speaker, Trish Johnson, a solicitor and a barrister from the Legal Services Commission with extensive experience representing and supporting people with intellectual disability in the criminal justice system, provided an address on what to do if you are supporting a person who is charged with an offense; described South Australia's 'Diversion Court' and provided general information about the court system. The presentation was practical and gave participants an invaluable summary of issues pertinent to service providers and advocates, including handouts and contact numbers. Subsequent interest has been expressed by SA membership in developing an updated summary guide on legal issues. The event was well attended. The AGM saw several new members join the regional committee which we like to interpret as an indicator of the vitality of and interest in ASSID(SA).

On 28th October, a research showcase event was held at Flinders University in conjunction with the Disability and Rehabilitation Professionals Association (DARPA).

Dr Brian Matthews, of the Department of Disability Studies at Flinders University, provided an overview of the nature and extent of research activities that have been undertaken by students and staff at Flinders University. Invitations were extended to professionals and service providers to identify possible areas for collaboration along

with opportunities for networking and further discussion over a choice of beverages. Approximately 30 people attended representing a mixture of advocates, service providers and students and staff from the universities, with parents of people with an intellectual disability found represented in each group. A range of research questions and general issue of interest were discussed, with the general shared sense that these types of gatherings should occur more often. The ASSID (SA) committee would like to see a regional conference that includes all three of Adelaide's universities at the same event as part of a collective effort at bridging the research and practice gap.

Planning for events in 2006 will commence at our November meeting. If, as a SA member you have ideas (specific or general) pleas let us know. E-mail rolstmarys@esc.net.au

Tasmania

by Donna Ryan

I attended the Australasian Conference in New Zealand and have to say I was 'thrilled to bits' with the inclusive practices demonstrated throughout the conference. The New Zealanders were very welcoming to us (their neighbours from "over the ditch") and I for one brought home with me many new contacts, information to follow up on and a wealth of new ideas. A huge congratulations to the New Zealand conference team!

Back here in Tassie our committee has been hard at work (while I skipped off to New Zealand!) organizing a hugely successful Fragile X Workshop. This workshop was sponsored by DHHS and had over 60 participants! We have held our AGM and office bearers for 2005/2006 for the Tasmania Region are as follows: President, Donna Venn (nee Ryan); Vice President, Darryleen Wiggins; Secretary Anne Salt and Treasurer, Moira McPherson. We are holding a Planning Day to review our Strategic Plan and schedule activities for 2006 on the 15th March 2006.

WA

by Kate Randall

ASSID WA is continuing our research theme with another forum held in conjunction with the Developmental Disability Council in September. This session focused on the identification of information that is available regarding disability support services in Western Australia. Consideration was also given to information that might be needed in the future to inform service development

and evaluation. Associate Professor Sherry Sagggers and Deirdre Croft presented current data about accommodation support funding in WA.

At the time of reading this, ASSID WA will have hosted our regional conference on November 14th in Perth. Our theme this year is 'Ethics and Practice' and we are welcoming Robyn Mildon from the Victorian Parenting Centre to speak about developing successful partnerships with parents who have an intellectual disability. We are looking forward to the day!

NSW & ACT

by Tony Tinlin

The Regional Group has had a quiet period resting after the Canberra conference and preparing our strength for next year and the Australasian Conference in September. Planning is under way for the Australasian Conference in Canberra next year with Linda Goddard at the helm. The committee decided to hold this year's AGM by teleconference in an attempt to enable members throughout NSW and the ACT to participate. Unfortunately only a very few people participated, so the committee will have to decide how to move forward. Another meeting will need to be held to elect a committee for the next 12 months. Look out for information regarding this meeting as it is important we have an active committee to assist with the planning for the conference.

Join ASSID - L now

ASSID-L is a spam protected mailing list for people with an interest in intellectual disabled individuals and their families.

To join the list, send an email to ddu@med.monash.edu.au with 'subscribe to ASSID-L' in the heading.

Postings assid-l@med.monash.edu.au

We look forward to increased relevant traffic on the list!

Video/DVD Review: Self Advocacy for People with Disabilities

OUR VOICE SA

available from OUR VOICE SA,
Disability Action Incorporated,
295 Torrens Road, West Croydon, SA, 5008
Price \$50 Pensioners & Students \$25

Reviewed by Ruth Davey,

B.Sc.(Hons), M.Pol.Admin



There is much to admire in this effort by a South Australian group of people with disabilities to make a Video/DVD on self advocacy. The Our Voice SA committee was assisted by Monika Baker from Disability Action Inc. The 25 minute Video/DVD was produced by Peter Waterhouse on behalf of the Our Voice SA committee. Sponsorship was provided by the Intellectual Disability Services Council (IDSC) in South Australia. The Video/DVD was launched jointly by IDSC and ASSID at a joint event in Adelaide in late April, 2005 and was well attended by both people with disabilities and service providers.

Who is it for?

It is aimed at educating people with intellectual disabilities and professionals working in the disability sector about self advocacy.

What's it about?

The Our Voice SA committee members speak spontaneously about work, housing and acceptance in the community, expressing strong views about important issues in their lives. They talk about the importance of standing up for yourself. The accompanying music is very appropriate to the advocacy theme, "get up, stand up, stand up for your rights, don't give up the fight", as it fades in and out when new sections of the Video/DVD are introduced by clear section titles.

An educative booklet accompanies the Video/DVD, introducing the members of the Our Voice SA Committee and inviting new members to join them. The booklet and Video/DVD arose from a workshop which was held to address some key questions around advocacy:

- What is Self Advocacy?
- Why we need Self Advocacy.
- What kind of support self advocates need. This question addressed the point that supporters should not take over the advocacy.

- Why groups are important to self advocates, and
- How they prepared this presentation.

The minutes from the initial workshop formed the basis for a further workshop held later during the November 2004 ASSID Conference in Adelaide at the Adelaide Hilton Hotel. The booklet also traces the growth of the self advocacy movement from the 1960s in Sweden to the present time, and expands on the above dot points addressed by the committee in the Video/DVD. Other points covered in the booklet include the framework for services to support self advocacy, ways of supporting individual self advocacy, supporting participation of self advocates and generally supporting self advocacy groups. Although the booklet states that it is written in plain English, there is room for simplification.

The Video/DVD concludes with a very pertinent statement from the Our Voice SA Committee "Nothing about us should be decided without us. If we are given a chance and treated with respect, we will speak up."

This is an admirable first Video/DVD with participation from the newly formed Our Voice SA committee which has been meeting regularly since April 2004. The Video/DVD is encouraging to new self advocates and portrays a clear message of where advocacy begins.

The workshop situation where the sound and video recordings were made also impacts on the quality of the recording. The ASSID event is worth recording, but a future Video/DVD would be improved from an instructional viewpoint using a sound studio and more consistent camera settings.

The reviewer commends this Video/DVD to people with disabilities who want to learn more about self advocacy, and to those working in the field who want to hear directly from the Our Voice SA committee what it is like to stand up for your rights when living and working in our community.

Depression and Asperger Syndrome: An overview of some issues

by Kim Davies,

PhD Candidate, University of Queensland

Depression is a severe and debilitating medical condition. Even though it is considered a 'mental' illness, it typically affects a person's physical, emotional and social experiences, including:

- When you sleep
- What and how much you eat
- Whether you get out of bed, or remain there throughout the day
- If you will brush your teeth and hair, get dressed or bathe
- How tired you feel
- How easily irritated you are
- Whether you want to be with others, including your family and friends
- What you think is happening and whether it matters
- Whether you make plans and what those plans might be
- Whether it is worth going on

Depression, it would seem, influences almost every aspect relating to a person's quality of life and necessarily therefore, it also has consequences for the families to which people with depression belong.

Prevalence

While estimates are that between 4% - 5% of Australians experience major depression (AIHW, 2004), the prevalence of clinical depression for people with Asperger syndrome (AS) is even higher and research indicates that depression is the most frequently experienced comorbid condition for people with AS. Ghaziuddin and Greden (2002) reported that of the participants in their study diagnosed with AS, 37% were concurrently diagnosed with major depression. Although an area in which little research has so far been undertaken, existing studies consistently report prevalence rates of depression higher than general community levels (e.g. Wing, 1981; Tantam, 1988). Kim, Szatmari, Bryson, Streiner and Wilson (2000) found that in their community-based sample of 1751 children, those with AS and other diagnoses along the Autistic Spectrum, demonstrated greater than average rates of anxiety and depression. Indeed, Lainhart and Folstein 1994 on the basis of their review of 17 published studies, have suggested that depression is under-diagnosed in the population of people with AS. It may be that some of the socio-emotional and communication impairments that form part of AS also effectively 'mask' key symptoms of major depression and render diagnosis (and therefore treatment) problematical (Ghaziuddin, Alessi & Greden, 1995).

What causes depression?

Currently, the most widely-supported, credible and evidenced-based notion about the cause/s of depression, posits a genetic predisposition that, given the 'right' (i.e. the wrong) circumstances, may develop into major depression. Recent research conducted into the family history of people with AS supports this proposition. Ghaziuddin (2005) has reported that "subjects with Asperger syndrome tended to show an excess of AS in their families and a trend toward an excess of relatives with depression" (p.181). These are very heavy loads for families to bear.

Research evidence consistently supports a connection between Autistic Spectrum Disorders and an increased prevalence of depression in families. It is uncertain, however, whether co-morbid psychiatric conditions, like major depression, are "independently occurring disorders or whether they result directly or indirectly from the pathogenic processes causing autism" (Lainhart, 1999, p.278) Research is ongoing and work by Bolton, Pickles, Murphy and Rutter (1998) however has indicated that increased rates of depression are not limited to the time immediately following the birth of a child with an Autism Spectrum Disorder and are not fully explicable by the burden placed on families by such changes. While no incontrovertible link has been established, existing research identifying the so-called "clustering" of major depression and Autistic Spectrum Disorders in families strongly suggests the interplay of common genetic factors.

However, genes appear to provide only one part of a more complex picture since research also indicates that life events also have their part to play in the onset of major depression for people with AS. In a study of children with Pervasive Developmental Disorders (including AS) children also diagnosed with major depression experienced significantly more major life events, particularly those that impacted in a negative way (like bereavement, changes at school and parental discord) in the twelve months preceding the onset of depression (Ghaziuddin et al., 1995).

Adolescence is a time of acute vulnerability during which people with AS are more prone to develop depression (Lainhart, 1999). Moreover, depression may cause the greatest impairment for young people with AS during adolescence, when social relationships are pivotal to most major achievements. More than twenty years ago, Wing (1981) argued that the increased prevalence of major depression for young people with AS during puberty may relate to their increased awareness of *continued page 12*

social differences. Barnhill and Myles (2001) investigated the relationship between depression and attributional or explanatory style in adolescents with AS. They reported that the greater the number of depressive symptoms reported by adolescents, the more likely those adolescents were to explain negative events by internal, stable and global causes – effectively a “reformulated theory of learned helplessness in adolescents with Asperger syndrome” (Barnhill & Myles, 2001 p.175). Incidentally, 70% of participants were already taking anti-depressant medication, suggesting that if the prescribed medication was influencing depressive symptoms, it did not appear to be affecting underlying maladaptive attributional patterns, which may be extremely resistant to transformation given the very nature of AS.

AS is frequently described as being at the ‘higher functioning end’ of the Autistic Spectrum. While the connotations implied by this description are undesirable and although debate about the validity of this description itself continues in the literature, people with AS typically are of average or above average intelligence (even though they may still experience and demonstrate major cognitive impairments). It has been argued by some researchers that the supposed “higher functional” nature of AS constitutes the very basis of the apparent vulnerability to depression experienced by people with AS. In their study, Butzer and Konstantareas (2003) reported that participant’s awareness of their disability (sic) was related to higher self-reported depressed mood and they concluded that “a higher level of cognitive ability and social awareness comes with a price, in that the children’s self-concept may be affected in a negative fashion” (p.70). In a similar vein, Ghaziuddin et al. (2002) argued that “higher functioning people (diagnosed with an Autistic Spectrum Disorder) because of their vulnerability to lower self-worth, may be more predisposed to depression” (p.303). Research links this diminished sense of self-worth to higher reported levels of social adjustment and the greater ability to understand others typical of people with AS (Ghaziuddin et al., 2002). However, effective social skills, according to research, are related to lower levels of depression (Butzer & Konstantareas, 2003).

How will I know?

Given the likelihood that people with AS will at some stage experience depression, how will they, and those dedicated to their well-being, know? The importance of this query is even more strongly underlined when you consider the nature of AS itself. Many people with AS have difficulty understanding, appropriately expressing and communicating with others about their internal states. Life for people with AS is inevitably stressful, and they may focus moment to moment almost exclusively upon

managing life’s stressors, stressors that are of no apparent concern to others. How then can we judge the difference between behaviour typical of AS and behaviour typical of depression, especially when so many of the symptoms are in each other’s shadows? Many of the features characteristic of depression listed in the introduction to this article will be familiar to those of us who are close to people with AS – the lethargy, the loss or increases in appetite, the sleep disturbances, the anger, frustration and irritability, the social abrasion and the withdrawal from interpersonal contact, for example.

For people with AS, depression might look like...

Given that most people with AS and depression do not present clinically until the depression is severe and often after it has been present for a prolonged period of time (Howlin, 1997) it is extremely important to maintain a high index of suspicion. The advice from experts is to be alert to changes in the level of adaptive functioning, especially around puberty (Ghaziuddin et al., 2002). According to Lainhart (1999), key indicators of the onset of depression include “new or worsened agitation, aggression, self-injurious behavior, temper outbursts, social withdrawal, vegetative changes in sleep or appetite, increased compulsive behaviors, hypoactivity and inertia, or general deterioration in functioning at home, at school, or at work (p.287). Ghaziuddin et al. (2002) also flag recent changes in the character and/or flavour of interests and preoccupations as important indicators. For example, a pre-existing passion for space may transform into a fixation with black holes and being lost to one.

Treatment options

Effective treatment for people debilitated by depression is crucial, but not necessarily an easy or inexpensive journey. As would be anticipated, access to diagnosis and effective treatment depends upon where you live (rural and regional Australians are particularly disadvantaged in terms of health care) and other personal, family, financial and community resources. Possible treatments include medication (SSRI’s and other anti-depressants), cognitive behaviour therapy (including attribution re-training), psychotherapy, group therapy (including social skills training) and any combination of the above. Advice and information can be sought from GP’s, psychiatrists, psychologists, school counselors, social workers and support groups.

Is early intervention, or even prevention, possible?

Given what the research has reported regarding the interplay between genetic and environmental factors in the onset of depression for people with AS, it is not only important but feasible to be proactive in the face of high prevalence rates.

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Book Review:

Achieving Learning Goals Through Play: Teaching Young Children with Special Needs

by **Anne H. Widerstrom**

(2nd Edition) Paul H Brookes Publishing Company, USA, 239 pages

Reviewed by Katy Gerner

MEd (Support Teaching), GradDip Adult Education (Basic Education), GradCert Education (Special Education), BA (Journalism), Cert TEASOL

Dr Widerstrom, Professor Emeritus of Early Childhood Special Education at San Francisco State University and consultant to Head Start and child care programs, has written a very readable book for early childhood education teachers on how to use play as a teaching tool.

Dr Widerstrom, whose doctorate is in educational psychology and early childhood special education, believes that play is essential for children, particularly children with learning disabilities. She writes:

“Children engage in play more readily than in other means of learning such as through memorization or direct teaching, and what they learn in play is generalizable to other situations, unlike rote learning.....Play is an excellent medium for achieving learning goals for several reasons related to acquisition, practice, mastery and integration of learning. First, play creates a safe, non-competitive arena for children to experiment with materials, objects and people; to test hypotheses; and to try out new roles. Play also provides opportunities for learning through trial and error. As a result, through play children can acquire new skills and understandings in all of the developmental domains.” (p.4)

She said the book will help its readers understand the role of play in early childhood education; provide ideas for using play as a means for helping children with special needs achieve individualized learning goals; teach you how to plan and write goals and objectives for children with disabilities, how to embed teaching and learning goals in play activities and how to encourage children to play together and make friends.

“Achieving Learning Goals Through Play” is divided into four parts: The Role of Play in Early Childhood Education: Planning and Writing Goals and Objectives for Children with Disabilities; Let’s Play: Embedding Techniques and Learning Goals in Play Activities and Playing Together and Making Friends.

Section one explains the skills that children gain from teaching, education philosophers’ thoughts on play and how to develop play for children with special needs. Section two covers individual education programs, planning matrix, individualizing goals for play and developmental play

sequences with several examples of each to follow.

Section three includes information on block play, sand and water play, pretend play, manipulative play, outdoor games and play, play with music and rhythm, play with creative materials and emergent literacy. Section four covers working with groups, learning social skills through play and helping families. It also gives an example of how one child could achieve her learning goals through play.

Section four is followed by five appendices, which include information on adaptive equipment and learning materials; guidelines for developmentally appropriate practice: adaptations for preschool children with disabilities; resources for including children with special needs; play checklists and reproducible planning matrices.

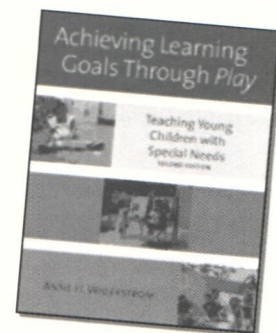
Unfortunately for Australian readers, the list of sources for adaptive equipment and learning materials, are naturally enough, all American. Fortunately, the list of books and training materials include some web site addresses.

The adaptations in appendix B is list of sensible advice on adapting learning opportunities for children with mild or moderate delays and disabilities for three year olds and four and five year olds. The advice would be soothing to a teacher nervous of taking children with disabilities into their classroom, particularly as many of the activities listed have “no adaptation is necessary” written next to them.

Appendix C provides useful guidelines on helping children with a variety of disabilities cope in the preschool classroom. The section includes information on hearing impairments and the role of hearing aids and sign language; visual impairment and how to help a child find their way around and physical disabilities, the principles of physical development, positioning and handling techniques. It also includes a table with strategies for adapting play materials with concrete examples on how to do this.

Appendix D is a chart that teachers can photocopy and use straight away. It is divided into three columns – the developmental sequence of various play activities including block, sand and water play and pretend play with two columns to tick – achieved and not achieved. This is followed by a detailed explanation of the checklist, and covers situations such as children who will not role play, children who only want to talk to adults in play, children with short attention spans and children who try

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to resolve conflict inappropriately or do not understand how to take turns.. This is followed by a summary of symbolic play development for children aged from 18 months to five years old.

Appendix E's reproducible matrixes are for individual play and group play.

Dr Widerstrom's advice in sections one to four is also very practical and something a teacher can use immediately. For example in the chapter "Emergent Literacy", she explains the developmental sequence of Literacy, adaptations and modifications for children with disabilities and short lessons that include the developmental age the activity is planned for and the learning objective.

The section on "Play with Creative Materials" provides excellent advice on the role of the adult in successfully facilitating creative play, the developmental sequence of creative skills and embedding learning goals in creative

play. This section includes activities to help children learn the meaning of big, biggest, small and smallest (gluing macaroni on construction paper), how to recognize circles, squares and triangles and distinguish between them (using rice cakes, cheese and vegetables) and helping children with sensory integration disorder become comfortable using objects of various textures (by having a texture table.)

"Achieving Learning Goals Through Play" is an excellent resource for early childhood education teachers. I also feel that it would benefit parents of young children with disabilities, without a teaching background.

Katy Gerner works in TAFE as a disability support teacher (intellectual and acquired brain injury), teacher /consultant for students with physical disabilities and an English for specific purposes teacher. She is also a foster mother and a book reviewer.

Depression and Asperger Syndrome: Overview

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Actions could be oriented around three dimensions of care:

- 1) Social care, including choices about schooling (e.g. inclusion and IEP goals) responses to bullying and victimization, support and respite, employment and community participation.
- 2) Self care, including choices (to provide support and respite) to support and assist the core carers, especially given their pivotal role in managing environmental stressors for those people with AS.
- 3) Kid care, including choices to develop resilience by focusing on the individual's strengths and abilities, the development of effective social skills and personal and community networks, positive habits of thought and a positive self-concept.

These dimensions of care reflect the inexorable connections between individuals, families and communities and highlight the impact that effective intervention at any one level can have on the others. Fostering resilience in individuals, families and communities may equate to early intervention for people with AS, which, it is self-evident, can be a life changing experience by minimizing the risk and maximizing the protective factors.

Conclusions

Given the prevalence and family studies conducted thus far, it seems apparent that people with AS are at greater risk of developing depression. Work continues teasing out the complex interplay between genetic and environmental factors that trigger its onset, however, it seems clear from the research conducted to date, that despite the genetic loading or "clustering" of depression in families of people

with AS, and which remain intractable, environmental factors (especially around adolescence) relating to social skills, habits of thought and self-concept are open to effective, and ideally very early, intervention. Early intervention in these areas to promote the resilience of people with AS may tilt the balance between risk and protective factors just enough to lessen the severity of any depressive episode, improve the quality of life for the affected individual and substantially ease the burden of care.

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UPCOMING EVENTS

<p>29 Nov - 1 Dec 2005</p>	<p>University of New England (Hosted by Challenge Armidale Ltd) <i>Inspiration, Innovation, Information: National Best Practice in Disability Conference</i> The conference will feature presentations, workshops, and posters on leading practice in the areas of governance, management practice, ageing and disability, health and well-being, employment services etc Program, abstract and registration details: www.une.edu.au/campus/confco/bpdc2005</p>
<p>8 - 10 Feb 2006</p>	<p>National Council on Intellectual Disability: <i>Having a Say Conference</i> To be held at Costa Hall, Geelong, Victoria. Further information: http://esvc001127.wic004u.server-web.com/conferences_events.htm#has2006</p>
<p>20 - 21 Feb 2006</p>	<p>ACROD NSW Division Annual Disability Services Conference To be held at Manly Pacific Sydney. Further information: http://www.acrodsw.net/</p>
<p>13 - 15 March 2006</p>	<p>Annual Pacific Rim Conference on Disabilities To be held at the Sheraton Waikiki Hotel and Resort, Honolulu, Hawaii. Further information: http://www.pacrim.hawaii.edu/general/about/</p>
<p>2 - 6 July 2006</p>	<p>International Society for the Study of Behavioural Development 19th Biennial Conference To be held at the Carlton Crest Hotel, Melbourne. Further information: http://www.issbd2006.com.au/</p>
<p>4 - 6 July 2006</p>	<p>4th International Conference on Developmental Disabilities: Policy, Practice and Research To be held at the David Intercontinental Hotel, Tel Aviv. Pre Conference Workshops will also be held 2-3 July 2006. Further information http://www.ortra.com/beitissie</p>
<p>1 - 3 Sept 2006</p>	<p>National Conference on Autism Spectrum Disorders (Hosted by Autism New Zealand Inc) To be held at the Duxton Hotel, Wellington, NZ. Further information at http://www.autismnz.org.nz/.</p>
<p>5 - 8 Sept 2006</p>	<p>Australasian Society for the Study of Intellectual Disability (ASSID) 41st Annual Conference: <i>Risk and resilience: Hope for the future.</i> To be held at the National Convention Centre, Canberra, Australian Capital Territory</p>

Depression and Asperger Syndrome: Overview

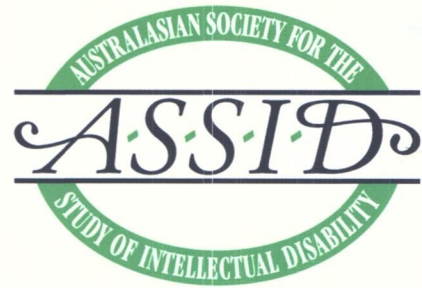
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**Australasian Society for the Study of Intellectual Disability:
41st Annual Conference**

Risk and Resilience : Hope for the Future

**5 - 8th September 2006
National Convention Centre
Canberra, Australian Capital Territory**

The theme is linked to the changes that have occurred over the last twenty years in the lives of people with disabilities, their families, service providers and professionals.

Much has been achieved; however there are major challenges to face in the next twenty years.

The forecasted increase in the number of people with disabilities and in the ageing population will have an impact on what is rapidly becoming an 'invisible population'. A population which will still have the right to a good life and access to quality services.

Many people have shown a remarkable resilience in adapting to bizarre circumstances which numerous risk factors present.

Yet despite the lack of support in some areas, people with disabilities and their families cope.

This conference needs to look at how we can all prepare for the future with a drawing together of strengths and a vision for the future.

[This is an initial preamble more discussion will follow.]

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