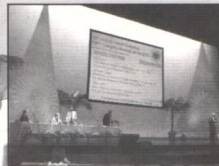


INTELLECTUAL DISABILITY *Australasia*

Special Focus Issue:

Challenging Behaviours



& 12th  IASSID
World Conference

Inside:

*The Signposts for
Building Better
Behaviour Program*

*12th IASSID
World Conference*

*Youngsters with
Very Difficult
Behaviours:
Whose Problem?*

Region Reports

*Intensive
Intervention*

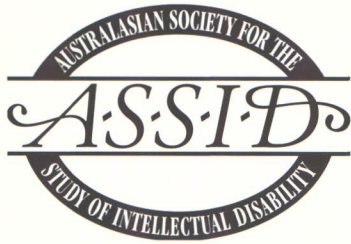
Book Review

Fellow of ASSID

*Obituary:
Mr Jim Woodworth*

*More information
on upcoming
conferences*

...and more



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) 3365 6868

Email: deb.keen@uq.edu.au

Editorial Assistant:

Ross Tudman

Advertisers:

Rates are available, on inquiry, from the editorial assistant at krvt3@bigpond.com

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

Artwork:

Karen Vance - KRVT Design
krvt3@bigpond.com

Printed by:

Unik Graphics

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Editorial

We are excited to present this special edition of WIDA focusing on challenging behaviour. Over the past few decades, there has been an exciting growth in our understanding of why individuals with intellectual disabilities may engage in challenging behaviour and how we may support those individuals to find alternative ways to express themselves. Theories, strategies and techniques of applied behaviour analysis that have evolved from years of research dating back to the first half of the 20th century have been complemented with a growing understanding of the importance of environmental contexts to the way individuals behave.



Deb Keen

During the 1980s, important research was undertaken that caused a shift in the way researchers and clinicians thought about challenging behaviour. Until then, the predominant view was that difficult or inappropriate behaviour should be eliminated, usually through some form of punishment or extinction. Punishments could involve placing the person engaging in the behaviour into time out, or using unpleasant consequences such as sipping lemon juice when the behaviour occurred. Extinction involved ignoring the behaviour or reinforcing a different behaviour that was incompatible with the problematic one. While these techniques achieved some success in reducing or eliminating problematic behaviour, they were not always successful and there were serious ethical and moral concerns about the use of punishment. Sometimes the problem behaviour ceased, only to be replaced by a behaviour more severe and concerning than the original one. Sometimes, punishments were harsh and inhumane, such as the use of cattle prods to punish self-injurious behaviour. There were also occasions when behaviours were considered problematic but later found to be useful. An excellent example is the use of echolalia by individuals with autism. Once treated as a behaviour that should be extinguished using some of the approaches described above, it is now seen as part of a developmental process that may assist the child to better understand language.

What seems obvious to many now, took the work of some insightful researchers such as Anne Donnellan, Pat Mirenda, Edward Carr, and V. Mark Durand to discover. They identified a link between challenging behaviour and communication. Many problem behaviours were found to be motivated by communicative functions, the most common being attention, escape / avoidance, tangibles (wanting to obtain something), and self-stimulation (behaviours that are intrinsically rewarding for the person). This discovery led to the development of interventions that used information about the function of the challenging behaviour to replace it with an acceptable behaviour that would serve the same communicative function. It became clear that

Never forget
you are
invited to
contribute!

Send your news, views, letters,
reports on best practice to
deb.keen@uq.edu.au

The Signposts for Building Better Behaviour Program

A. Hudson, S. Gavidia Payne, & K. Nankervis (RMIT University)

J. Matthews, C. Cameron, & F. Arney (Victorian Parenting Centre)

The Signposts for Building Better Behaviour program consists of a set of materials and a system for implementation of support for families of children with an intellectual or developmental disability. The program was developed as the result of an initiative of the Victorian Department of Human Services (DHS) who provided all funding for the development, evaluation, and dissemination of the program. The materials for the program were initially developed in 1999 after extensive consultations with parents and service providers, and were based on what the scientific literature indicated was effective for supporting families that had children with an intellectual disability and difficult behaviour (Gavidia-Payne & Hudson, 2002).

Signposts materials

Signposts consists of materials for both parents and workers (facilitators) in the field.

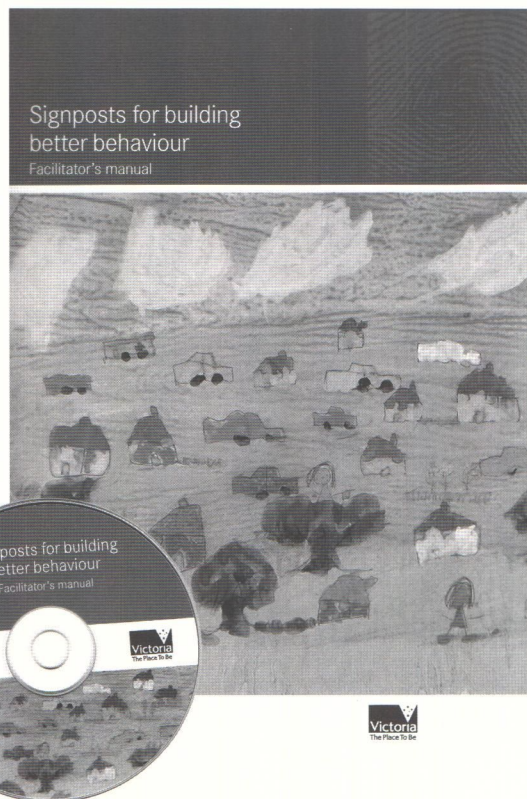
Parent materials

The parent materials consist of eight information booklets, a videotape, and a workbook. The information booklets are entitled (a) Introduction, (b) Measuring your child's behaviour, (c) Systematic use of everyday interactions, (d) Replacing difficult behaviour with useful behaviour, (e) Planning for better behaviour, (f) Teaching your child new skills, (g) Dealing with stress, and (h) Your family as a team. The first six of these are core booklets and the last two are adjunctive booklets. The materials are designed so that the parents can proceed through the core booklets one at a time, with time in between to practise skills that they had been learning. The adjunctive booklets are completed when families think they would be useful in their own particular situation.

Editorial

punishing a child's behaviour would have limited success when used in isolation, and helped to explain why eliminating one behaviour may result in a more problematic behaviour emerging. The child may still be trying to communicate the same message through a different, yet more challenging behaviour.

In this special edition of IDA, we have a series of articles that demonstrate how best practice in supporting individuals with challenging behaviour, their families, teachers, and



The videotape comprises a series of 33 brief scenes that illustrate particular points being made in the booklets. As parents work through the booklets, they are directed when it is appropriate to watch the videotape and to complete the relevant exercises in the workbook. Most of the actors in the videotape were members of families of children with disabilities. The children with disabilities all had Down syndrome.

By combining information with videotaped modelling and problem solving exercises, the learning process for parents is active rather than passive

continued page 4

continued

others can be implemented successfully. In addition to these articles, we bring you a report on the IASSID conference recently held in France together with information and updates on ASSID activities. We hope you enjoy this edition of IDA and encourage you to consider contributing to our next special edition that will focus on Health and Wellbeing for Individuals with an Intellectual Disability.

Deb Keen (Editor)

The Signposts for Building Better Behaviour Program

continued from page 3

Facilitator materials

The facilitator materials comprise three manuals, one for each of the three modes of delivery. These are available in a loose leaf folder and on a compact disc. They contain directions for facilitators to deliver the Signposts program. They also contain tools such as overhead projections, recording sheets, and recommended valuation measures to assist the facilitator.

Signposts as a system

The Signposts program is conceptualised as a service delivery system with parent materials that can be delivered in three different modes, depending on the needs and circumstances of the families involved. The three modes are (a) group support, (b) telephone support, and (c) self directed.

Group support

In this mode parents meet as a group at a venue such as a kindergarten or school. The group meets with a facilitator on six occasions on a fortnightly basis with meetings that last for 2 hours, on average.

Telephone support

In this mode, an initial mail out includes the first core booklet, the adjunctive booklets, the videotape, and the workbook. The remaining core booklets are delivered on a fortnightly basis, and the parents receive a fortnightly phone call from a facilitator to discuss progress and trouble shoot any difficulties that may have arisen. The length of the phone call should be as long as is necessary to deal with any issues and is typically of about 20 minutes duration.

Self directed

In this mode parents work through the materials with no support from a practitioner. After the initial mail out, the core booklets are delivered on a fortnightly basis to allow enough time for parents to practise what they learn from each booklet.

Evaluation

In 2001 and 2002 a comprehensive evaluation of the program was conducted with 115 families in Victoria (Hudson et al., 2003). All three modes of delivery were found to be effective in assisting families across a range of outcome variables. In summary, parents' sense of efficacy

increased, their stress levels decreased, the amount of their daily hassles decreased, their children's difficult behaviour decreased, and they were satisfied with the Signposts materials.

Further evaluations of the program are ongoing. One of these is examining the use of the telephone and self directed modes with families in rural and remote areas. This research is funded by the Australian Research Council and the Victorian Government Department of Human Services in conjunction with RMIT University and the Victorian Parenting Centre.

Dissemination of program

Training to use the Signposts program with families has to date been conducted by the Victorian Parenting Centre and has been funded by the Department of Human Services for a broad range of practitioners from government and non-government family support services.

The training consists of two workshops, one focusing on the parent materials and the other on the facilitator materials. Between workshops, training participants complete learning exercises to consolidate their understanding of the parent materials. Approximately 300 practitioners from the field have attended such workshops. In addition, as part of their training some staff have had the opportunity to co-facilitate parent groups with staff members from the Victorian Parenting Centre.

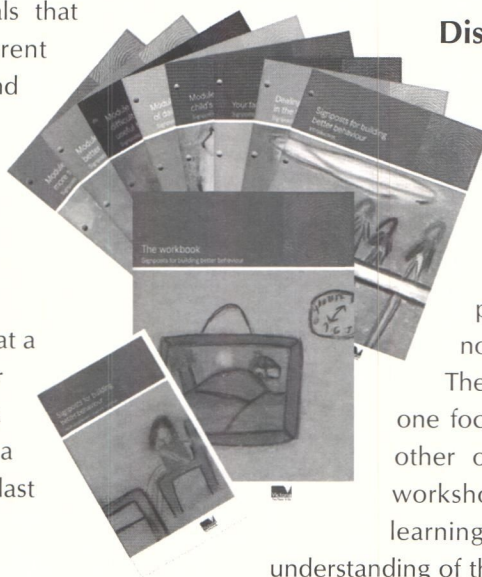
Further information

Further information about the Signposts program is available by telephoning Professor Alan Hudson on (03) 9925 7360 or by emailing him on alan.hudson@rmit.edu.au.

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- Gavidia-Payne, S. & Hudson, A. (2002). *Behavioural supports for parents of children with an intellectual disability and problem behaviours: An overview of the literature*. *Journal of Intellectual and Developmental Disability*, 27, 31-55.
- Hudson, A. M., Matthews, J. M., Gavidia-Payne, S. T., Cameron, C. A., Mildon, R. L., Radler, G. A., & Nankervis, K. L. (2003). *Evaluation of an intervention system for families of children with an intellectual disability and challenging behaviour*. *Journal of Intellectual Disability Research*, 47, 238-249.

[27/08/04 The federal government announced a \$4 million funding boost towards telephone and web counselling, training for 300 support group facilitators, and a co-ordinator for the Signpost program. Editor]



12th IASSID World Conference

Montpellier, France 14 – 19 June 2004

Report by Deb Keen

The 12th IASSID Conference, entitled Towards Mutual Understanding: Person, Environment, Community was conducted over six days with 13 themes. The themes were Biological Understanding; Mental Health & Behaviour; Cognition & Communication; Physical Health & Profound, Multiple Disabilities; Families; Education & Work; Community Living; Lifespan & Ageing; Quality of Life; Individual in Society; Populations & Service Systems; Environment and; Science & Research Methodology. As you can see by this extensive list, the coverage of topics was both broad and informative. For the many of our readers that were unable to attend the conference, abstracts for all presentations are available through the IASSID Journal of Intellectual Disability Research, Volume 48. The journal provides a wonderful way of reviewing the conference presentations and of contacting presenters whose email addresses appear with their abstracts.

... no support for a correlation between MMR and prevalence or between mercury and autism

The format of the conference involved a series of keynotes and then numerous parallel and poster sessions. It was sometimes difficult to choose between the 20 papers

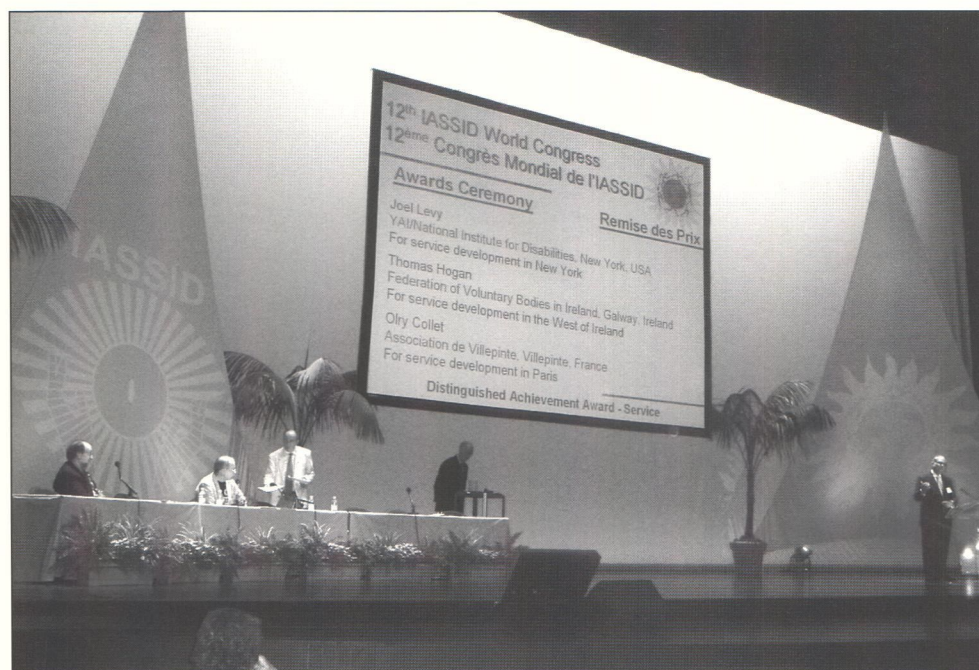


being presented simultaneously in some time slots. In this report, I have chosen to summarise some information gleaned from keynote and session papers around the topic of autism, as this is a personal interest that I pursued at the conference.

Eric Fombonne (McGill University, Montreal, Canada) was a keynote speaker on day one of the conference and his topic was The Changing Epidemiology of Autism Spectrum Disorders. Dr Fombonne examined methodological differences and issues related to various epidemiological surveys that have been conducted over the past 10 years or so, particularly those that have been used to claim an increase in the prevalence of autism. Most studies were not informative in gauging trends over time

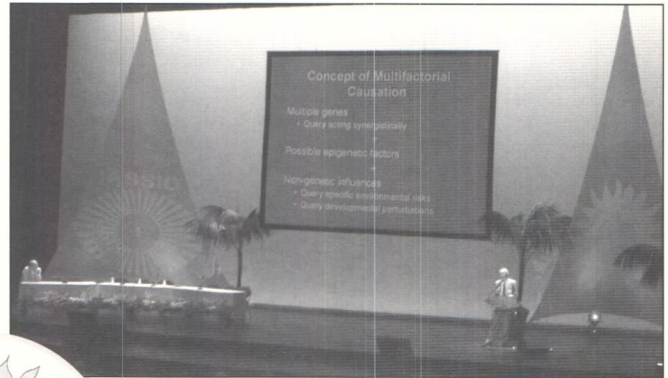
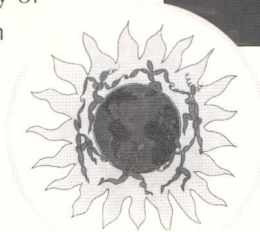
because there were so many methodological differences, making comparison almost impossible. In essence, most studies also failed to control for changes in case definition. Dr Fombonne concluded that methodological factors may account for a substantial part of the observed increase in prevalence. He then went on to look briefly at issues of MMR and mercury with respect to prevalence. Other presenters at the conference also addressed these issues (e.g., Sir Michael Rutter) and it was clear

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from the evidence presented that there was no support for a correlation between MMR and prevalence or between mercury and autism. A study by Honda et al. (2003) for example, showed that the rate of autism diagnosis increased in Japan after 1992, the year MMR vaccines were discontinued in that country.

Sir Michael Rutter (Institute of Psychiatry, University of London) was both a keynote speaker and presenter at a parallel session. His keynote topic was Aetiology of Autism: Findings and Questions and his session paper was on Clinical Implications of Genetic Research. Sir Rutter began by describing what is meant by Autism Spectrum Disorder and then went on to describe how causation is multifactorial. He explained how multiple genes were acting synergistically with possible epigenetic factors and non-genetic influences impacting. Clearly there is a strong heritability factor evident with the incidence of ASD at about 70% for monozygotic twins compared with about 10% for dizygotic twins. Based on statistical modelling using data from twin studies, it is estimated that somewhere between about 3 and 12 genes are acting together. Findings from linkage studies (e.g, Folsteing & Rosen-Sheidley, 2002) suggest that chromosomes 2, 7, and 16 are likely to carry susceptibility for autism. Due to the genetic factors involved in autism, Sir Rutter stressed the importance of expert genetic counselling for families with a history of autism and



will lead to gene therapy or population screening because non-genetic influences and other genetic background factors may effect the expression of genes and therefore the manifestation of autism.

Pat Howlin (St George's Medical School, University of London) gave a keynote on the first day of the conference entitled Interventions and Outcome in Autism. Dr Howlin reported on a study (Howlin et al., 2004) that followed up

...unlikely that genetic research into autism will lead to gene therapy or population screening ...



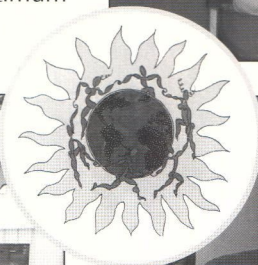
considering further pregnancies. When looking at the implications of genetic research, Sir Rutter had some important recommendations and insights. He stressed the importance of understanding that genes don't cause behaviour. That is, there is a pathway that must be understood regarding the expression of genes and how this may lead to autism. This pathway has not, as yet, been defined for any multifactorial genetic disorder, including autism. Given the complexities of multifactorial genetic disorders, it is unlikely that genetic research into autism

68 children with autism with respect to outcomes in adulthood. Of those surveyed, approximately 20% had achieved formal qualifications and about 30% had a job. Some 30% reported having some friends and 10% were living independently. These findings were somewhat disappointing in that the survey involved individuals that had been identified as 'high functioning'. This led on to an examination of therapies and interventions for individuals with autism. Within the research literature, the best evidence of intervention effectiveness comes from behavioural and structured educational interventions however there is no evidence to suggest

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that any one therapy or intervention is any better than others. For example, Magiati conducted a 2 year follow-up study of children that were involved in either an ABA program for 2 years or an autism-specific nursery school program. Both groups were similar with respect to outcome measures at follow-up. As yet, there is no evidence to recommend any one particular approach. Furthermore, evidence is lacking with respect to the optimum level of intensity of intervention, degree of structure, and optimum age at which to commence intervention.



Call for Contributions

INTELLECTUAL DISABILITY Australasia

will focus on **HEALTH AND WELL BEING** in the next edition.

Book reviews and articles will provide up to date information on current research and practice in this area. If you would like to contribute, or get in touch with me about this special edition, please email deb.keen@uq.edu.au.

Intensive Intervention

By Richard O'Laughlin, Senior Psychologist

Specialist Intervention and Support Services, Intellectual Disability Services Council

This article has drawn heavily upon material produced by the staff of the Intensive Intervention Team (IIT) in collaborative efforts to summarise how the team operates for the benefit of the families and agencies with whom we work.

The Intensive Intervention Team (IIT) is part of the Specialist Intervention Support Services (SISS) within the Community Services division of Intellectual Disability Services Council (IDSC). IDSC is the lead public sector agency in South Australia for people with an intellectual disability and provides a range of services including accommodation, community based case management and developmental services, service planning and development, purchasing and evaluation of services.

The IIT provides a home and community based service to people with an intellectual disability, their families and carers, who are considered to be of high priority for an intensive or specialised response. The service is intended to complement the services available in regional community teams.

The IIT provides services to:

- Families who have a child with an intellectual disability, who are experiencing significant stress and have serious concerns about their capacity to continue to care for their child. Their ability to cope may be significantly affected by factors such as very difficult child behaviour, family relationship problems, physical or emotional health issues in the family, lack of support or financial difficulties.
- Adolescents and adults with an intellectual disability who exhibit extreme challenging behaviour that places them at risk of losing their accommodation, day activity or participation in the community.
- Carers and service providers who are having significant difficulties in providing support to people with an intellectual disability who are behaving in ways that pose a risk to the safety of themselves and those around them.

The service aims to work in partnership with families, carers, and service providers to:

- Prevent family breakdown or permanent, premature out of home placement of a child with intellectual disability.

- Strengthen the family's knowledge, skills and resources so that it is able to cope more effectively in the future.
- Enhance the safety and wellbeing of individuals with intellectual disability and extreme challenging behaviour, their families and carers.
- Assist the individual to maintain his/her accommodation or day activity when in his/her best interests, and encourage meaningful community participation.

Depending on the key issues identified and agreed upon by the family, service providers and the team, the intervention may involve:

- Counselling to address family, couple and individual problems.
- Information and support with parenting skills and child development.
- Interventions to address an individual's communication, sensory processing and developmental needs.
- Teaching an individual new skills
- Eco-behavioural interventions focused on offering parents and service providers different ways to approach and manage an individual's difficult and challenging behaviour.
- Education and training for families and service providers to understand factors contributing to challenging behaviour, and support to carry out specific intervention strategies.
- Practical supports for families such as budgeting and household management.
- Building on the strengths of families and service providers.

The IIT is an interdisciplinary team and consists of psychologists, a social worker, intervention support workers, a developmental educator, speech pathologist and an occupational therapist. The team member involved in an intervention will depend upon the needs of each family and the specific goals for change.

Intervention is divided into four phases:

Assessment takes 4-6 weeks and involves gathering of information in order to develop goals and a plan of intervention.

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Intensive Intervention

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Intensive Intervention involves the implementation of the intervention plan over approximately 12 weeks.

Planned closure during the final 8 weeks of the team's involvement, aims to achieve a smooth transition from intensive intervention to ongoing support arrangements provided by the IDSC case manager and/or other service providers. Effective planned closure also gives an opportunity for people involved to consolidate the skills acquired during the intervention.

Follow-up to provide support to the IDSC case manager and/or service provider in their ongoing support role occurs at 1, 3 and 6 months after intervention.

The IIT utilizes a systemic framework to guide its practice. The approach is holistic, taking into consideration the person's disability, skills and development, and their family,

social and physical environment. Intervention focuses on developing the competencies of the individual and those involved in that person's care. The IIT approach is flexible, matching the mode of intervention to the specific needs of the person, family, carer or service provider. Consequently, the work may have a behavioural, developmental, family or service system focus depending on individual needs.

The IIT seeks to implement evidence based practice, and has a focus on ongoing research and evaluation, and the development of creative and innovative strategies.

The IIT draws on a number of key theoretical and practical frameworks.

1. Eco-behavioural Model
2. Family therapy approaches

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39th Australasian Society for the Study of Intellectual Disability Conference
9-12 November, 2004

Visions and Realities *

www.plevin.com.au/assid2004

Visions and Realities -

The way things are and the way things should be.

Empowering people with intellectual disability and supporting their families in the 21st century.

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

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

For further information contact:
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New Zealand

The main event for NZASID members since the last edition of IDA appears to have been the attendance by a goodly number at the Montpellier IASSID Conference, where we had the opportunity to catch up with colleagues from Europe and America as well spend time with colleagues from across the Tasman.

The NZASID conference Journeys is to be held at the Holiday Inn ,Christchurch 30 September to 1st October.

Keynote Speakers:

Prof Glynnis Murphy (UK) on Sexual offending

Assoc Prof Bob Davis (Au) on Health Issues

David Corner (NZ) on Self Advocacy Issues

Stephnie Roberts (NZ) on Residential and Lifestyle Issues

Christchurch is just over an hour's drive from some of the best ski fields in the South Island so if you have time for a break this could be an option.

The ASSID Australasian Conference will be held in Auckland in 2005. Planning is well underway and we hope to release details at the ASSID conference in Adelaide in November this year.

Angus Capie

Tasmania

In the past few months the Tasmanian ASSID committee have been working on organising a 3-day series of workshops in October with 2 interstate speakers confirmed (Roy Brown Ph.D, Emeritus Professor Flinders University, Australia and University of Calgary, Canada and Eddie Bartnik from WA). A Tasmanian speaker is still to be confirmed. We have been developing our own student award to recognise outstanding achievement of a student completing certificate 3 or 4 in disability studies and we are again sponsoring The Institute for Applied Behaviour Analysis Association to complete a 4-day training series entitled "Positive Approaches to Solving Severe Behaviour Challenges". The latter will be held from the 20th September til 23rd September 2004 at the Corus Hotel, Hobart.

Upcoming event include:

IABA - 20th -23rd September 2004 to be held at the Corus Hotel, Hobart

Workshop Series - 25th - 27th October 2004 to be held at Laetare Gardens

Darryleen Wiggins

Western Australia

In May this year ASSID WA hosted an evening presentation by Eddie Bartnick, the Director of the Disability Services Commission's Metropolitan Services Coordination.

Eddie recently spent time working with the Interim Authority for Community Living in British Columbia, where services for people with disabilities are being devolved from a large government Ministry for Children and Families to a separate stand alone statutory authority that has a community based board of governance.

Key directions for services in the province focus on more choice and control for individuals and families, increased individualised funding and facilitation of individual planning and a greater engagement of local communities around the province.

Eddie's presentation was followed by discussion about the impact of broad level service change for service users in British Columbia and some comparison of ways that services have developed in Western Australia over the past few decades. Several key participants in the WA disability sector over the last thirty years were present and provided a great deal of material for reflection. This was a great learning opportunity for some of us who have not been around for so long!

We are holding our annual conference on October 25 this year, with the theme:

"Quality of Life - its relevance in the 21st century"

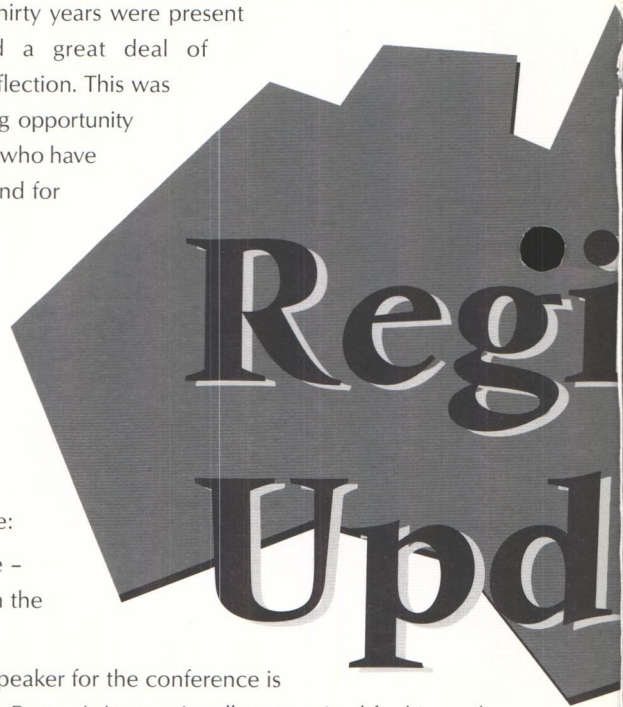
Our keynote speaker for the conference is Ivan Brown. Dr Brown is internationally recognised for his work around quality of life for people with disabilities. He has published widely on the topic, including his recent book with Roy Brown 'Quality of Life and Disability: An Approach for Community Practitioners.' He has carried out numerous quality of life research projects with adolescents, seniors, children, adults with developmental disabilities, adults with mental health problems, and other groups. Dr. Brown is Manager of the Centre of Excellence for Child Welfare, a national Canadian centre for policy development and research, and an Associate Professor in the Faculty of Social Work, University of Toronto. We are excited to have Ivan Brown visiting for our conference and look forward to an informative and enjoyable time spent together.

Kate Randall

South Australia

The South Australian committee has been preoccupied with arrangements for the annual Australasian conference in November (see website for details: www.plevin.com.au/assid2004).

Our publicity campaign is proceeding well with postcards having been distributed at the IASSID conference in Montpellier in July, posters in the process of being distributed locally and interstate,



and electronic reminders being circulated through a variety of networks, in addition to the usual 'hardcopy' mail outs of registration brochures.

We have received a substantial number of abstracts (136 at last count) from all over the country covering a wide range of topics. We are chuffed that we have received a significant number of submission from overseas including from the UK, Sweden, Canada and the United States (and of course New Zealand). Notification of acceptance of abstracts will doubtless have been received by the time this edition of IDA is distributed.

We have been successful in our application to the commonwealth department of Family and Community Services for a grant to assist people with a disability to participate in conference. We are now working out how the available funds will be allocated.

It is shaping up to be quite an event. The SA conference organising committee remembers Juan Antonio Samaranch- former president of the International Olympic committee- summarising the Sydney Olympics in 2000 as the 'best ever'. In South Australia we have similar aspirations for the ASSID 2004 conference.

Aside from conference preparations, we had invited the state government minister to another 'meal with the minister' event - although the Minister has agreed to officially open

the conference in November, he will not be able to meet with us before then.

The SA committee is currently considering an event to run in conjunction with our upcoming AGM. (at a date yet to be set) .We are considering holding an event at one of the three universities to foster closer links between ASSID (SA) and the tertiary education sector in South Australia. Members will receive information soon.

The only other ongoing activity at this stage is responding to the steady flow of requests for the Roy Brown monograph that the SA branch published in 2003.

The SA committee is actually a small number of people trying to keep ASSID in SA active and viable. We are hoping that the conference this year will inspire more people to join the Society and hopefully to take a more active role in joining the SA committee and running events of interest to our membership.

We would appreciate your ideas, energy enthusiasm, and time. We need your help to make a difference.

Richard O'Loughlin

Victoria

Recent excursions to France for many Victorian committee members have meant a fairly quiet events list for the last few months. However the coming events schedule is somewhat busier. The Direct Support Workers Conference, coming up on the 25th and 26th of November, will once again host the Victorian Government Direct Support Worker Awards. The program, based on topics raised in a survey of Direct Support Workers, is currently being developed.

The Victoria region State Conference (2004), to be held on the 12th of October, will be an exciting variation from the norm. With several other conferences being held in Victoria in the latter half of this year, the committee focused on making the State conference unique in its perspective, and what it has to offer. For this reason, the event will host Anne Deveson, author of the book *Resilience* (Allen & Unwin, 2003) and notable for her insight into human rights issues. The conference is expected to interest professionals in other fields related to the intellectual disability sector, as well as those who regularly attend the event. A focus on inspiring quality partnerships between disability workers and those in generic organisations, has led to the theme 'Beyond Boundaries'.

The newsletter relaunch is imminent, in a new electronic format, and will keep Victorian members up to date on these events, as well as the Victoria region Annual General Meeting, which is expected to be held in early October.

Daniel Pennefather

Queensland

The Sharing the Road conference for Disability Support Workers happened in Brisbane on July 19 - 21. The conference was a great success with plenty of learning and sharing. Of particular interest was the opening Keynote by Glen Sheppard, who has Down syndrome and autism and uses facilitated communication. Glen's personal story of living with autism, Down syndrome and the impact of FC, which has enabled him to start a degree in the Social Sciences, held delegates spellbound and was a great start to the conference, the theme of which was "The Fire Within - Exploring Commune-ity".

The Cairns Sharing the Road conference is being held on August 11 and 12 at the Cairns Convention Centre. It will follow the theme of the Brisbane conference but will have a strong focus on local issues.

Local members should look forward to receiving information about the upcoming Annual General Meeting to be held mid-September.

Chris Montgomery



3. Ecology of Human Performance
4. Functional communication
5. Developmental approach.

The IIT views these approaches as distinct but not mutually exclusive. All are considered to provide valuable tools for assessment and intervention for people with intellectual disability and their families, carers and service providers. IIT aims to utilise and integrate different approaches depending on an assessment of individual client needs and the priority areas for intervention.

The expertise required in applying this range of approaches is achieved through an interdisciplinary teamwork model that incorporates contributions from a range of professional disciplines including psychology, social work, occupational therapy, speech pathology and disabilities studies. Team members contribute to a pool of shared skills and knowledge as well as maintaining discipline specific expertise. The outcome is an integrated approach to the work, which allows for flexibility and creativity in the design of individual client interventions.

A brief summary of these models follows:

1. Eco-behavioural approach

This approach was developed in the United States by the Institute of Applied Behavior Analysis (IABA) and involves the application of applied behaviour analysis within a broader systemic framework. It provides a systematic approach to understanding behaviour within an environmental context. The approach considers the person's abilities, health, history, support needs, social and physical environments. It views challenging behaviour as serving a legitimate, practical and usually communicative and/or sensory purpose. The approach focuses on identifying the function of the behaviour and assisting the

client to develop alternative and more socially acceptable ways of behaving, communicating and having their needs met. Interventions based on this approach are generally multifaceted and utilize non-aversive proactive and reactive intervention strategies.

2. Family therapy approaches

These provide another perspective and dimension of understanding the person's situation and are particularly important where significant family or systems issues are identified. Family Therapy is an intervention discipline that views individuals as being embedded in an ongoing social, familial and cultural context. A distinctive feature is its systemic perspective, which considers that individuals are best understood by examining their relationships to others and the environment with which they interact. A central notion is that the whole is made up of more than a group of individuals [the sum of its parts], as it includes the relationships between members. Interventions may be focused on changes to the system rather than the individual and aim to assist the family to develop strengths to better meet the challenges that intellectual disability brings to family life.

Well known approaches to family therapy include: Strategic, Structural, Systemic, Psychodynamic, Solution Focused and Narrative.

3. Ecology of Human Performance

Ecology of Human Performance is a framework developed by Occupational Therapists. This framework focuses on how the person, tasks and context interact and determine an individual's performance range. A person is considered to be a product of their genetic endowment and life experiences that result in sensorimotor, cognitive and psychosocial abilities and limitations. The context includes the physical, social, cultural, and *continued page 18*

Web Sites

**for useful information and resources
on positive behaviour support:**

<http://flpbs.fmhi.usf.edu>

<http://interact.uoregon.edu/wrrc/Behavior.html>

<http://www.pbis.org/english/default.htm>

Youngsters with Very Difficult Behaviours: Whose Problem?

Dr Mike Steer

Renwick College, Royal Institute for Deaf and Blind Children; The University of Newcastle

The gradual move by school systems towards inclusive education has likely resulted in increasing numbers of students with difficult behaviours, those that challenge successful education, now being found in almost every public school in Australia. These are individuals, in some instances children with intellectual disabilities, who have made a reputation for themselves by their reaction to the various attempts at schooling they have received. If they have already spent several years failing at school, they are sometimes designated by principals and counsellors as "not yet ready for general education" and consigned to special units: In some of today's ordinary neighbourhood schools, the reverse is held to be the case- i.e. it is the school that is "not yet ready to receive them". More often than not, in listening to what the behavioural language of such youngsters is telling us, two propositions become evident:

- Many students with difficult behaviours tell us more about what is wrong with our schools and school systems than what is wrong with themselves as individuals, and
- Many such students have needs that are currently being inadequately met.

If their behaviour is seen as a "disorder", the question of who "owns" the disorder is an important one. The notion of "owning" a disorder might at first glance appear odd, and indeed a fiction. However, if a student is labelled behaviourally disordered or emotionally disturbed, the problem is apparently the student's. The answer of ownership is, however, not that simple. If having a behavioural disorder is also partially determined by environmental expectations, it is likely that many children who have found themselves thus labelled, have become so because the expectations made of them were inappropriate.

The history of schooling for children with intellectual disabilities, particularly where so-called challenging behaviour is a feature, seems to me to have been a particularly bleak one. Many such students currently and in the past are and have been, world-wide, subjected to life and schooling (where this has been possible) in very restrictive environments, offering limited experiences

together with negative, punitive treatment, loss of real relationships and opportunities for independence. This is still the case, I suspect, for many hundreds of students with intellectual disabilities in our state.

Until very recently these factors had reflected Jerry Jones' experiences and life fairly accurately. His name is fictitious, to safeguard the innocent. He had apparently lived in one or other of the State's large institutional settings (euphemistically called Developmental Centres) for most of his life and had engaged in numerous forms of severe and life-threatening self abuse. In 2001, Jerry moved from a relatively large institutional "home" on the outskirts of

... at age 18, he has graduated to a full-time job in his local community and seldom, if ever, engages in self-injurious behaviour.

Sydney, into a supervised small group home. Now, in 2004 at age 18, he has graduated to a full-time job in his local community and seldom, if ever, engages in self-injurious behaviour. It is my hope that his story will inspire readers who want to help students with difficult (or challenging) behaviours to live with dignity and lead satisfying lives in our ordinary everyday Australian communities.

Jerry Jones at 18 years old, lives on the New South Wales Central Coast. His records indicate that he has been labelled over the years as having low vision and having first "mental deficiency", later "mental retardation" and more recently "intellectual disability", together with "mental health problems" (which we would perhaps today term "a psychiatric disorder"). He was first placed in a custodial setting in 1990, when he was about four years old. He does not speak, but does use vocal sounds, gestures and pointing to let people know what he wants. Since his pre-school years he had been reported as having "severe self-injurious behaviour". These were at times life and health threatening. His behaviour often resulted in extensive tissue damage, periodic hospitalisation, serious malnutrition and extensive weight

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Fellow of ASSID

Guidelines

ASSID has introduced an ASSID Fellowship. Information is presented here for those who may wish to consider nominating an ASSID member. Further details about the guidelines for the Fellowship can be found on the ASSID web site, including a nomination form and details about supporting documentation about the nominee that is required.

The honorary title, Fellow of ASSID (FASSID) may be conferred on individual ASSID members (including all classes of individual membership) in recognition of the member's exceptional and significant contribution to the field of intellectual disability. This contribution will have been in one or more of the following areas:

- ▶ Research,
- ▶ Service provision (including service development or improvement, administration),
- ▶ Advocacy and/or self-advocacy,
- ▶ Professional practice, and
- ▶ Teaching and staff training.

Nominations need only address one of these areas, but may address more than one if the nominee has made an exceptional contribution in more than one area.

Individual members who are awarded the title Fellow of ASSID (FASSID) will receive a certificate, presented at the Annual Conference, and thereafter will have the right to use the title Fellow of ASSID (FASSID).

Fellow of ASSID (FASSID) is an honorary title, not a class of ASSID membership, and the member will need to continue to pay his or her membership dues to maintain current membership.

Criteria

The decision to award an ASSID Fellowship is based on the following criteria:

- ▶ *Exceptional and significant contribution to the field of intellectual disability.* It is assumed that all members have made a contribution through their years of service to persons with intellectual disability, so clear evidence of exceptional and significant contribution is essential.
- ▶ *Substantial duration.* The contribution must be of substantial duration (at least 7 years).

- ▶ *Broad impact.* The contribution must have broad impact beyond the nominee's own immediate activities and local area – substantial impact must demonstrated at one or more of the following levels:
 - Province- or state-wide,
 - National,
 - International.
- ▶ *Current financial member of ASSID.* The nominee must be a current financial member of ASSID (any class of individual membership) and must have a significant period of ASSID membership. No specific minimum period is specified, but it should be assumed that at least several years of membership will usually be the minimum appropriate.
- ▶ *Nominated and seconded.* The nominee must be nominated and seconded by current financial members of ASSID (any class of membership).

Service to ASSID is not a criterion for selecting ASSID Fellows because the ASSID Distinguished Service Citation focuses of service to ASSID as an organisation.

Nomination Process

- ▶ Any current financial individual ASSID member (including all classes of individual membership, members of the Board, office holders, and members of the Fellowship Committee) may be nominated.
- ▶ Nominations must be made in writing using the official nomination form. The nomination must be signed by the nominee (to indicate his/her willingness to be nominated)
- ▶ The nomination requires two (2) letters of reference, from the persons who have nominated and seconded the nomination and can speak to the nominee's exceptional and significant contribution to our field.
- ▶ The nomination and the letters of reference should be submitted direct to the ASSID Secretariat and marked Attention Fellowship Committee. *continued page 15*



Please keep your ASSID contact details up to date

with your State Councils at the main ASSID database.

Phone: 1800 644 741 PO Box 84, Rosanna VIC 3084 Australia

E-mail submission (supported by a mailed hard copy) is encouraged.

Selection Process

A Fellowship Committee, made up of the President, Journal Editor, an Australian member and a New Zealand member, will consider all the nominations prior to the ASSID Annual Conference. Any member of the Fellowship Committee with a conflict of interest regarding a nomination will withdraw during the committee's

consideration of that nomination. The President may co-opt additional committee members as needed, for example if several committee members need to withdraw because of conflict of interest, or because there is a need for special expertise when considering some nominations. The committee reserves the right to select any, all, or none of the members nominated to become a Fellow of ASSID. The Nomination Committee makes its recommendations to the ASSID Board about nominees who will have the title Fellow of ASSID (FASSID) conferred.

Youngsters with Very Difficult Behaviours: Whose Problem?

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loss. Some of the very serious behaviours that were a feature of his earlier institutional record include; frequent vomiting, ruminating, head-slapping, excessive scratching and rubbing, picking and tearing off his finger and toenails, body slapping, eye-poking and body-banging. On average he received monthly medical treatment while at the "home" for injuries sustained from his self-abuse. He also yelled and cried frequently, hit and kicked others, spat, vomited and defecated on others.

Because of these behaviours he rarely attended the educational day program that had been arranged for him outside the "home". In fact he seldom left the "home" grounds, or his living unit except to receive treatment for his injuries. A wide variety of procedures, using both positive and aversive (negative) forms of reinforcement had failed to modify his behaviour in any significant way within the institutional environment and his vomiting had escalated to the point of serious weight loss.

Whenever he injured himself, he was physically restrained until he was calm. The restraint was used frequently and sometimes resulted in injury to the staff. Because of the vomiting and weight loss problem he had to be released if he vomited while being restrained. The institution's psychologist prepared a pro-active treatment program for Jerry in which he was taken for 10 minute walks as a reward for not engaging in self-injurious behaviour.

The psychologist observes

The psychologist noticed that during these short walks off the living unit Jerry did not engage in self injury. The program was revised so that he could spend longer periods of time away from the unit in a variety of community environments. Continued improvement confirmed staff suspicion that there was a relationship between the self injury and his "home" institutional environment. The staff

also reported that they avoided using aversive procedures, for example, restraint and time-out, because they considered those treatments to be responsible for the increased vomiting. In fact, it appeared that Jerry might himself be using self-injury for a variety of purposes including getting attention and avoiding tasks. It was as though he was using these various life-threatening and negative behaviours to gain control within the institutional "home" environment, over which, in fact, he had little or no control.

As a result of these observations, the psychologist developed an alternative positive intervention program for him, with the assistance of an academic from a neighbouring university. The alternative plan provided Jerry with some long overdue choices in, and control over his daily life. The aversive procedures were all dropped. In contrast to past procedures, an emphasis was placed upon implementing extensive programs and placements. These completely changed both the circumstances and environments associated with his previous self-injurious behaviour and replaced them with meaningful alternatives.

The new strategy

The new plan had four very basic components:

- 1 A radical change in the conditions and situations associated with self injury. This resulted in a move from the institution to a supervised foster placement apartment in the community;
- 2 To replace self-injurious behaviour (such as those mentioned above), over the long-term Jerry was instructed in positive alternative behaviours and participated in various functional, community-based activities, including employment;
- 3 Rather than imposing alternative activities and community living upon him (as

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Book Review:

Challenging Behaviour and Developmental Disability

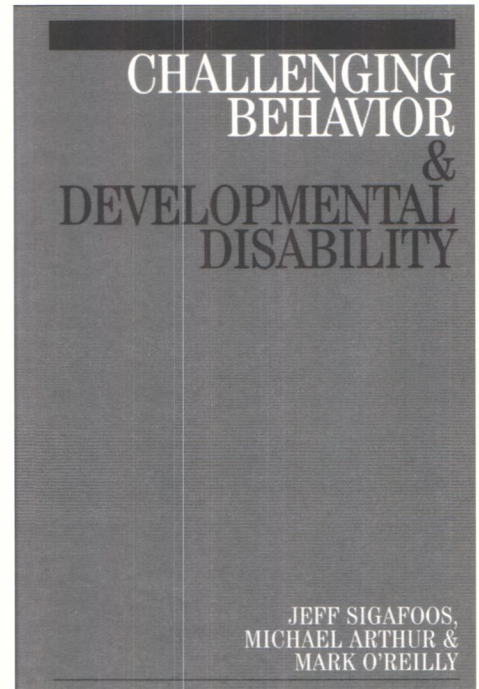
Authors: Sigafoos, J.,
Arthur, M., and
O'Reilly, M.

London: Whurr Publishers, 2003

Review by: Dr Deb Keen,
Lecturer,
University of Queensland

Challenging Behaviour and Developmental Disability is an excellent introductory text on challenging behaviour from a behavioural perspective. The authors use a style of writing that is easy to read and the layout follows a logical order. This is not a technical book but provides an overview of current research and practice in relation to behavioural assessments and interventions for individuals with a developmental disability and challenging behaviour.

The book is divided into four parts. Part 1 is titled Conceptualising Challenging Behaviour and consists of three chapters that consider issues of definition, risk factors and underlying theories for why challenging behaviour occurs. It is important to note that the authors have not attempted to cover all the theories about challenging behaviour, focusing on a behavioural account that is presented in a manner that makes it easy to understand.



The second part of the book is entitled Fundamental Issues in Service Provision and consists of only one chapter. This chapter presents the reader with information about ethical considerations and quality of life issues. At the recent IASSID conference, there were many *continued page 17*

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Challenging Behaviour and Developmental Disability Journal of Intellectual Disability

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presentations on quality of life and it is pleasing to see a chapter devoted to this area in this book.

Part 3 of the book is entitled Assessment of Challenging Behaviour and consists of two chapters. This part describes the importance of health and medical screening to any assessment of challenging behaviour and then proceeds to describe ways of assessing challenging behaviour using functional assessment techniques such as questionnaires and scatter plots.

The final section of the book, part 4 is called Treatment and Prevention. In two chapters of this section, we are given a guide to the development of interventions for use with individuals that have challenging behaviour. In relatively few pages (13 pages) the authors are able to provide a summary of some of the basic principles behind the design of a behavioural intervention based on functional assessment data. Clearly it is not the intention of the authors or within the scope of this book to explore

other, non-behavioural approaches to challenging behaviour and the information provided is perhaps most relevant to interventions for individuals with more severe disabilities.

The final chapter addresses the importance of early intervention to the effectiveness of any behavioural intervention. An introductory section in this chapter explains the inter-relatedness of individual-centred, family-centred, and context centred intervention. A figure is then used to describe the relationship between these interventions, stressing the importance of a more ecological approach to challenging behaviour. This book is a useful introduction to interventions for individuals with more severe disabilities and would be of particular benefit to service providers new to the area. It would also prove useful as a text for introductory courses about disability and challenging behaviour.

Youngsters with Very Difficult Behaviours:

Whose Problem?

institutional living and other activities had been earlier imposed upon him), he was actively involved in making choices and decisions about his daily life and the changes in his program;

- 4 Back-up (crisis management) procedures were put in place to deal with self-injurious behaviour.

The significant relationships established by Jerry in the past were also of primary concern. Attempts were made to reintroduce him to his family. In addition, his primary direct-care staff person at the institution, who had also become his friend, was asked to move with Jerry to his apartment as a carer. A second full-time staff person was hired prior to his move in order to establish a positive relationship before the move from institutional setting to community.

In June 2000 the move was made. Two other children also with disabilities live in the apartment. Jerry participated actively in preparing for the move. For example, he helped plan, buy and arrange all necessary personal items prior to moving. He packed his belongings and placed them appropriately in his new home. He also participated in selecting furniture for the house and choosing which bedroom would be his.

He also completed two vocational training placements at job sites in the community, doing clean-up work and found a full-time job in the community. He was now been living in the community for a year and the dramatic

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improvements in his life and behaviour have been maintained. He continues to work a full day in the community and no longer requires one-to-one staffing during the work day, or evenings at the apartment. He takes part actively in all household duties including cooking, cleaning, laundry and shopping. He takes part in

Jerry participated actively in preparing for the move.

social and recreational activities and attends parties, movies, picnics and other social functions. He also attends church regularly. His general health and weight have improved.

The new Jerry Jones

Jerry is responding positively to new demands that reflect a more meaningful lifestyle and is learning to make choices and exercise proper control of his life. His story teaches us the importance of providing the same kinds of resources and efforts to implement non-aversive, community-based supports as those used in developmentally restricted group settings. In his case, all previous efforts had been unsuccessful. In fact they had been life-threatening. Long standing behavioural patterns were finally reversed by providing the experiences that should have been in place for anyone in any good service delivery system.

temporal environment. Tasks are sets of behaviours that are generally available to anyone and individuals tend to engage in tasks based on their interests, skills, and available contexts. As a team we consider how limitations or strengths in a person's skills or restricted context limit or support performance opportunities. When performance opportunities are restricted the team works to expand the performance range using strategies aimed at increasing the number of activities available to the person.

4. Functional Communication

This model moves away from focusing solely on one's development of speech as the primary communication mode. It is based on the view that communication begins before speech i.e., a person develops a repertoire of conventional behaviours that serve a communicative purpose or function. These behaviours or modes of communication include vocalisations, body language, gestures, written language, pictures, as well as speech. Hence, an individual's communication pattern is analysed from a multi-modal perspective and in terms of the variety of functions it serves, or is not serving. Functional communication is often incorporated in a behavioural perspective for people who present with complex or challenging behaviour. Challenging behaviour is analysed in terms of the communicative function(s) it may be meeting for that individual. This model is also considered in the development of Alternative and Augmentative Communication systems for people with congenital and/or acquired disabilities who do not have functional speech or verbal skills.

5. The developmental approach

A developmental approach considers what to expect of a person's functioning according to his or her age and stage of development. Development typically occurs along a continuum, is linked to social norms and generally follows a predictable course. Many skills emerge over the life span and a wide range exists in the timetable for normal development. Yet regardless of the rate, every person develops continuously according to his or her pattern. Despite variability from person to person, there is a general order in the progressive development of individual skills. Simple skills precede the more difficult ones. For people with an intellectual disability, development may be more complex, fragmented and not follow the typical developmental continuum. The IIT uses theories of development to understand a client's skill acquisition in core developmental domains in the context of their environment.

The IIT (in its current incarnation) is just over two years old. Its current structure and theoretical underpinnings are the result of an amalgamation of two 'precursor' intervention teams. One such team was the 'Intensive Family Intervention Team' that was set up to work with families with a child with an intellectual disability who were at risk of family 'breakdown'. This team was based upon a family systems approach. The other precursor team was the 'Adolescent and Adult Intensive Intervention Team' that was designed to work with an older client population who may be living with their families or in supported accommodation. The AAIT team implemented an 'eco-behavioural' model based upon the work of LaVigna, Willis and Donnellan (1987).

It was recognised that at times children living at home with families would benefit from a more eco-behavioural approach while sometimes adults who presented with difficult and challenging behaviour may best have their needs met by working systemically with support staff from accommodation services or family members. The view was developed that it would be of greater benefit to all our clients if we could match the particular mode of intervention to the needs of the client rather than make the client fit the model.

Clinical meetings are held on a fortnightly basis where all current interventions are discussed and issues arising are 'brainstormed'. These meetings have been the 'litmus test' indicating how successful the team has been in applying multiple theoretical perspectives and recognising and respecting different approaches. Each theoretical approach tends to not only utilise different methods but also raises different questions and generates different goals for intervention. Applying multiple perspectives to the challenging issues with which the team work has generated some very interesting discussions. Approaching these issues with good humour and the recognition that there is strength in diversity has been essential.

The common denominator amongst the IIT staff is that they are excited by the work that they do and that they aspire to 'worlds best practice'. The team continues to seek to refine its model of working. The IIT is a work in progress.

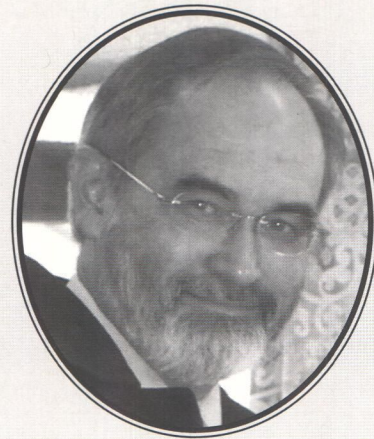
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Obituary:

Mr Jim Woodworth



The disability community, especially in Tasmania and Western Australia was greatly saddened at the sudden death, in June, of Mr Jim Woodworth. Jim was a passionate advocate for the rights of people with disability. Families who knew him well described him as "a man who shared our dreams of a better life for our sons and daughters in the community". Those who worked with Jim described him as "a man of great vision and great compassion", "a humble man" who was "an inspiring leader", "a wise mentor" and "a dependable friend".

Jim came to us from Malaysia. He joined the Disability Services Commission in Western Australia in 1976, where he is fondly remembered and well respected for his contribution to, and leadership in, the formation of the newly emerging profession of Social Trainers. Jim was always a man ahead of his time. He was quick to recognise the importance of developing community options for people with disability; and played a vital role in moving many people from the Swanbourne Hospital to community residences.

In 1982 Jim took up an appointment at the Rocherlea Training Centre, in Launceston. This marked the beginning of Jim's 22 years of tireless and selfless commitment to people with

disability in Tasmania. Moving to Hobart, Jim began the expansion of the community-based disability service, from its then three positions to its current complement of over 100 staff in the southern region alone. Together with the gradual expansion of the community-based government service, Jim also fostered the development of a vibrant non-government sector. In particular, Jim will be well remembered for his leadership role in the downsizing and final closure, in 2000, of Australia's oldest institution, Willow Court Centre; bringing about, for the first time in Australia, a totally community-based disability service system.

There are so many of us who owe so very much to Jim; people with disability, their families and his colleagues. We extend condolences to his wife, Diana and his children, Rosalind and Peter. We honour Jim's memory by affirming our commitment to his vision of a better life in the community for people with disability.

Intensive Intervention

continued from page 18

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Upcoming Events . . .

30/9/2004 - 1/10/2004

Journeys NZASID conference is to be held at the

Place: Holiday Inn ,Christchurch

Keynote Speakers:

Prof Glynnis Murphy (UK) on Sexual offending

Assoc Prof Bob Davis (Au) on Health Issues

David Corner (NZ) on Self Advocacy Issues

Stephnie Roberts (NZ) on Residential and Lifestyle issues

12/10/2004

Beyond Boundaries:

Victorian ASSID State Conference

The event will host Anne Deveson, author of the book Resilience (Allen & Unwin, 2003) and notable for her insight into human rights issues.

25/10/2004

Quality of Life – its relevance in the 21st century:

West Australian ASSID Annual Conference

Keynote speaker is Dr Ivan Brown

25/10/2004 - 27/10/2004

Tasmanian ASSID Workshop Series

Place: Laetare Gardens

28/10/2004 - 29/10/2004

Medical Conference "Well Beyond 2004"

Place: Bardon Centre - Brisbane QLD

Contact: Jude McPhee

Phone: (07) 3840 2496

Email: j.mcphee@sph.uq.edu.au

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

9/11/2004 - 12/11/2004

39th ASSID Annual Conference

Place: Adelaide Hilton Adelaide, SA

The 39th Australasian Conference has the theme Visions and Realities: The way things are and the way things should be - supporting and working with people with intellectual disability and their families in the 21st century. The Organising Committee invites all professionals with an interest in intellectual disability related fields to join colleagues in Adelaide, South Australia 9-12 November 2004 for ASSID2004. A four day program is planned in association with a trade exhibition, a comprehensive partner program and opportunities for all delegates to enjoy pre and post conference tours to some of Australia's major attractions.

25/11/2004 - 26/11/2004

Victorian Direct Support Workers Conference

Details to be announced