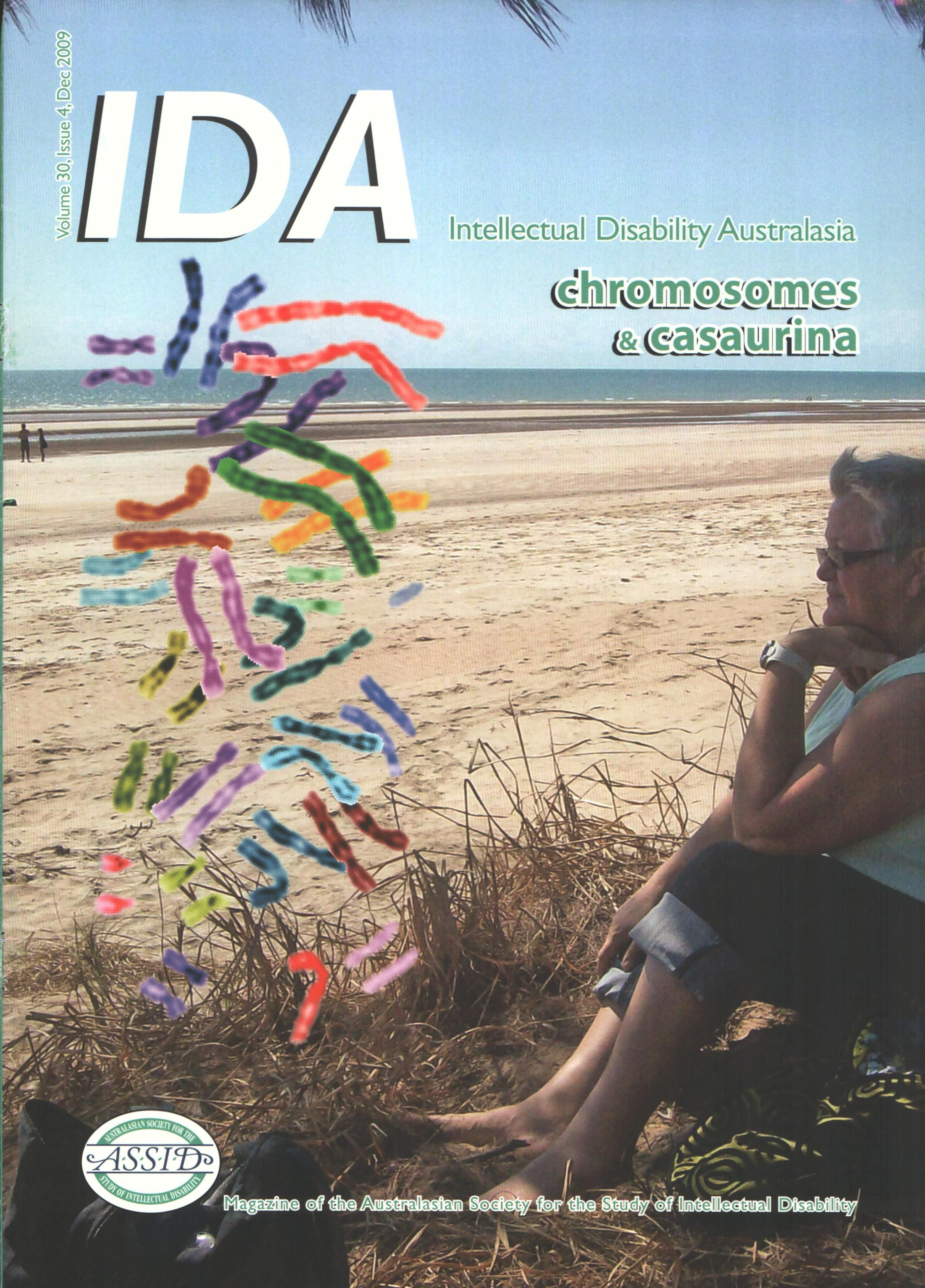

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IDA

Intellectual Disability Australasia

chromosomes & casaurina

ASSID

Magazine of the Australasian Society for the Study of Intellectual Disability

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photo of Olive Webb on Casaurina Beach
by Richard O'Loughlin
Coloured Chromosomes
from the US National Institutes of Health

Editorial

The IDA team wish you all the very best of wishes for a happy Christmas and a peaceful New Year.

This year has been quite a roller coaster for the ASSID Board and it seems fitting that the last editorial for 2009 provides readers with not only a summary of the delights to come in the following pages but also a round-up of all the major issues and initiatives that have been discussed by the Board over the last twelve months.

This edition of IDA contains a thought provoking article on the emerging research into rare chromosomal disorders and their effects on child development. For those people who did not make it to Tasmania for the conference, we have included an article from one of our keynote speakers on community partnerships and the Awakenings festival. Richard O'Loughlin, our newly elected ASSID President has provided a report on the Board visit to the Northern Territory, where we hope to support the development of a new regional association in coming years.

IDA is pleased to include an advert for the position of Executive Officer for the association as mentioned in earlier editions this year. The position details are also advertised on the ASSID web-page and with SEEK.com.

The Board has addressed several major issues over the last twelve months:

- The appointment of an Executive Officer
- Public liability insurance for ASSID events
- A governance framework for board members and regional representatives
- ASSID's name and logo
- Participation by people with an intellectual disability at the annual conference

Please go to page 18 for more details.

Finally, on behalf of the Board, IDA wishes to thank Dr Olive Webb for her presidency of ASSID for the last four years. Her dedication, vision and energy have proved the leadership that ASSID needed.

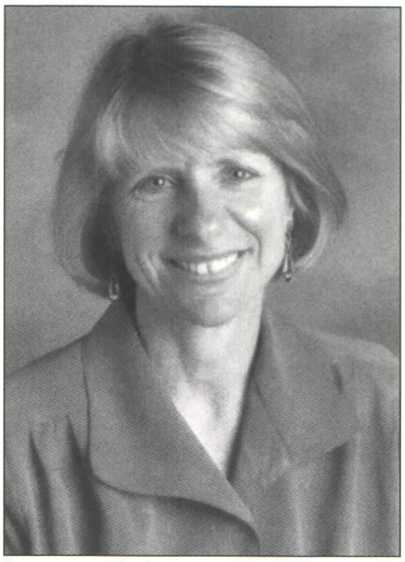
The Board unanimously elected Richard O'Loughlin as our next ASSID President and wish him well in his new role.

Sue

Rare Chromosome Disorders

and their developmental consequences

by Linda Gilmore
Queensland University of Technology
Brisbane



Introduction

Professionals working in disability services often encounter clients who have chromosome disorders such as Williams, Angelman or Down syndromes. As chromosome testing becomes increasingly sophisticated, however, more people are being diagnosed with very rare chromosome disorders that are identified not by a syndrome name, but rather by a description of the number, size and shape of their chromosomes (called the karyotype) or by a report of chromosome losses and gains detected through an advanced process known as microarray-based comparative genomic hybridisation (array CGH).

For practitioners who work with individuals with rare chromosome disorders and their families, a basic level of knowledge about the evolving field of genetics, as well as specific knowledge about chromosome abnormalities, is essential since they must be able to demonstrate their knowledge and skills to clients. In addition, knowledge about the developmental consequences of various rare chromosome disorders is important for guiding prognoses, expectations, decisions and interventions.

The current article provides information that aims to help practitioners work more effectively with this population. It begins by presenting essential information about chromosomes and their numerical and structural abnormalities and then considers the developmental consequences of rare chromosome disorders through a critical review of relevant literature.

Chromosomes and Chromosome Abnormalities

With the exception of egg and sperm cells and erythrocytes (red blood cells), every cell in the body contains 23 pairs of chromosomes that are numbered from 1 to 22 according to their length, with 1 being the longest, plus a 23rd pair consisting of the sex chromosomes, XX or XY. Resembling long threads, chromosomes have a short arm (referred to as p) and a long arm (q) that are joined in the middle by a centromere. The normal complement of chromosomes produces 46,XX in females and 46,XY in males. Based on chromosome banding patterns, a numbering system is used to describe regions, bands and sub-bands on chromosomes.

Occurring in 0.5 to 1% of live births, and accounting for around 50% of all spontaneous miscarriages, chromosome disorders result from the addition, deletion or rearrangement of varying amounts of chromosome material either as inherited or, more frequently, as spontaneous (de novo) events. Numerical anomalies involve either missing or extra whole chromosomes, while chromosome breakages can result in a range of structural disorders involving the loss or addition of varying segments of chromosome material. Duplications (sometimes referred to as partial trisomies) involve an extra copy of a chromosome segment. Deletions (also known as partial monosomies) may occur at the end of the chromosome (terminal) or a piece may be missing from some point within the chromosome (interstitial). Translocations result when the broken segments of two or more chromosome exchange places. Such rearrangements are usually inconsequential for health and development in the carrier, provided all the chromosome material is still present in each cell and the translocation is thus "balanced". However, there are likely to be problems with reproduction and a risk of unbalanced rearrangements occurring in future generations. Other chromosome anomalies include inversions, which result when two breakages are followed by reconnection of the intervening segment in reverse order, and rings that are formed when both chromosome tips break off and the two sticky ends fuse.

The most common chromosome disorder, Down syndrome, usually involves a third copy (trisomy) of chromosome 21 in every cell of the body. Trisomies 13 (Patau syndrome) and 18 (Edwards syndrome) are occasionably survivable, although they generally produce much more severe developmental consequences than does Down syndrome. Trisomy mosaicism, in which only a proportion of cells carry the

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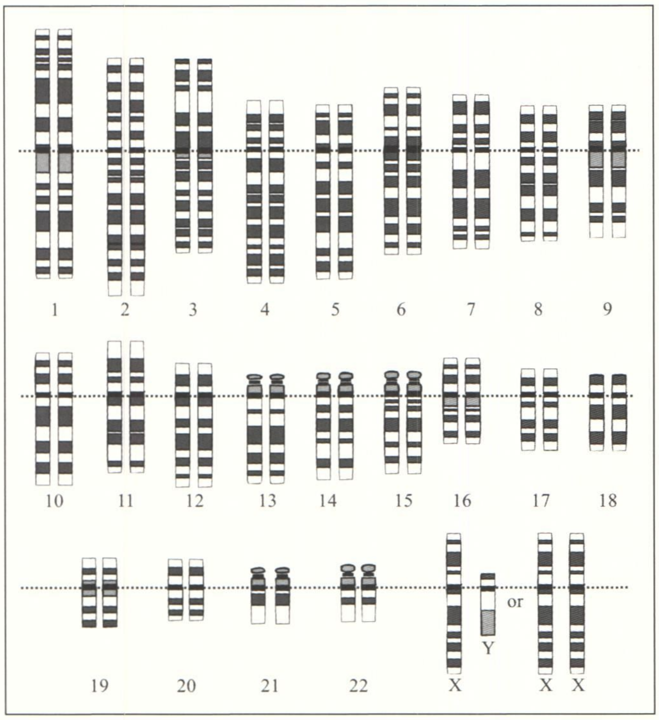
Rare Chromosome Disorders

continued from page 3

additional chromosome, has been reported for most chromosomes including 4, 8, 12, 20, 21 and 22, in some cases with no apparent detrimental effects on development.

Because they occur with sufficient frequency and because their presence results in a distinctive phenotype, some chromosome anomalies have been classified as syndromes. Among the more familiar ones are Wolf-Hirschhorn, Cri du Chat, Williams, Smith-Magenis and Velocardiofacial (and the related DiGeorge and Shprintzen-Goldberg) syndromes which involve deletions on chromosomes 4p, 5p, 7q, 17p and 22q, respectively. Turner syndrome results when only one X chromosome is present (producing the karyotype 45,X in affected females) while in males an additional copy of the X chromosome leads to Klinefelter syndrome (47,XXY). In most cases, Prader-Willi syndrome in caused by a deletion on 15q derived paternally while, intriguingly, the same deletion on the maternally derived chromosome produces Angelman syndrome. Other less familiar syndromes include Jacobsen (terminal deletion 11q) and Miller-Dieker, which involves a deletion on 17p, but at a breakpoint different from that occurring in Smith-Magenis syndrome.

There is also a wide array of less common or less distinctive chromosome disorders that occur in live births and it is these very rare abnormalities that are the focus of the current article. When diagnosed, rare chromosome disorders are given a label that correspond to their karyotype, such as "Duplication (9)(p22pter) with Deletion (11)(q23.3qter)" or "Ring (20)(p13q13.13)" rather than an actual name, making it difficult for families to communicate their child's diagnosis to others and for service providers to categorise the disability. At times more than one chromosome abnormality is present, leading to complex karyotypes with as many as seven affected chromosomes and up to 10 separate breakpoints. The vast number of possible anomalies and their extreme rarity and possible uniqueness sometimes lead to diagnoses that are accompanied by the pronouncement that an individual is the only known case in the world. However, as methods of testing become more advanced, more accessible and more commonly performed, it is likely that an increasing number of cases will be identified and reported in the literature.



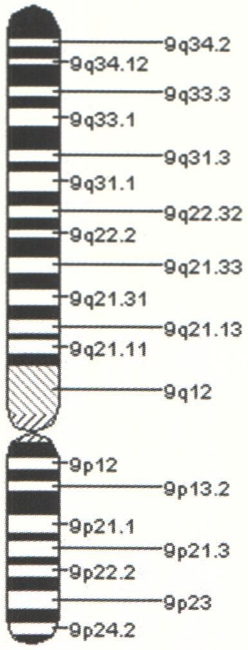
Modified from [http://www.genome.gov/Pages/Hyperion/DIR/VIP/Glossary/Illustration/Pdf/trisomy.pdf Human Genome Project]

Developmental consequences of rare chromosome disorders

Most case reports about rare chromosome disorders are published in the medical, rather than psychological, literature. Consequently, the focus is on genetic, medical and physical data with very little, if any, consideration given to cognitive, social-emotional and behavioural outcomes. In an analysis of case reports of trisomy 17p, for instance, Paskulin, Zen, Rosa, Manique and Cotter (2007) provided a table of 50 clinical findings, 49 of which were physical and medical features and just one developmental (specifically, neuropsychomotor delay). Only a very small number of papers feature detailed neuropsychological assessments.

Among reports of developmental outcomes, characteristics such as growth retardation, developmental delay, intellectual disability, delayed or impaired speech, behaviour problems and sensory deficits are frequently mentioned. Some researchers have identified phenotypic patterns that appear to be associated with certain karyotypes including 1p36 deletion, 6q deletion, 9p deletion, trisomy 17p and 18q deletion. However, studies have been based on small samples and, unlike some of the more common chromosome syndromes, typical features such as the hyperphagia seen in Prader-Willi syndrome have not been reported.

Despite a general impression of deficits and adverse developmental outcomes, the literature also reports individuals who appear to be developing typically in some



Ideogram of the human chromosome 9

Made by Mysid, based on http://ghr.nlm.nih.gov/chromosome=9 (US National Library of Medicine)

respects. For example, there are reports of average intelligence in children with deletions on 2p, 6p, 6q, 8p, 11q, 18q, 20p and 21q, as well as ring chromosomes 2, 3, 7, 15, 19 and 21.

Few published reports document developmental progress at more than one point in time. When available, descriptions of progress over time are usually retrospective and dependent on the recollections of families or the availability of medical records, and data about developmental outcomes are limited. Melis et al. (2006) reviewed the progress of a child with mosaic 13q deletion annually from 13 months of age for 15 years but the only developmental information across those years was a single IQ score.

In reports of developmental outcomes, conclusions are sometimes questionable. In particular, claims or inferences of intellectual disability are often unsubstantiated by psychometric data, appearing instead to be derived from anecdotal observation or speculation rather than from standardised cognitive testing. In the absence of psychometric data, evidence of abnormal cerebral imaging is sometimes cited as sufficient grounds for presumptions of severe intellectual disability, and at other times useful developmental descriptions are offered to support claims of developmental delay, although interpretations are dubious at times. For example, Stalker, Gray, Bent-Williams and Zori (2006) decided that developmental milestones such as walking at 15 months and first words at 12 months of age represented delays, when in fact both of these milestones are within normal limits. One of the children with a partial 2q duplication described by Eussen et al. (2007) as having developmental delay was reportedly functioning "at the level of a 4-year-old toddler" at the chronological age of 5 years. No assessment results were given, and no information was provided about the basis for this conclusion.

Even when psychometric data are available, they are at times reported vaguely or inappropriately, as evidenced by descriptions of "almost normal intelligence" (Kitatani, Takahashi, Ozaki, Okino & Maruoka, 1990, p.138), "severe retardation, to between 40% and 50% of normal" (Schinzel et al., 1991, p.354) and a borderline IQ of 75 that was interpreted as confirmation of an assumption of severe intellectual disability (Paz-y-MiĐo, Benitez, Ayuso & Sánchez-Cascos, 1990). Incorrect interpretations of IQ scores are also found. For instance, in their report of five cases with 6q deletion, Striano et al. (2006) wrongly classified IQs of 60 as representing moderate intellectual disability (cases 1 and 3), while a lower IQ of 55 was correctly referred to as mild intellectual disability (case 4). Netzer et al. (2006) claimed that their case with 18q- had 'above average' verbal skills, a claim that was arguably inaccurate and misleading in the light of an IQ of 74 (derived from five WAIS-R subtests) and the result of a 'German vocabulary IQ test' result of 104.

In summary, rare chromosome disorders have been associated with a range of developmental consequences including intellectual disability, language impairments and behaviour problems. These shared characteristics may be due to the more general effects of chromosome imbalance, rather than specific anomalies. At the same time, evidence about normal intelligence in some individuals with rare chromosome abnormalities suggests that adverse developmental outcomes are not necessarily inevitable.

These conclusions about development are, however, drawn from a relatively limited literature base that is inadequate in some respects. Because it is likely that cases with more negative developmental outcomes are being diagnosed and reported, the literature may not be accurately portraying the range of possible outcomes that are attainable. Moreover, data are usually collected at only one point in time, comprehensive assessment batteries are rare, and interpretations of results are not always rigorous. In particular, conclusions about intellectual functioning are sometimes vague or unsubstantiated.

Implications for practitioners

Clearly, the limited literature about the developmental consequences of rare chromosome disorders makes it difficult for practitioners to work effectively with this population. Most rare chromosome

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Rare Chromosome Disorders

continued from page 5

disorders occur, or are identified, so infrequently that their developmental course has not yet been well documented and at times it is impossible to locate a single published case matching the karyotype of an individual seen in clinical practice.

Even when appropriate literature is available, the developmental data can be sparse, inadequate or inconsistent, and consequently practitioners need to search and evaluate the literature carefully and critically, with an awareness of its limitations. For example, assertions in the literature about the inevitability of certain outcomes (e.g., "mental retardation is always present" in Mircher et al., 2003, p.177) need to be examined and rejected if they are based on small samples and inadequate or non-existent psychometric data.

adverse developmental outcomes are not necessarily inevitable

Practitioners should also seek sources of information beyond the academic and professional literature. Of particular value is the Unique Rare Chromosome Disorder Support Group (www.rarechromo.org) which has established a rich database containing the developmental histories of more than 6,900 individuals with a rare chromosome disorder. Their descriptive data, collected worldwide and periodically since 1984, track development across all domains including cognitive and behavioural, thus providing an exceptional resource for families and professionals. In addition, Unique and other support groups provide a range of services, advice and support, including valuable contact with other families whose children have the same, or similar chromosome abnormalities.

Because of the notable within-group variability that characterises some chromosome abnormalities, prognoses about future development need to be tentative, taking into consideration the range of possible outcomes that have been documented in the literature, as well as the unique individual, family and contextual characteristics that are also likely to influence developmental outcomes. In particular, developmental predictions need to be sensitively expressed, since the prognostic uncertainty associated with rare chromosome disorders is likely to produce significant emotional stress and anxiety for families.

There may well be grounds for being cautiously optimistic about future development and indeed families tend to resent early negative prognoses, irrespective of whether or not they are well-informed and well-intentioned, and to appreciate acknowledgments of their children's strengths and accomplishments. Families may benefit from clear explanations about the cause of their child's chromosome abnormality (e.g., an accident in cell division around the time of conception or the inheritance of an unbalanced translocation from one parent) and guidance on how to explain their child's diagnosis to others, particularly since the overwhelming majority of diagnoses are not associated with a syndrome name.

Finally, practitioners may have opportunities to contribute to the research literature by producing developmental case studies of individuals with rare chromosome disorders. Case studies have the potential to provide rich data about cognitive, behavioural, social, academic and personal development that can illuminate developmental processes and trajectories. Despite limited generalisability, case reports represent the only viable research methodology for karyotypes that are so truly unique that obtaining an adequate sample for systematic investigation appears impossible or unlikely. An increasing number of reports that include robust data about developmental outcomes will provide a stronger knowledge base to guide prognoses, ongoing supports and services, and specific interventions for individuals with rare chromosome disorders.

Note. A copy of this article containing full referencing is available by emailing the author.

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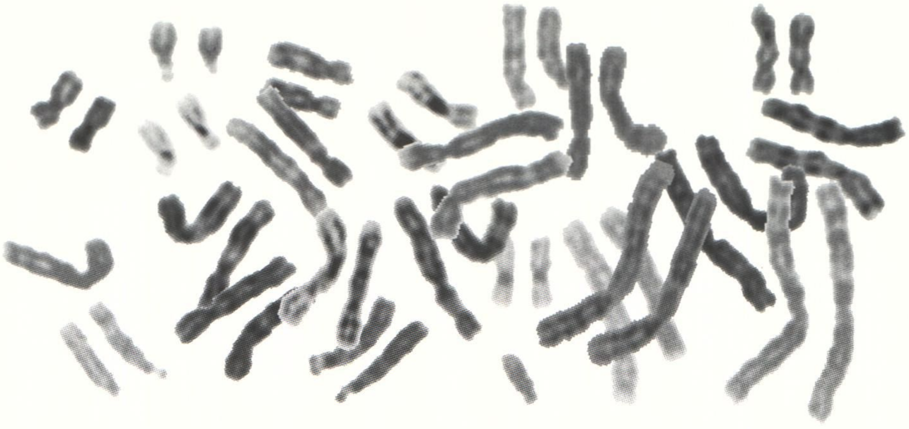


References

Eussen, B. H., van de Laar, I., Douben, H., van Kempen, L., Hochstenbach, R., De Man, S. A., Van Opstal, D., de Klein, A., & Poddighe, P. J. (2007). *A familial inverted duplication 2q33-q34 identified and delineated by multiple cytogenetic techniques.* European Journal of Medical Genetics, 50, 112-119.

Kitatani, M., Takahashi, H., Ozaki, M., Okino, E., & Maruoka, T. (1990). *A case of ring chromosome 15 accompanied by almost normal intelligence.* Human Genetics, 85, 138-139.

Melis, D., Sperandeo, M. P., Perone, L., Staiano, A., Andria, G., & Sebastio, G. (2006). *Mosaic 13q13.2-ter deletion restricted to tissues of ectodermal and mesodermal origins.* Clinical Dysmorphology, 15(1), 13-18.

Mircher, C., Rethore, M-O, Lespinasse, J., Fert-Ferrer, S., Lundsteen, C., & Kirchoff, M. (2003). *Interstitial deletion of the short arm of chromosome 1: Attempt to establish a clinical phenotype* (46,XX,del(1)(p22p32)). American Journal of Medical Genetics, 118A, 176-179.

Netzer, C., Helmstaedter, C., Ehrbrecht, A., Engels, H., Schwanitz, G., Urbach, H., Schröder, R., Weber, R. G., & Kornblum, C. (2006). *Global brain dysmyelination with above-average verbal skills in 18q- syndrome with a 17 Mb terminal deletion.* Acta Neurologica Scandinavica, 114, 133-138.

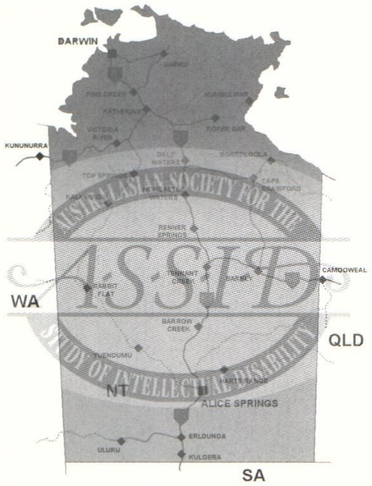
Paskulin, G. A., Zen, P. R. G., Rosa, R. F. M., Manique, R. C., & Cotter, P. D. (2007). *Report of a child with a complete de novo 17p duplication localized to the terminal region of the long arm of chromosome 17.* American Journal of Medical Genetics, 143A, 1366-1370.

Paz-y-MiĐo, C., Benítez, J., Ayuso, C., & Sánchez-Cascos, A. (1990). *Ring chromosome 6: Clinical and cytogenetic behaviour.* American Journal of Medical Genetics, 35, 481-483.

Schinzel, A., Binkert, F., Lillington, D. M., Sands, M., Stocks, R. J., Lindenbaum, R. H., Matthews, H., & Sheridan, H. (1991). *Interstitial deletion of the long arm of chromosome 18, del(18)(q12.2q21.1): A report of three cases of an autosomal deletion with a mild phenotype.* Journal of Medical Genetics, 28, 352-355.

Stalker, H. J., Gray, B. A., Bent-Williams, A., & Zori, R. T. (2006). *High cognitive functioning and behavioural phenotype in Pallister-Killian syndrome.* American Journal of Medical Genetics, 140A, 1950-1954.

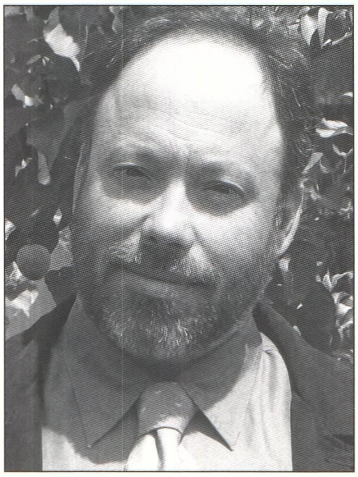
Striano, P., Malacarne, M., Cavani, S., Pierluigi, M., Rinaldi, R., Cavaliere, M. L., Rinaldi, M. M., De Bernardo, C., Coppola, A., Pintaudi, M., Gaggero, R., Grammatico, P., Striano, S., Dallapiccola, B., Zara, F., & Faravelli, F. (2006). *Clinical phenotype and molecular characterization of 6q terminal deletion syndrome: Five new cases.* American Journal of Medical Genetics, 140A, 1944-1949. ◆



New Frontiers

ASSID in the Northern Territory

from Richard O'Loughlin



There have been several drivers associated with ASSID seeking to increase its engagement with the Northern Territory.

At the 2007 Australasian conference held in Fremantle, Western Australia, at the general meeting where ASSID members are welcome to raise issues, a delegate made the point that ASSID had been neglecting Northern Territory and threw down the gauntlet – challenging ASSID to respond and to fulfill its mission in the territory ie "to enhance the skills, knowledge and commitment of it's members and to facilitate a supportive network in order to enhance the quality of life of people with intellectual or developmental disability". The ASSID board's recommendation was that that the South Australian regional association should respond to this challenge.

In 2008 there was considerable media attention on issues in a number of the isolated aboriginal communities in "the Lands". These issues and the government of the day's response to it; "the intervention" attracted media attention here and overseas. In conversations with Board members from New Zealand in particular the questions was raised 'what were we doing'? The identified issues of abuse and neglect made it plain that there were Australian communities with inadequate infrastructure, support or opportunities. In these circumstances it is a safe assumption that people with an intellectual disability – amongst the most vulnerable in any community – would be suffering. What has been the impact of these issues for people with an intellectual disability? How should these issues be addressed? What role could ASSID play? A major challenge for us is to determine what role ASSID can take in identifying the evidence and how to disseminate it so as to raise awareness and inform debate.

The South Australian council resolved to look at how to engage with the Northern Territory membership and what we can do to support them to run events that address their issues and interests. We began by writing letters to ASSID members in the Territory and to senior staff within the Northern Territory government. Working out precisely who to contact was in itself a challenge!

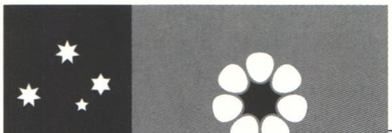
A third influence arose at the end of 2008. One of the ASSID board members serving as the International Association for the Scientific Study of Intellectual Disabilities (IASSID) representative had a role in organising the IASSID conference in Singapore. At IASSID's request, this board member raised the question of whether the Australasian board would consider sponsoring someone from one of the disadvantaged communities in the Pacific Islands to attend the IASSID conference. The board considered that although there was some merit to this suggestion it was important to recognise that Australia had its own disadvantaged and neglected communities. This resulted in extensive and passionate discussion regarding the best way to support those who were doing valuable work with people with intellectual disability in disadvantaged communities. The notion of the community action scholarship developed – the notion being that where we could identify innovative and effective good practice we should develop a mechanism to recognize, support and promote this work. How to do this in a way that was effective and helpful while being respectful and culturally appropriate presents a range of challenges.

In the meantime correspondence with members in Alice Springs had resulted in plans to run an ASSID sponsored event in Alice Springs in the first half of 2010. The area of interest identified was foetal alcohol syndrome. This is a work in progress.

In an effort to engage with the Top End ASSID(SA) sought the assistance of a researcher and practitioner who had worked in these communities and has lived in Darwin for some years, Phil Flint. Phil was enormously helpful in identifying who in Darwin to contact in order to get things moving. Phil also cautioned us against the 'seagull syndrome' where 'white fellas' flew into communities, do what seagulls do and left what seagulls leave and flew out again. It was imperative that we did what we said we were going to do and didn't give undertakings and make promise we couldn't keep. We needed to follow through – to make good.

One of our necessary first steps seemed to be the need to make contact with people who could introduce us to the people 'on the ground'.

Taking advantage of the fact that the ASSID president – Dr Olive Webb, was going to be attending the IASSID confer-



ence in Singapore 'just up the road' Richard O'Loughlin from ASSID (SA) using the contacts provided by Phil arranged to meet with a number of key people in Darwin. At the end of June, representatives of ASSID's Australasian executive and ASSID (SA) met with a number of key stakeholders in Darwin to progress ASSID's engagement with those agencies and individuals who have a role in supporting people with an intellectual disability in the Northern Territory. ASSID was able to meet with government representatives, senior staff from the Department of Health and Families who have executive responsibilities in the Aged and Disability program, as well as representatives of some of the significant non-government service providers in 'Top End'. After discussing the nature of ASSID as an organisation, its mission and purpose, and identifying what ASSID could do, a proposal was developed in consultation with the everyone. The proposal provides an outline of our proposed undertakings. ASSID will organise and run, on a cost recovery basis in collaboration with local agencies, a couple of events based in Darwin, over the next year, targeted at direct support professionals on topics of pressing concern to staff working in this area. It is ASSID's intention, through an ongoing process of consultation and local involvement, to establish a 'community action grant' that looks at how to support innovative and effective ways of supporting people with an intellectual disability from disadvantaged and isolated communities initially targeting 'The Lands'. The people ASSID met in Darwin were welcoming, generous with their time, and very positive about the potential role that ASSID could take in the Northern Territory.

In an effort to keep up the momentum, Dr Keith McVilly, who was attending an Australian Psychological Society conference in Darwin at that time, convened a roundtable discussion in Darwin on Tuesday 29th September 2009. About 15 people attended the meeting. There was a brief presentation on the history and role of ASSID; discussion of the potential role of ASSID as a conduit to both deliver knowledge and skills to support the development of initiatives in the Northern Territory , and as a means of disseminating knowledge and skills developed by people working in the territory to the wider Australian disability community – particularly the expertise developed by territory staff in working with indigenous communities and developing supports in remote communities. There was also discussion of current issues in the Northern Territory and how ASSID might engage with these – including strategic partnerships with National Disability Services (NDS), along with a number of service provider agencies, Charles Darwin University and the Northern Territory government's Aged & Disability Programme. The group resolved to work with ASSID to progress several events that would promote engagement with communities in the Northern Territory . The group will work towards establishing a regional association, for formal incorporation into ASSID at the South Australian conference in 2011. Many thanks to: Vicki O'Halloran (Chief Executive Officer) and Elaine Castles (Administration Officer) of Somerville Community Services Inc., and Lyndell Chambers of NDS for facilitating publicity and to Penny Fielding, Director with the Northern Territory government's Aged and Disability Programme, for supporting the event and subsequent offer of support for ASSID's fledgling regional group.

So we have made a start but have a long way to go. Aside from following through on our current commitments, the next leg of our ongoing journey is to use our existing networks and contacts as well as those that we are in the process of developing, to make our way into the communities beyond the Alice and outside of Darwin; to leave the city behind and get out into 'The Lands'. ◆

Queensland

by Lisa Fraser

Qld ASSID held our Annual General Meeting on the 21st October 2009 at Centacare Disability Services. Qld ASSID were very pleased to see all previous committee members accept positions for the coming year and very warmly welcomed Peter Smith and Karen Nankervis as new members to the committee. The new committee members include: Madonna Tucker, President; Lyn McPherson, Treasurer; Julianne Kelly, Secretary; Hamish Millard and Lisa Fraser, National Councilors; Karen Grogen, Ankica Melbye, Cindy Nicollet and Karen Nankervis, Committee Members.

Following the Qld ASSID AGM Centacare Disability Services (CDS) hosted a Site Visit which was attended by 20 people. Qld ASSID have continued to promote the opportunity for interested parties to host Site Visits as an opportunity for ASSID members and others to network and learn more about the host organisation. Stewart Thompson, Director of CDS, provided an informative presentation on the historical development of the organisation within the context of the broad range of community services provided by Centacare and more specifically discussed the range of services within CDS available for adults who live with a disability. A warm thank you is extended to CDS for hosting this enjoyable evening, for providing the venue for the ASSID AGM and the venue for ASSID meetings throughout the year.

Qld ASSID supported an event on the 23rd of October organised by The Relationships and Sexuality Disability network (RSDn). Speakers were convened to discuss a range of topics regarding sexuality and disability with a view to positively raising awareness and generating dialogue and debate in an area that is too often given little consideration. Qld ASSID would like to thank the RSDn for the opportunity to support this pertinent event.

The first meeting of the new committee is to occur on the 16th of November and will couple as our Christmas celebration. We look forward to the opportunity to welcome new members and turn our attention to planning for 2010 events. ASSID, the Australian Association of Developmental and Disability Medicine and the Centre for Excellence in Behaviour Support are working in collaboration to convene the 2010 National Conference to be held in Brisbane on the 29th September to the 1st October. "Seeking Excellence" will be a conference not to be missed!

Qld ASSID send our wishes for a Merry Christmas and prosperous New Year. We look forward to seeing you in Brisbane in 2010 for the National Conference!

Victoria

by Loiuse Mountford

It's been an action packed end to a very busy year for the Victorian ASSID committee.

We held an intimate AGM in October with guest speaker Bruce Bonyhady, Chairman of Yooralla, speaking to us about the National Disability Insurance Scheme. The night was very informative and provided a forum for in depth discussion around this initiative and other contemporary issues for people with an interest in intellectual disability in Victoria. Copies of the minutes from the AGM can be made available on request and will be distributed to all Victorian members shortly.

The new Victorian council for 2009-2010 was also elected at the AGM. Congratulations to Samuel Murray for retaining the Presidency and representation on the National board, Alyson McKenzie for her continuing role as Vice President and , and Glen Jose for his unwavering support to the role of Treasurer and representation on the National board. The Victorian committee would also like to thank Paul Tomaszewski for his role as Secretary, which he has decided to step down from ad welcomes Louise Mountford to this role for the coming year. Members of the committee for 2010 also include Jon Slingsby as an ASSID National representative, Niall Hewitt, Paul Tomaszewski, Trevor Skerry, Erin Lindley, Bill Taylor, and Keith McVilly. The AGM also marked a time of change for the Victorian Committee as we said farewell to Karen Nankervis who has left us to further her career in Queensland. We would like to take this opportunity to thank her for her support and dedication to ASSID Victoria. We thank Sheridan Forster for her continued service and support to ASSID Victoria over recent years as she commits more time to the successful completion of her PhD.

The DSW conference for 2009 has also just come to a close. A preliminary glance through the evaluation forms have provided very positive feedback thus far – stay tuned for an in depth report by conference convener Samuel Murray in the next edition of IDA. The conference was booked to capacity this year and the strength of the papers submitted allowed for us to present a wide range of information to delegates across eight concurrent streams, which is no mean feat for a team of volunteers! This year saw DSW 09 host the Disability Support Worker of the year awards which we were privileged to have presented by the honourable Lisa Neville, the Minister for Mental Health, Community Services and Senior Victorians, as well as having the Honourable Bill Shorten, Parliamentary secretary for disabilities and children's services, as the opening keynote address. We would like to thank all involved in making this years conference a success, in particular Sue Mason for all her hard work throughout the year, Sheridan Forster for organising all of the IT equipment and ensuring that all the presentations ran smoothly, and the conference program committee.

The Victorian committee are all looking forward to a well-earned rest over the festive season and are hoping to make 2010 an even better year for our membership. Stay tuned for the reinvention of the newsletter and for upcoming events.

Tasmania

by Craig Jones

HOBART 2009- a huge success.

Watch out for a full report in the next issue of IDA

Craig Jones, Olive Webb and Darryleen Wiggins at the Governor's reception and welcome to the ASSID 2009 Hobart Conference.

New Zealand

by Gary Wyatt

Since the last update in IDA, New Zealand has held its annual conference and AGM meeting at the Novotel Tainui Hamilton.

The conference was held on the 26th and 27th August and the choice of Hamilton as the location for this years conference appears to have been a positive move after a record number of delegates attended. Key notes speakers included Professor Gwynnyth Llewellyn from the University of Sydney, Professor Ian Evans and Dr Martin Sullivan from Massey University. There was also a wide ranging mixture of presentations from self advocates to those wishing to effect change and thinking in the disability sector in New Zealand.

Although the Minister for Disability Issues could not be in attendance due to attending a Tangi, the Rt Hon Tariana Turia compiled a speech that was suitably delivered by Jan Scown from the Office for Disability Issues, which can be viewed on the New Zealand page of the ASSID website as well as all of the conference papers.

The Annual General Meeting for NZASID was also held during the conference and Sharon Brandford stepped down as President after a number of years in the role. Sharon has guided NZASID through some difficult times but yet has seen the profile of NZASID grow in New Zealand to a point where our conference and seminars are seen as instrumental in the disability sector in New Zealand.

Elected as the new President of NZASID, Adrian Higgins has taken on the baton from Sharon and will no doubt be keen to continue the hard work off the last few years to grow NZASID even further. Adrian will be assisted by Debbie Espiner who was elected as Vice President, Martyn Matthews (re-elected as Treasurer) and Gary Wyatt (re-elected as Secretary). We also say thank you to Caroline Mohr who has decided not to stand for NZASID Council this year. We welcome the existing council members back for another term as well as welcoming new council members, Jennifer Mofflin and Tanya Breen.

NZASID also held a workshop with Dr Nick Lennox, facilitated by Dr Olive Webb, in September in Wellington. Dr Lennox is an Associate Professor at the University of Queensland and was in New Zealand to present at the annual conference of the Royal New Zealand College of General Practitioners.

The workshop looked at barriers to health care for people with intellectual disabilities and from this we have seen the development of a health network list between various providers and professionals. This workshop highlighted a huge need for the support of health professionals in the area of intellectual disability. NZASID would like to thank Dr Lennox for taking the time out of his busy schedule to present at this workshop and we would also like to acknowledge his recent promotion to Professor.

The NZASID council met in Wellington on the 7th December 2009 to plan events and strategies for next year. The council will be reviewing the feedback from the 2009 conference, other seminars and events as well as planning the 2010 conference which will be held in Dunedin.

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NZASID is keen to host and facilitate seminars around the country addressing key issues affecting the intellectual disability sector in New Zealand.

The NZASID Council has members spread throughout New Zealand from Auckland in the north to Dunedin in the south. NZASID council members can be contacted by visiting the ASSID website and looking under the New Zealand branch or by emailing gary@accessability.org.nz

South Australia

by Richard O'Loughlin

On 8 October ASSID SA held a joint forum with In Control (a group whose purpose is to advocate for and promote the adoption of self managed funding) on the topic of the Application of Individualised Funding to Individuals with an Intellectual disability. Approximately 20 people were in attendance, representing a range of non government service providers, self advocates and parents. The forum considered: the recent history and experience of other countries and Australian states in implementing individualised funding; examples of individualised funding arrangements in the South Australian context; a review of the research and evidence; an update from the state government's Office of Disability and Client Services on its plans for rolling out self managed funding; and presentation of range of assessment methods and tools. The forum concluded with question and discussions and light refreshments.

In conjunction with our AGM (held on 28 October 2009), we invited a representative from the Victorian Community Visitor scheme to present on the operation of the Community Visitor scheme in Victoria. Ms Sheila Narayan – coordinator for the Victorian Community Visitors' scheme for people with a disability living in accommodation, presented on the history of the scheme, the legislative and human right framework that informs their approach, and the practical experience of the scheme's operation in Victoria (which has been in existence for over 20 years and involves over 500 volunteers state wide). Over 30 people attended the event including self advocates, parents of people with an intellectual inability, management staff from NGOs, service coordinators and senior bureaucrats from the public sector. There were many questions from those that attended and much discussion. The AGM resulted in a number of members, who have not taken on such a role previously, nominating to participate in the state committee; the current ASSID president (Richard O'Loughlin) stepped aside from his role after 8 years, and a new executive committee 'stepped up', (with Denice Wharldall taking on the ASSID SA presidency) although the role of treasurer stayed in the capable hands of Ruth Davey (for which the whole state committee is grateful). The committee was reminded that SA would be hosting the Australasian conference in 2011 and that planning for this event needed to commence ASAP. ASSID SA will begin the process of consultation with the sector immediately to ensure that the 2011 conference addresses the compelling and critical themes for those involved in the area of intellectual disability in SA. Our aim for the 2011 conference is that it is at least as successful as the last Australasian conference held in SA was, in 2004. We believe the success of the 2004 conference was attributable to the participation of the whole sector. ASSID (SA) will be seeking a similar level of involvement and participation from the research community, service providers from both the public sector and non government, people with an intellectual disability and their families and carers.

Western Australia

by Angus Buchanan

2009 has been successful year for ASSID WA with an enthusiastic and hard working Committee. The most recent event to be held was the State Conference. This year new format was used which proved to be a success. The Conference theme this year was "What does the future hold for a person with an intellectual disability?" and focussed on the issues facing people with an intellectual disability into the future on a personal, societal and environmental level.

The Conference was extremely fortunate to have as it key note speaker, Rhonda Galbally AO who spoke about the recently released Shut Out report. Other presenters also include the Hon Fred Chaney AO, Professor Trish Harris, Deidre Croft and a range of other important researchers and presenters in this area. The Conference had 110 people attend and was sold out due to venue size. Feedback was very positive.

The Conference was followed by the Annual General Meeting and the Committee for 2009/10 is Angus Buchanan (President), Nicole Beresford (Vice President), Sue Peden (Treasurer), Jill Mackenzie (Secretary) and the State Councillors are Chris Yates, Mauricio Sanabria Isabelle Valk, Jo Sharland and Allyson Thomson.

A major priority of the Committee remains the development of membership through the provision of quality activities. The coming year plans include exploration of an annual research forum in partnership with a University, the annual State Conference and three development events.

Delegates at the WA State Conference

NSW & ACT

By Tina Purdon

Activity has continued in the NSW and ACT branch of ASSID, to ensure that the Association is properly incorporated in this Region.

Having achieved Incorporation status with the NSW Office of Fair Trading in June, we have now been able to successfully change the registered name to Australasian (not Australian) Society for the Study of Intellectual Disability. So now ASSID NSW is properly registered and Incorporated – just in time for the Society to decide to give us all a new name!

Following from the August State Conference, preparations commenced for the AGM and linked training opportunity.

The NSW and ACT Annual General Meeting was held on 29th October in Sydney. The Meeting was preceded by a very well received and informative session conducted by Dr. Vivienne Riches, exploring the topic of "Who Supports the Support Staff?"

Dr. Riches outlined research into the methods and success rates of staff support and supervision, in relation to both the satisfaction of staff working with people with disabilities and the impact this has on the lives of the people they support. A number of areas were explored including the importance of clear expectations of staff behavior in the role of support professional and the importance of celebrating high quality performance. Participants then had the opportunity to contribute to Dr. Riches research in this area with the completion of the 3SQ (Staff Support and Supervision Questionnaire).

The ASSID NSW and ACT Committee expresses our appreciation to Dr. Riches for her presentation and the opportunity to support research into this very important area.

ASSID NSW and ACT are also pleased to announce the results of the AGM and the election of the 2009 / 2010 Regional Committee.

The bearers of all Committee positions were re-elected and we thank Tony Harman (President), Dr. Vivienne Riches (Vice President), Linda Ward (Secretary) and Dennis Robson (Treasurer) , for their ongoing and solid commitment to ASSID NSW and ACT. We also welcome back returning general committee members and new faces to our committee.

All Committee Members, look forward to the next 12 months and activities which will raise the profile of ASSID in both NSW and ACT.

The 2009 / 2010 Committee would like to issue a special invitation for members in ACT. – we are hoping to recruit some representatives to the Committee from ACT and would welcome any enquiries. Please contact the Secretary, Linda Ward – lindaw@ucsl.nsw.uca.org.au. The Committee meets regularly in person and by teleconference. We would be very pleased to provide financial support to a Committee member from the ACT to attend meetings as required. The current Committee would also be very pleased to rotate meetings between Sydney and Canberra as appropriate.

From all members of the ASSID NSW and ACT Committee, we wish all ASSID members a very Merry Christmas and the very best of years ahead in 2010! ◆

community partnerships that work

The following presentation is taken from the recent keynote address given by Denise Leembruggen at the ASSID 2009 conference in Hobart. Denise was involved in the Awakenings festival for 11 years, from 1997 – 2007 with 9 years in the position of festival director.

Horsham is located in Victoria on the Western Highway with a population of about 20,000. It is the retail, business and service heart of the Wimmera region which is an agricultural district.

The region recently endured terrible drought – so throughout the entire evolution of the festival, Horsham and the Wimmera region experienced 11 consecutive years of drought, resulting in the river drying up and crop failures, which had a significant economic and social impact on the town. The success of the festival happened **despite** the drought.

Awakenings is Australia's largest and longest standing disability arts festival; Australia's event of a million smiles. **It is powerful and is fuelled by passion in fact it is life changing.**

In 2007 the 12th annual Awakenings festival ran for 10 days, boasted 51 events, hosted 846 performers from around Australia and New Zealand and recorded event attendances over the 10 days of 12,500. It had a volunteer force of over 400 and there were no less than 100 community partnerships proudly supporting it.

But it wasn't always like that.

When the Awakenings festival was born, 11 years ago, it was a concept ahead of its time.

The genesis of the festival came from a state government funded program which promoted leisure and recreation opportunities for people with a disability under the auspices of Wimmera Uniting Care.

The potential for the program to focus on the arts as a sustainable recreation opportunity was recognised and in 1995 the development work began, to create an arts and theatre production for people with a disability.

In 1996 the inaugural Awakenings drama festival (Drama in the Wheat Fields) took place. The program consisted of a half day workshop with a performance outcome involving 40 people with and without disabilities. There were 2 community partners involved in that inagural festival .

In 1997 Denise joined the festival team as a volunteer. At that time there was little or no interest by the community apart from the groups (scouts, service clubs) that worked as volunteers for the event. However the number of participants tripled from 40 to 120 including some performers from South Australia. The festival ran for 3 days with a mix of performing arts and outdoor recreational events. There was a strong Grass Roots philosophy which was proudly maintained.

In that year 1997 the world renowned pianist David Helfgott became Patron.

Gaining community support was hard work. Briefly in the years 1998 - 2000 the festival attracted increased government and philanthropic funding. It began to attract more performers from Victoria as well interstate support. Participant numbers flourished, growing exponentially every year to 532 in 2000.

By 2000 the festival report listed 30 community sponsors including local sport and recreational groups, businesses, service clubs, churches, and disability organisations. This was a significant improvement on previous years, but involved a lot of hard work to develop these partnerships.

However, the general community did not join in and it remained difficult to articulate the benefits of the festival to the broader community.

To generate a higher community awareness it was decided that if the community wasn't going to come to the festival then the festival would come to them. In 2003, with 450 registered performers on board, the festival arrived in town. Streets were closed off and a street festival to end all street festivals took place called "Awakening Roberts Place". It featured bands, poetry, performances, wheelchair basketball activities, bungie trampolining, visual arts activities, stalls, belly dancing, live art, rock and roll and dancing in the streets. The event brought the Awakenings community and the local community together in an atmosphere of fun, friendship, acceptance, inclusion, active pursuits, drought relief and

health promotion. A significant milestone in community partnership!

From that moment onwards, the most amazing thing happened: people started coming to the festival organisers to develop partnerships.

However, the festival was growing like a mushroom and needed support and funding to support that growth. It became a struggle every year to successfully apply for funds. The feeling that the festival was generating was too good, no-one wanted it to fail.

Attracting a high profile patron was an excellent way of initiating, developing and consolidating partnerships.

In 2005 several milestones were celebrated: the 10th Awakenings festival: David Helfgott returned for the festival and a Presentation Ball was held. Awakenings participants came from every state in Australia; there was a strong sense of 'family' happening between the Horsham community and Awakenings participants; Awakenings had become an annual pilgrimage for many participants.

"When we arrived in Horsham the whole team felt like they had come home. It's the highlight of our whole year! I don't know what we did before Awakenings – I think we were asleep!"

"No other the event welcomes people with disabilities, makes them the centre of attention, honours them and treats them with respect like Awakenings does. Our performers look forward to it every year."

In 2004 the local ANZ branch became involved. Sponsorship included volunteering, pink pigs, photo competitions, prizes and merchandise.

In 2005 the ANZ provided every registered Awakenings participant with a pink pig money box. 1000 pink pigs went home to all parts of Australia and overseas. The aim was for everyone to start saving for the next festival!

In 2006 as a result of the plethora of pink pigs around Australia the festival and the ANZ ran the inaugural ANZ Pink Pig Adventure Competition and exhibition. The pink pigs became the subject of a photographic competition drawing entries from around Australia and the world.

In 2007 the Awakenings festival's partnership with the ANZ celebrated ten years.

Again the local branch provided core sponsorship, managed and displayed The Pink Pig Adventure Photographic Competition number 2; placed posters at all regional branches, and provided strong volunteer support.

The University of Ballarat (Ballarat and Horsham Campuses) commenced as major sponsor for 'Awakening Roberts Place' in 2003.

In 2006 the Arts Department of The Horsham Campus became the venue for a visual arts project funded by Regional Arts Victoria entitled 'Artsplash'. It also supported two projects: the Performance Marketing Department was appointed to undertake market research as a student project. Theatre Production Students were seconded to work as technical crew for the festival which became part of their assessment for their results.

In 2007, the Artsplash Project (one off funding) was thrown a lifeline by The University of Ballarat which embraced the philosophy of this project and made it available as an ongoing subject for TAFE students. The university also hosted the Awakenings Visual Art Exhibition.

The local Catholic Secondary School Parents and Friends committee commenced the 'Easy Evening Meals' program and provided home cooked 2 course meals at a very reasonable price for performers and their support crews to minimise the costs of attending the festival.

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community partnerships

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In 2006, the mental health and wellbeing impacts of the Awakenings Festival were evaluated as part of a larger program evaluation for the Victorian Health Promotion Foundation (VicHealth), a long standing Government Sponsor of the festival. The evaluation assessed the individual, organizational and community-level impacts of the festival on wellbeing, with a particular focus on social inclusion.

The following outcomes for community partners and sponsors were:

Individual / social

- Their involvement with the festival improved staff's disability awareness and attitudes toward working with people with a disability.
- Being involved in the festival encouraged people to work together and thus build networks across and between organisations in the area.
- Volunteering for the festival improved the wellbeing of staff in their organisation.
- Staff exposure to diverse groups in the community was a motivating factor in being involved. These respondents suggested that improved staff knowledge and appreciation of the community they served assisted them to take responsive and creative approaches to their work.
- Being involved with the festival helped staff to 'think outside the square', and encouraged staff growth and positive attitudes toward achieving professional and community goals.
- Being involved in the festival had improved the ability to recognize and respond to different client needs.

Economic

- The influx of visitors to the festival had been good for retail businesses, and that this helped stimulate the local economy.
- The festival attracted financial resources to the area – through funding and in-kind contributions – both supporting local activities and raising the profile of the area.
- The financial resources brought into the area by the festival helped expand the range of services and activities available for people with a disability within the region.

Organisational

- Cross-promotion of organisational activities and services, which widened the exposure of organisations at minimal cost;
- Opportunities to boost the membership of community organisations through participation in hosting festival workshops; and
- Creation of training and education opportunities

The following quotes summarise the thoughts and feelings of the community and the participants themselves:

2001 festival (post 9/11 in America) Barb Olsen Ballarat:

"The residents of Horsham should feel very proud of themselves. The enormity of the impact that Awakenings must have on Horsham and it's residents, needs far greater acknowledgement and accolade. To the people of Horsham you should all feel an incredible sense of pride and ownership of a festival which has an enormous impact on improving the lives of thousands of people. In these days of strife and sadness world-wide, once a year in October, your corner of the world is proof of the power of the human spirit. The manner in which you open your town and your hearts to such a diverse range of human beings is a magnificent testament to you all. If your actions were emulated world wide the power of the people of one town could change this world to become a better place. We thank you with our collective hearts."

From an Awakenings performer in 2006 which is quite simply:

"The worst thing about Awakenings is going home."

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ASSID Awards 2009

Journal for Intellectual and Developmental Disability Awards

2009 AUSTRALASIAN RESEARCH PRIZE (for a paper published in JIDD during 2009 and judged to be the most innovative contribution by an Australasian author/s resulting in positive life changes for people with an intellectual disability)

Kate Davis and Susana Gavidia-Payne

The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities

2009 JIDD EDITOR'S PRIZE (for the paper judged to be the most outstanding contribution among all papers published in JIDD throughout 2009)

Kathleen Fisher, Michael Green, Frederick Orkin and Vernon Chinchilli

A content analysis from a US statewide survey of memorable health-care decisions for individuals with intellectual disability

2009 ASSID Research Grant

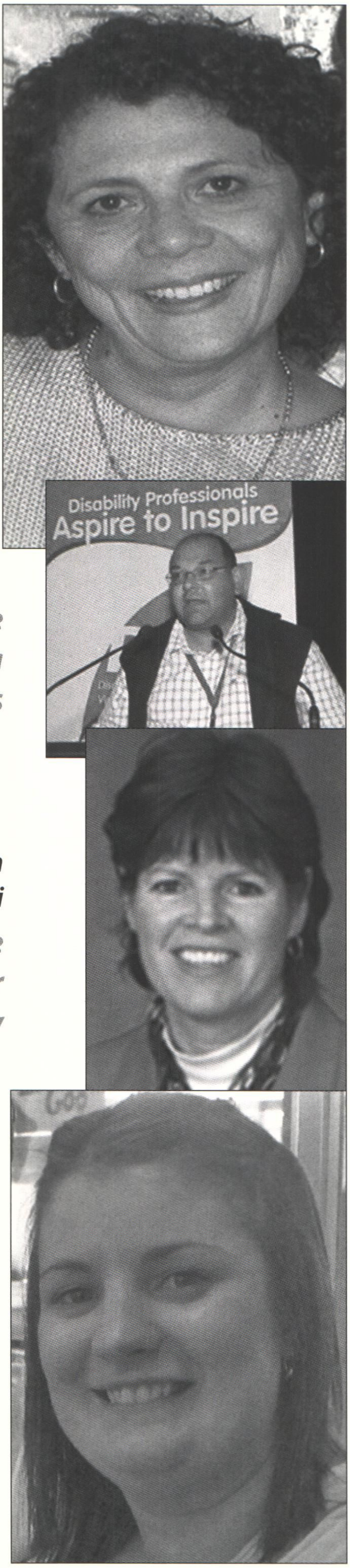
1) Julie Wilmot's

Perceptions and Planning of Individual Planning Documents

2) Paul Ramcharan, Chris Bigby and Patsie Frawley's

Developing a Research Tool for Inclusive Research around Self Advocacy History

There were two applications for research awards this year. After careful consideration the publications sub-committee recommended that both applications should be recognised by ASSID.



Photos: (from the top)
Susana Gavida-Payne, Paul Rancharan, Kathleen Fisher, Kate Davis

Australasian Society for the Study of Intellectual Disability

EXECUTIVE OFFICER

$100,000 package pro rata based on experience and track record

ASSID is a highly regarded professional association for people with an interest in:

- the rights and contribution of people with an intellectual disability,
- research that promotes the wellbeing of people with disabilities,
- high ethical standards of practice in the field, and
- the dissemination of information that supports all of the above.

ASSID is a collaborative network which means that you will need to be able to work with different people across diverse organisations and backgrounds in order to bring out their strengths and engage them in our activities.

The Board of Management is seeking to appoint a new Executive Officer to build further on ASSID's success. We seek a strategic, entrepreneurial and community focused individual to lead the exciting next phase of this respected organisation. To effective in this role you will need to have:

- Experience in securing foundation/corporate funding
- High level analytical skills, including ability to analyse funders' needs and requirements
- Capacity to develop and implement growth strategy, including working with potential industry and community partners
- Excellent written communication skills, including professional tender writing skills
- Excellent project management skills
- Ability to communicate with and engage people effectively to achieve result
- Commitment to the people with disabilities, the goals and objectives of ASSID
- Ability to understand and apply Business Excellence principles
- Proven experience as a member of an organisation's Senior Management Group
- Business acumen
- Flexibility and adaptability

This is a rare and career defining opportunity and will offer an attractive remuneration package to secure a unique professional keen to lead the organisation forward.

For a job and person specification and further information please visit http://www.assid.org.au/

Applications are required to be submitted electronically in MS Word format only and should be forwarded to assid.nat@bigpond.com

Telephone enquiries are welcome on (08) 8100 8807 and may be directed to Heidi Jones.

The closing date for applications is January 29 2010

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Editorial

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The Appointment of an Executive Officer

The ASSID board hopes that the successful applicant for the Executive Officer will be able to commence in the New Year, and start the task of developing and implementing an ASSID strategy to increase the profile, and connection of ASSID to its members and the sector.

Public Liability Insurance for ASSID events

For some time the Board has been aware of the costs to regions of providing public liability insurance for ASSID events. In particular, the annual conference insurance cover is a financial burden for the host region every year. The Board has investigated the possibility of one insurance policy that will cover all the regions, and would also include indemnity insurance for Board members. A final decision will be made in 2010 with consideration given to a small levy to each region based on size and membership numbers.

A Governance Framework for Board Members and Regional Representatives

In discussing the Board decision to employ an executive officer, and to provide insurance to all regional associations, the Board also recognised that they, as regional representatives, were not entirely clear about their roles, responsibilities and decision-making authority and therefore the mid year meeting in May will focus on developing a 'governance framework' for future ASSID board members and regional representatives.

ASSID's Name and Logo

The 2009 Board has determined that a final decision will be made regarding the name and logo for the Australasian Society for the Study of Intellectual Disability. The next issue of IDA will include a discussion paper on the history, options and a proposed process for change.

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upcoming events

28 - 29 January 2010	*Social Inclusion Conference* *Melbourne* *www.socialinclusionconference.com.au*
28 - 30 April 2010	**8th National Deafblind Conference** Venue: Jasper Hotel, Melbourne Enquiries: Able Australia Services, 1300 225 369, patricia.karagiorgos@ableaustralia.org.au
10 - 11 April 2010	**The Third Pacific Rim International Forum on the Rights of Persons with Disabilities** Honolulu, Hawaii www.pacrim.hawaii.edu
11 - 13 August 2010	**ARATA Conference** ***The tip of the iceberg*** Hobart, Tasmania www.ebility.com/arata/conf.php
29 Sept - 1 Oct 2010	**45th ASSID Conference** ***Seeking Excellence*** Brisbane, Queensland For more information contact assid2010@optusnet.com.au

If you want to advertise your conference in IDA's upcoming events section, please e-mail: susan.peden@dsc.wa.gov.au

Editorial

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Since 2008 there have been many opportunities for members to contribute to the debate and all those who have had an opinion to voice have supported the need to change the association's name to better reflect a contemporary approach to people with an intellectual disability and the research that supports the development of good quality support services. There is universal agreement that ASSID must retain its focus on research and evidence based practice, and that this must be reflected in all its promotional material.

Regions will be involved in the final decision and constitutional amendments proposed accordingly.

Participation by People with an Intellectual Disability at the Annual Conference

This year's conference was a great success, thanks to the amazing Tasmanians. Once again people with an intellectual disability were represented in the delegates and the presenters to the conference. The ASSID Board acknowledges that how to best support people with disabilities remains a challenge to conference organisers. Every year, based on feedback from delegates with disabilities, ASSID members and self advocacy groups, organisers aim to offer a conference that is fully inclusive and responsive to diverse needs. Commonwealth funds are always accessed, and local sponsorships sought. Various options including dedicated 'self advocacy streams', individualised supports and post presentation round tables have been offered in the past, with varying degrees of satisfaction. Thanks to Sheridan Forster, a 'plain English' abstract has been included in the conference book in recent years. ASSID by-laws require conference conveners to work with self advocates to ensure their participation. The Board has proposed that in order to strengthen its approach the bylaws will be amended to include a specific role allocation within the organising committee for a 'self-advocate liaison officer'. ◆

AUSTRALASIAN SOCIETY FOR THE
A·S·S·I·D
STUDY OF INTELLECTUAL DISABILITY

SEEKING EXCELLENCE

45th ASSID AUSTRALASIAN CONFERENCE

29 September - 1 October 2010
Hilton Hotel, Brisbane

Co-sponsored by AADDM and CEBS

CALL FOR ABSTRACTS: 9 November 2009
REGISTRATIONS OPEN: 9 November 2009
Abstract deadline: 1 March 2010
Early Bird Registration closes 30 June 2010
Standard Registration closes

For more information contact:
assid2010@optusnet.com.au
www.assid.org.au or 07 3136 2196

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