



VOLUME 2, Issue 2

Spring 2007

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Chairperson's Update Sarah MacDermott

Welcome everyone to our first newsletter of WAADF's new financial year. The AGM, which was conducted as a part of the September 6th Forum meeting, included voting for Board members and resulted in the return of myself as Chairperson, Ritu Campbell as Vice-Chair &

Forum Coordinator, Helen Bolton and Sandra Gray as Co-Secretaries and John Wray, Alana Maley-Berg, and Sabrina de Beer as Ordinary Members. Sue Midford stepped down as Treasurer but returned to the Board as an Ordinary member and Jane Klinken, previously an Ordinary member, was elected to the Treasurer's position. We wish to extend our deepest thanks to Sue for all of her efforts as Treasurer over the past 3 years and we are very happy that she is able to continue on the Board.

The AGM also included voting for proposed changes to WAADF's constitution. All 9 resolutions were unanimously accepted. The majority of these proposals involved clarifications and expansions of the descriptions of Board members' duties and the qualifications for membership. These changes have resulted from the Board's experience of working with the constitution over the past 3 years and can be expected to ensure a more efficient application of these guidelines in the future.

The AGM also saw a review of WAADF's achievements over the past year. We discussed the establishment of WAADF's own website and its ongoing development. Our updated membership form makes it easy for members to provide information that can be included in the **on-line Membership Listing** that will soon be posted on the website. Any financial members who wish to be included on this listing can complete the appropriate part of the membership form (it's on the website) and send it to the Secretaries. We are continuing to work on a Members Only section of the website and when available it will be a password protected section. An Annual Calendar to assist with your planning, particularly of Forum attendances, will include all upcoming Forum events and speakers and will be posted soon on the website. WAADF also has a new postal address and this will be included on all new and past WAADF communications. WAADF has also had some international exposure over this year with a paper presentation of our group at the Autism Congress in South Africa. As a result of that event we have also developed an ongoing collaborative relationship with the National Ireland Special Interest Group. Through that contact we were provided with information about a national Scottish assessment, diagnosis and clinical interventions booklet which is available on the web at www.sign.ac.uk and is well

worth a look.

We also had a poster presentation at the Biennial Australian Autism conference on the Gold expanding our membership and providing even more benefits to members. We urge you to encourage any colleagues who are working in the field but not yet members to consider joining WAADF so that we can continue to support the highest possible standards of practice as well as providing opportunities for ongoing professional support and development.

We look forward to seeing you at the December 6th Forum.

Regards, Sarah

Coast which attracted considerable interest. We urge you to encourage any colleagues who are working in the field but not

yet members to consider joining WAADF so that we can continue to support the highest possible standards of practice as well as providing opportunities for ongoing professional support and development. We look forward to seeing you at the December 6th Forum. Regards, Sarah



The WAADF poster was displayed at the last Forum meeting by Dr John Wray, Sarah MacDermott and Sandra Robertson

Activ Library... new acquisitions



STEPPING STONES TRIPLE P: A SURVIVAL GUIDE FOR FAMILIES WITH A CHILD WHO HAS A DISABILITY.

Studman, Lisa J; Sanders, Matther R.; Mazzucchelli, Trevor. Milton, Qld: Triple P International Publishing, 2003. 1 videocassette (82 min) + 1 booklet (32p).

Stepping Stones Triple P is a version of the Positive Parenting Program (Triple P) for children with disabilities. This video and accompanying quick reference guide provides a step-by-step approach to parenting, which presents children's development and the management of their behaviour in a constructive and non-hurtful way. It includes explanations and demonstrations of positive parenting; causes of behaviour problems; promoting children's development; managing misbehaviour; and family survival tips.

LEARNING ABOUT FEELINGS. Linke, Pam. Watson, ACT: Australian Early Childhood Association (AECA) 2003, 19p.

This booklet is a guide to young children's feelings (babies, toddlers and preschoolers), what to expect and how to help children manage their feelings in a loving and safe environment.

EASING THE TRANSITION TO SCHOOL FOR THE YOUNG CHILD WITH SPECIAL NEEDS: A RESOURCE BOOKLET FOR PARENTS AND TEACHERS. Luscombe, Suzanne. University of WA. Child Study Centre, Nedlands, WA, 2000, 32p.

Included in this resource booklet are tried and evaluated ideas and strategies that can enable children with special needs to make the transition from early childhood settings to school. There are separate sections for what the parents and teachers can do, and the major issues for the child in the early years of school.

IT'S A LONG ROAD. Lange, Noreen.

This website has been created by Western Australian women who are parents of children with intellectual disabilities, to provide a support network for other parents. It contains information about the video "It's a Long Road" which is the first hand account by 4 mothers of their experiences in raising their children with disabilities. The resources section of the website includes contact details for useful organizations and agencies in each state. The website is at www.itsalongroad.com or it can be accessed via the Activ Parent Portal at www.activ.asn.au/parentportal and clicking on Life Events – Diagnosis – Websites – itsalongroad.

For further information or to borrow items:

http://www.activ.asn.au/2/2085/8/activ_library.pm

"It seems that for success in science and art," he wrote, "a dash of autism is essential." Hans Asperger



Have you seen this website? It appears to be a national forum with a political bent, representing some views on Autism Spectrum Disorders and associated issues. The current issue has a WA education focus.

To have a look:

www.a4.org.au/documents

WAADF WEBSITE

The website is gradually coming together. Members of WAADF can nominate to be listed on the site.

SPEAK TO A WAADF MEMBER ABOUT MEMBERSHIP FORMS AND BENEFITS!

Call for Case Presentations

We're always on the look-out for volunteers to share diagnostic case studies with members at the WAADF meetings. In the past we have had wonderful presentations from our members on topics such as elective mutism, visual impairment, Down Syndrome and semantic-pragmatic disorder. These presentations not only make our meetings more interesting, but add to the professional development of our diagnostic community. If you have a case to present, don't be shy! We'd love to hear from you. Please contact the WAADF agenda coordinator,

Ritu Campbell on ritucampbell@bigpond.com. Cheers!

The WA Autism Register... a contribution from Glenys Dixon

The WA Autism Register recently gave a sponsored presentation at the 2007 International Meeting for Autism Research (IMFAR) in Seattle Washington. The presentation was part of an invited educational symposium titled "A world view of autism epidemiology". The conference had over 900 attendees from all over the world and it was a wonderful opportunity for the Register to be showcased internationally and to enhance possible research collaborations. The presentation was well received and was immediately followed up with an invitation to submit a poster for the "Autism Speaks to the World" international autism research congress in Mexico City July 2007.

Prior to the IMFAR conference the WA Autism Register also participated in the international Epidemiology of Autism Network meeting sponsored by Autism Speaks and the Center for Disease Control (CDC) in the USA. At this meeting, which was held immediately prior to the

IMFAR conference, an opportunity to participate in an international collaboration examining trends in autism diagnoses arose and this will be pursued by the WA Autism Register and the Department of Epidemiology and Social Medicine at Aarhus University in Denmark.

It was clearly evident from both the international meeting and the IMFAR conference, that WA has a unique resource which really is the envy of many international researchers and clinicians. However, it is also very evident that it was the great work and foresight of those that established both the Register and WAADF that Western Australia has such a resource as the WA Autism Register, and it is the hard work of many clinicians and passionate people that the data is still being collected and is of high integrity with consistent diagnostic processes and minimal confounders. We would like to thank all the notifiers to the WA Autism Register, without you this valuable data would not exist.

Obtaining consent affects the value of the Western Australian autism register ... from Emma Glasson and John Wray

There is growing international awareness about the realities and difficulties of obtaining written informed consent from patients to compile and use data recorded in population-based registries. In some cases, such data could be of substantial benefit to the community, while posing relatively low risk of infringing patients' privacy.

The Canadian Stroke Registry achieved only a 39% participation rate from 4285 eligible patients when applying a policy of written informed consent to their data collection, resulting in significant representation bias. The issues and consequences are mirrored in our own endeavour, since 1999, to maintain a prospective register of people diagnosed with autism spectrum disorders in Western Australia.

As protocol, diagnosing clinicians in Western Australia ask

parents for written consent to allow their autistic child's name, date of birth and postcode to be forwarded to the register. However, for many reasons, parents are not always asked and diagnostic information is not always forwarded. Missed cases are collected annually from the major diagnostic and service provision centres, but only the sex and year of birth are recorded for the child.

Between January 1999 and December 2002, 757 new cases of autism were registered in WA, but only 35% of parents gave written consent to include identifying details. Forty-three per cent of the 757 cases were identified by cross-referencing to diagnostic centres. When clinicians remember to notify new cases to the register, 56% of parents give consent, either at the time of diagnosis, or by sending the forms directly to the register, indicating that

clinicians are instrumental in encouraging patient participation. Sometimes clinicians send anonymous diagnostic information without giving parents information about the register, and sometimes parents forget to send permission forms to the register.

Various characteristics of the child or the child's family have a bearing on whether consent is given. For example, consent is received for only 31% of children living in rural areas, 25% of children with no intellectual disability, 23% of children not Australian-born, and 16% of children from families whose primary language is not English.

Without consent for every case, the register cannot accurately reflect the age or geographic distribution of children with autism. If the register only collected information on consent-

ing cases, there would be severe under-ascertainment and the output would be notably biased. Perhaps more importantly, unidentifiable records cannot be linked to other datasets. Other WA population databases include information on hospitalisations, genetic testing, genealogical links, midwife notifications, birth defects, pharmaceutical history, and people with cerebral palsy. Linkage to these datasets would enormously facilitate population-based autism research to investigate the aetiology, associations and natural progression of autism disorders. The WA autism register is an internationally unique population-based resource, but its application is limited without the inclusion of identifying information. This remains the reality at a time when the research community and affected families desperately seek information about the condition and solutions for their children.

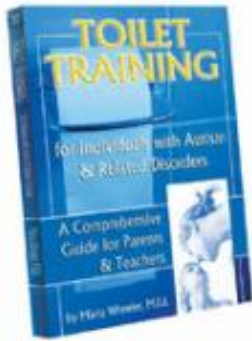
Tu JV, Willison DJ, Silver FL, et al. Impracticability of informed consent in the Registry of the Canadian Stroke Network. *N Engl J Med* 2004; 350: 1414-1421.

Ingelfinger JR, Drazen JM. Registry research and medical privacy. *N Engl J Med* 2004; 350: 1452-1453.

Williamson OD, Cameron PA, McNeil JJ. Medical registry governance and patient privacy. *Med J Aust* 2004; 181: 125-126.

Glasson EJ. The Western Australian Register for Autism Spectrum Disorders [letter]. *J Paediatr Child Health* 2002; 38: 321.

Book Review...



Toilet Training for Individuals with Autism and Related Disorders Vol. 1 :

A Comprehensive Guide for Parents and Teachers

By: [Maria Wheeler](#)

This comprehensive guide contains more than 200 toilet training tips and 60 case examples to guide parents and teachers of children with autism who need techniques beyond those used to toilet train other children.

The following websites may also be useful:

<http://www.teach.com/toilet.html>

http://www.autismtoday.com/articles/potty_training.htm

<http://www.tacanow.com/PTinfo.htm>

<http://groups.msn.com/TheAutismHomePage/toilettraining.msnw>

Have You Heard About... GF/CF Dietary Research

An article in the April edition of Scientific America magazine reported that the following researchers have just initiated controlled research studies into gluten free (GF) and casein free (CF) diets with autistic children in the US and they expect to report initial results by the end of the year:

- Robin Hansen at University of California, Davis – all participants go on a gluten free diet for 2 months then for the next 2 months half eat snacks containing gluten and half have indistinguishable gluten free snacks – they expect some results within 6 months
- Susan Hyman at University of Rochester – a similar study but involving both gluten and casein
- University of Pittsburgh Medical Centre – will monitor effects of combining GF/CF diet with supplements of Omega-3

Researchers have found it difficult recruiting subjects as many parents who are already committed to a GF/CF diet do not want to participate as their children might be in the control group.

AAWA announcements

The Autism Association has received a grant to run an EarlyBird WA project to provide 3 months intervention to 12 children who are on the waiting list for funded EI services immediately after diagnosis.

AAWA has received a grant to purchase AutismPro, an Autism programming tool.

For further information, contact:

Val McKelvey

Manager, Children's Services

Autism Association of Western Australia (Inc)

Tel 08 9489 8921

Fax 9489 8999

email valm@autism.org.au

Autism Pro free trial.....

By subscribing to AutismPro First Steps, a FREE TRIAL limited feature version of AutismPro, you get a 30-day demonstration of the use of this program for a preschooler with severe autism.

To subscribe, click on the First Steps link at: www.autismpro.com

Let's Talk About... DSM-V development

Suggestions for DSM-V

In order to submit suggested changes to DSM-IV or to provide new suggestions for DSM-V, you must first login to the web site: <http://dsm5.org/suggestions.cfm>

All of your DSM-V suggestions will be associated with your e-mail address. This will allow your suggestions to be entered into the DSM-V Prelude Project data base, allow us to contact you about your suggestions, and allow you to make additional supplementary comments or provide additional documentation and data for your previously submitted suggestions.

The DSM user community is an important source of information regarding the identification of problems and limitations with DSM-IV-TR. In advance of starting formal work on the preparation of DSM-V in 2006, we are providing the user community with an opportunity to provide us with comments about problems with DSM-IV-TR and possible suggestions for DSM-V. All suggestions will be entered into the DSM-V Prelude data base for eventual referral to the future relevant DSM-V Work Groups, which are expected to be appointed no earlier than 2007. The DSM-V Prelude data base functions primarily as a repository for such suggestions to ensure that they are routed to the proper Work Groups. It will be the responsibility of these future DSM-V workgroups to evaluate your proposal and to consider how to integrate it into their future deliberations, which will not begin until 2007. Upon receipt of your submission, we may contact you to request further clarification or possibly to recommend research directions that you might consider in order to provide the necessary empirical support for your suggestion.

Suggestions/comments have been categorized into one of five types. Please select the type that best fits your suggestion or comment:

- [Submit comments that serve to alert us about problems, limitations, or shortcomings with DSM-IV-TR \(without specific suggestions about how to fix them\). Miscellaneous comments that do not fit into the other categories go here as well](#)
- [Submit suggestion for specific changes to diagnostic criteria or diagnostic class groupings](#)
- [Submit suggestion for a new subtype to be added to an existing disorder](#)
- [Submit suggestions for a new disorder to be considered for addition to DSM-V](#)
- [Submit suggestions for deletion of an existing disorder.](#)

New Medicare items for Autism Spectrum Disorders ...

The current Enhanced primary care rebates are not to be used for the ASD diagnostic process however the Prime Minister announced on October 3rd that the Commonwealth Government will provide \$190 million in funding over five years to assist children with Autism Spectrum Disorders (ASD), their parents and carers.

This funding includes \$20.7 million over five years for new Medicare items for the diagnosis of ASD and early intervention treatment plans by clinicians and allied health professionals.

Specifically, these will include:

- new specialist Medicare Benefits Schedule (MBS) items for Paediatricians and

child psychiatrists for diagnosis and the development of treatment plans for children aged up to 12 years;

- new items for developmental psychologists and speech pathologists to assist with aspects of the assessment; and
- access to Medicare items for the provision of early intervention treatment following diagnosis for children with ASD, providing up to 20 services per child. The new services will be provided by relevant allied health professionals including speech pathologists and occupational therapists.

Treatment plans will identify the specific treatment needs of each child in relation to early intervention services available through

the Government's autism package and through other public, private and community based services.

Prompt and accurate diagnosis of children with ASD means that children can gain most benefit from treatment and support in their critical early years. These items should improve early and accurate diagnosis of ASD as well as improve access to early intervention to help children with ASD.

Details of the new Medicare items will be developed in close consultation with members of the relevant health professional organisations as well as representatives of the autism sector. The new items will be available from 1 July 2008.

" ... If we could eliminate the genes for things like autism, I think it would be disastrous," says Wilhelmsen. "The healthiest state for a gene pool is maximum diversity of things that might be good."

Research...

New Guidelines Promise Earlier Identification of Autism

Washington, D.C., April 23, 2007 (ICDL) – Leading experts on child development today presented a new framework for identifying children at risk of Autism Spectrum Disorders (ASD) and other developmental challenges, saying that current guidelines fail to identify many children who need and would benefit from early intervention.

The framework is contained in a report by a special working group formed by the Centers for Disease Control (CDC) and the Interdisciplinary Council on Developmental Learning Disorders (ICDL), co-chaired by Dr. José Cordero, former Director of the CDC's National Center on Birth Defects and Developmental Disabilities and currently Dean of the School of Public Health of the University of Puerto Rico, and Dr. Stanley Greenspan, chair of the ICDL.

The framework presents newly formulated indicators to identify at-risk children in the first and second years of life, components for a comprehensive evaluation of infants and children determined to be at risk, and essential elements of a successful early intervention program for ASD and other developmental disorders.

The authors say the new rubric casts a wider net than current common practice in an effort to identify all children at risk of developmental disabilities.

"Children identified with developmental or behavioral disabilities earlier have a better chance of reaching their full potential," said Dr. Cordero. "We believe this framework improves our ability to identify infants, young children, and families at risk and to organize truly comprehensive, developmentally-based intervention efforts."

The CDC-ICDL framework is based on current understanding of healthy developmental patterns and is designed to detect all possible deviations from those patterns. It uses risk indicators designed to detect a lack of mastery of age-expected emotional, social, and cognitive milestones during a child's first 2 years of life. These include the inability to:

- Be calm and focus on sights and sounds by 2 months of age
- Initiate and sustain warm, joyful interactions with caregivers by 4 months of age
- Exchange emotional and social gestures (using different sounds), reaching, exchanging, back-and-forth smiling, looking, and searching by 8-9 months of age
- Engage in shared social problem-solving and play-

ing, including taking a caregiver's hand to find a toy or favorite food; playing with a toy and caregiver together with lots of back-and-forth exchanges of sounds; and social gestures such as smiles, looks, and pointing by 12-16 months of age.

Early identification and preventive intervention for ASD and other developmental disorders have been long-standing goals, yet until now there has been no widely accepted framework for determining which infants and young children are at risk and the best ways to intervene. The new framework is intended to fill that gap to help more infants and young children overcome early challenges and acquire the foundations for healthy emotional, social, and intellectual development.

The CDC-ICDL report, which is being released during Autism Awareness Month, comes at a time when concern about autism and other developmental disorders is growing. A recent CDC study showed that an estimated 1 in 150 children in the United States has autism, a rate much higher than previously thought. Moreover, nearly 17% of U.S. children present a wide range of developmental challenges, including autism and other learning disabilities, that require early identification and preventive interventions. However, less than 50% of these children are identified as having a problem before starting school.

In presenting the new framework, the CDC-ICDL Working Group Report cautions against evaluations that are limited to specific behaviors or diagnostic criteria. During infancy and early childhood, all children who do not demonstrate mastery of the newly formulated healthy development milestones should receive early diagnostic evaluation and early intervention, the report says.

A comprehensive evaluation must include assessment of social, emotional, cognitive, language, motor, and sensory functioning; parental and family patterns of interaction; and availability of community support, says the report. It recommends that intervention programs focus on infant-parent relationships, family functioning, and overall social-emotional, cognitive, motor, and sensory functioning. The report concludes that narrowly focused intervention programs that target specific behaviors or symptoms may increase risk in infancy and early childhood.

"This report is important to the future of children and families all over the country," said Dr. T. Berry Brazelton, founder of the Child Development Unit at Children's Hospital Boston and the Touchpoints Center and member of the CDC-ICDL Working Group. "Without it, many adults would be thrust on our society with untreated

autism that might have been effectively treated had intervention been started early in their childhood. We know that the earlier in childhood --or even in infancy-- treatment begins, the more likely people affected by autism can adapt to society and the workplace."

Brazelton added, "With the frightening rise in the incidence of autism, we are facing a costly epidemic. The ICDL has been working to identify these babies early and to introduce therapeutic intervention as early as possible. This therapy works to increase the process of social and neurological organization that help these children learn to function, to help parents understand their role with them, and to assist the children themselves to reach out for the world they would otherwise shut out. This report is like a lifesaver thrown into a drowning society. We should all be grateful."

Dr. Greenspan also announced that the CDC-ICDL Working Group will periodically review early detection and intervention programs and the degree to which they are consistent with these new principles. "Early identification and intervention programs that occur early in life can have long-term effects and should receive the same rigorous long-term scrutiny as any pharmacological intervention does," he said.

Work group members included: **Co-Chairs** - José F. Cordero, M.D., M.P.H. (former Director, National Center on Birth Defects and Developmental Disabilities – CDC) and Stanley I. Greenspan, M.D. (Chair, Interdisciplinary Council on Developmental and Learning Disorders). **Members** - Margaret L. Bauman, M.D. (Massachusetts General Hospital), T. Berry Brazelton, M.D. (Harvard Medical School), Geraldine Dawson, Ph.D. (University of Washington), Barbara Dunbar, Ph.D. (Georgia State University), Peter C. Mundy, Ph.D. (University of Miami), Ruth Perou, Ph.D. (National Center on Birth Defects and Developmental Disabilities – CDC), Keith G. Scott, Ph.D. (University of Miami), Stuart G. Shanker, D.Phil. (York University, Toronto, Canada), and Ruth E. K. Stein, M.D. (Children's Hospital at Montefiore).

The Interdisciplinary Council on Developmental and Learning Disorders (ICDL) is a non-profit organization dedicated to improving the prevention, assessment, diagnosis, and treatment of emotional and developmental disorders in infancy and childhood by promoting dialogue and integrating knowledge from different disciplines.

For the complete report and more information, please visit www.icdl.com or contact Cecilia Breinbauer, M.D., M.P.H. at cbreinbauer@icdl.com

**We're on the web! Visit
www.waadf.org.au**

Waitlist Times

State Child Development Centre:

Preschool: 8-12 months
School Aged: 18-24 months

Private Practice:

Paediatricians: up to 6 months
Clin. Psychs: up to 6 months
Speech path: 1-6 months

Disability Services Commission:

Metropolitan

Preschool: 3-12 months
School Aged: 18-24 months

Country

Preschool: 6 months
School Aged: 12-18 months

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Dates of Meetings

Forum Meetings are held on the **first** Thursday of the last month of the quarter:

Venue: Conference Room
State Child Development Centre.
Time: 9.00am-11.00am
Next meetings: 6th December
then: 1st March, 7th June, 6 Sept., 2008

Board Meetings are held every 4–6 weeks
(next meeting 6 Dec)

Please contact a Board Member if you have any issues you would like discussed.

NEWSLETTER CONTRIBUTIONS

To keep the newsletter coming out quarterly, we need your help!

Please forward contributions for the next newsletter to Sabrina de Beer by mid December to allow for early February-publication.

sabrina@sabren.com.au

"If a child cannot learn in the way we teach ... we must teach in a way the child can learn."

Dr I. Ovar Lovaas

