



Olga Tennison

AUTISM RESEARCH CENTRE FORUM

A U S T R A L I A

**AUTISM RESEARCH
IN AUSTRALASIA:
WHAT DO WE
KNOW?
WHERE SHOULD
WE GO?**

**OLGA TENNISON AUTISM RESEARCH
CENTRE FORUM:
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One of the key objectives of The Olga Tennison Autism Research Centre (OTARC) from its establishment in 2008 was to build national and international research links and collaborations focused on understanding and treating Autism Spectrum Disorders (ASD). Hence an early initiative was the hosting of a focused research forum which brought together leading autism researchers from Australasia with the aims of identifying and fortifying current research strengths in Australia and New Zealand, developing and planning future research directions, and forging new Australasian autism research collaborations.

The forum was held at the La Trobe Technology Enterprise Centre at La Trobe University, Bundoora Campus on April 6 and 7, 2009. The meeting was opened by La Trobe's Deputy Vice Chancellor- Research, Prof. Tim Brown, who welcomed the twenty three delegates who attended the two-day meeting (see Delegate List in Appendix A).

Delegates provided a one-page summary of their main research areas which were circulated prior to the forum, and the program commenced with each researcher providing an introductory overview of their research interests (see Program in Appendix B). The diversity of both research and professional expertise amongst the delegates was notable (occupational therapy, psychology, special education, paediatrics, epidemiology, psychiatry). It encompassed research interests that covered a wide range of research areas from behavioral to biological studies, and basic to applied research.

This report outlines the proceeding of this highly successful forum which resulted in the formation of the Australasian Autism Research Collaboration (AARC). The report is available to the delegates (now members of the AARC) and to all interested parties in the wider research community.

The workshop concluded with the launch of an Olga Tennison Autism Research PhD Scholarship to be undertaken anywhere in Australia (3-years from 2010-2012).

The success of the workshop was a direct outcome of the enthusiastic and dedicated researchers who attended the two days, and the fine orchestration of the proceedings led by Professor Margot Prior. Ms Lisbeth Wilks (Administrative Officer at OTARC) duly attended to our organizational needs from the early planning stages to the conclusion of the workshop. I sincerely thank all of you for making this event an important and memorable one. Finally, I would like to acknowledge Mrs Olga Tennison whose generosity facilitated the hosting of this workshop.



Cheryl Dissanayake, Ph.D MAPS
Associate Professor & Reader

Director, Olga Tennison Autism Research Centre

Day One

Following introductions and the brief presentation of delegate research areas, there were four invited presentations which covered four central themes in autism. Assoc. Prof. Cheryl Dissanayake (LTU) provided an overview of what is currently known about autism in infancy and the current status of early identification of autism within the first two years of life, stressing the importance of this for early intervention.

Assoc. Prof. Jacqueline Roberts (USYD) spoke next on early intervention practice, giving an historical overview and outlining the relationship between theoretical notions of cause and cure in autism. She noted some recent reviews on intervention outcomes, highlighting significant issues for researchers involved in evaluating the efficacy of intervention programs.

Dr Katrina Williams (UNSW) discussed prevalence studies, focusing on the current situation in Australia, and outlining the limitations of the available autism prevalence data and the barriers to conducting epidemiological research in this country.

Dr Nicole Rinehart (Monash University) provided an overview of our current knowledge of biology and brain science in autism, concluding with a summary of the current work being undertaken at Monash within these relevant areas. The well established heterogeneity of ASD continues to be a constraining factor in advancing our knowledge across all areas of autism.

The next section of the forum focused on identifying key topics, from which a selection was made and debated in the following small group and plenary discussions. The topics generated on Day 1 were predominantly of a clinical/applied nature:

- Gaps between research endeavours and working with families in clinical services
- What is necessary and sufficient for a diagnosis of autism? What are the boundaries of the disorder? Issues of comorbidity.
- Behavioural intervention: the need for a program of research covering the whole age range.
- Establishing a national register with data linkage; ethical issues re privacy, opt in /opt out methods in informed consent; the importance of good public health data.
- Common standards for intervention: manualized programs; fidelity of intervention; need for tools to support research and clinical evaluation of interventions.
- Biological research: biomarkers, neurological issues, imaging, genetics etc.

Brief Reports on Group Discussions

Diagnosis

To date there is no international agreement re the “Spectrum”. The group agreed that in Australia we should adopt Autism Spectrum Disorder to mean the Diagnostic and Statistical Manual (DSM) categories of Autistic Disorder, Asperger’s Disorder and Pervasive Developmental Disorder – Not Otherwise Specified. It was noted that the ASD Branch of the Department of Families, Housing, Community Services and Indigenous Affairs (*FaHCSIA*) include Rett’s Syndrome and Childhood Disintegrative Disorder within the Spectrum although these groups are not part of the spectrum. The need for common diagnostic guidelines was specified, as interpretation of the diagnostic criteria differs (particularly around differentiation of Autistic Disorder and Asperger’s Disorder). A common framework around issues of co-morbidity is desirable and was discussed in terms of primary vs. secondary diagnoses and the use of the difference axes in DSM. Organic disorders identified take first priority.

The importance of taking a developmental approach was highlighted, particularly in recognition of the fact that very young children do not manifest many of the features necessary for a DSM diagnosis. The current DSM (IV-TR) is not applicable to these very young children. It is expected that this issue will be dealt with in DSM V, however this raised concerns about the non comparability of research across changes of DSM with changing criteria over time. The utility of specifying the particular subtype (Autistic or Asperger’s Disorder?) was reinforced for the purposes of research, although it was noted that this sub-typing at very young ages is problematic (particularly prior to the onset of language).

Biology

The group discussed how best to foster collaboration, noting the limitation of infrastructure across the country including equipment and resources. It was agreed that sharing imaging equipment (e.g., Macquarie and Neuroscience Australia as potential resources) was highly desirable and that therefore a record of equipment available at different sites would be useful. However it was noted that recruiting participants would still be an issue as families would need to be local to fixed equipment. The sharing of training in methods across sites was proposed, (e.g., gait analysis), as well as the development of basic data collection protocols for common issues with a potential biological basis (e.g., sleep). This type of training and protocol development would assist in achieving basic data sets with large samples sizes which is important given the difficulty that is often found in achieving large sample sizes in Australasian ASD research. The need for a clinical trials response group was endorsed. It was felt that such a group could respond rapidly to unproven, new or controversial drugs or other medical treatments.



Intervention

The gaps in intervention research were noted especially relating to adolescence and adulthood, to transitions, and regarding long term outcomes. The need for longitudinal research was highlighted. Research which is focused on 'reducing questionable practices' is also required. There is a need to: develop assessment tools based on age groups; investigate differential responses to intervention according to sub groups (i.e., just an AD diagnosis is not enough, we need particular characteristics of child and family to be documented to look at influences on response to treatment). The costs of mounting Randomized Controlled Trials was noted as was the need for being realists and focusing on what will add value. Are comparative studies on different intervention approaches beneficial? The reality is that we face challenges of achieving program fidelity. The group resolved to write a position paper in this topic. Discussion also covered the need for promoting a scientist-practitioner model especially where it is not well known or understood.

Day Two

The second day began with Prof. Prior providing an overview of Day 1, and calling for


- a focus during Day 2 on research of the more pure/basic/experimental kind, and
- to develop a clear research agenda for the future.

In so doing, she also stipulated the need to identify research gaps, as well as opportunities for collaborative research and data sharing across a range of topics. It was agreed, however, that at first we needed to spend the morning in plenary discussion of specific topics including epidemiology, public health, the need for a national data base/register, and the need for data linkage.

Epidemiology

Discussion initially focused on what is happening in this domain in the different States and in NZ. Oliver Mudford (NZ) commented that nothing is happening in NZ because of Ministry of Health barriers. SA is trying to set up a register, and is well on the way with plans, with Manya Angly playing a role in making this happen. Autism SA has the data to underpin this initiative which may in future be linked as contingent for service provision. Robyn Young informed the group about the newly established federal government Autism Advisor system with data collection at each point of contact (FaHCSIA Operational Funding Management System; FOFMS). This forms one potential data base encompassing young children up to 7 years. The WA Autism register was discussed as a model.

Katrina Williams spoke about data access across Australia, state differences, and privacy issues. She also covered the role of AIHW (Australian Institute of Health and Welfare) and CSTDA (Commonwealth States and Territories Disability Agreement), and the desirability of linking with Medicare data (cases up to CA 11). Katrina, with John Wray and others, have already drafted proposals and have been urging national and/or state data collection developments for some time. Centre Link data may also be available, but it is unlikely that identified information would be provided. The APSU (Australian Paediatric Surveillance Unit) has been discussed as a possible method for data collection, however autism is too prevalent for the existing system to deal with. It is clear that as a group, we need to persuade politicians that national data collection and collation is important (and we need to get round their 'fear of knowing' the data and present this information source as an advantage). We also need parent input in any initiative to allay their fears, and to enhance their willingness to be on a data base. A suggestion was made to contact Judy Fisher (who continues to reside in Australia). A proposal was made to link in with Autism Spectrum Disorder Expert Reference Group (ASDERG) in Canberra re data collection via Autism Advisors. Issues regarding cooperation between FaHCSIA and Health Departments, and their different constituents and sources of data were raised.



The resources required to begin to develop a framework for national data collection and collation, at the very least would be one research officer and some time allocation from staff, e.g. Centre Link staff, Medicare staff, AIHW etc. It is important to avoid duplication of effort. It was suggested that as a collaborative autism research expert group, we develop a statement for the need for an epidemiological study in Australia, which will be underpinned by adequate data collection across government services across the States. This is to be forwarded to the ASD Branch in Canberra. Vicky Brown, who manages the Branch is aware of the need for a national autism register. It was agreed that a 2-stage process be proposed, initially gathering de-identified data (more palatable) and then proposing the development of a richer data set. Katrina agreed to co-ordinate an options paper, and to identify parent advocates across a few States.

Following plenary discussion on the morning of Day 2, further research topics were identified as important, and discussion ensued within smaller groups. Summaries of these discussions are provided below.

Brief Reports of Group Discussion

Early screening, including tools for doing this most effectively

Early signs – social behaviours and preverbal communication; we should not rely on language development to identify risk, as we risk missing higher functioning children with normal age language onset. These children are currently diagnosed later, despite early social impairment signs being evident.

Screening Vs Surveillance tools – the use of the former approach at a single time point/given age, leads to insensitivity of tools; rather an ongoing developmental surveillance model is more likely to identify children. The American Association of Paediatrics recommends developmental surveillance from 12 months; we need to raise awareness of early signs.

Diagnosis is currently possible at 24-months but not earlier if ADOS is used; the toddler ADOS (ADOS-T) is not yet available for general use; reiterated that DSM IV not satisfactory for under 3-years.

Social Attention and Communication Study (SACS) undertaken at OTARC could be implemented in NSW as an NHMRC partnership grant with LTU and UNSW. Another possible project that could accommodate some of the group's common interests was discussed. We proposed a multisite early intervention study, with provisional title The Australian Communication and Socialization Early Intervention Study (ACSEIS). We hypothesised that, "certain characteristics at 12 to 18 months of age, for children with autism, would define outcomes from early intervention at 2 to 2-and-one-half years of age". We envisaged that the study design would utilise an early surveillance approach to identify young children at risk of autism. The identified children would undergo baseline assessments of communication, development, family functioning and biological parameters. The children would be subsequently randomised to receive one of two interventions over one year. The baseline assessments would then be repeated. Multifactorial analysis in a large sample size would enable us to compare interventions and determine baseline characteristics that influence outcomes within each treatment condition.



Language / Communication / Social Cognition / Information processing and visual perception

A clear need for research on communication in general in the ASD population was identified, as there has been a lack of research on language and huge gaps need to be filled. Because there is heterogeneity and large individual differences, longitudinal studies through childhood are essential to advance our knowledge about the development of communication and language of children with autism. One area identified as needing further research was the developmental pathways from gesture use as a means of communication, to the use of words and language structures.

The need to develop appropriate tools to measure communication and language skills in ASD was discussed; the assessment of language comprehension in non verbal children is a particular problem. Some current check lists used to assess communication development in young children were thought not to be suitable for children with ASD. However, interventions based on communication need pre and post assessment tools in order to determine the effectiveness of the intervention. It was questioned how we can test children's understanding without using verbal instruction. Methods such as intermodal preferential looking would be valuable for testing language knowledge in young children, and for older children, eye tracking is a useful technique. Different brain imaging tools (ERG, ERP and MEG) are also possible for investigating aspects of language processing at different ages.

Because language development is closely associated with cognitive development, studies on language need also to include assessments of memory and other cognitive skills. In addition, the communication (pragmatic) skills of young 4-6 years old children need further investigation: the motivation to communicate, turn taking, question and answer routines. With older children (6-8) studying the development of narrative skills will help reveal more about children's planning competencies, representation of the present, past and future, global organization of information, attention to detail and whether their narrative competence is greater in areas of special interest.

Literacy was also raised in the discussion, and the issue of assessment was again discussed. Other points raised included promoting joint attention with family facilitators, the use of symbols for non-speech users, the flexibility of word/sign/speech use with verbal children, and inner speech.

It was hoped that some joint research, allowing for larger sample sizes, might develop as an outcome of this meeting.

Challenging behaviour – older adolescents / adults

Little is known of the incidence of co-morbid psychopathology and complex challenging behaviours? How big a problem is it? What is its impact on families? The need for various studies was identified including qualitative studies of groups of parents; risk factors; gaps in service provision. Web data collection for young people was suggested; How are challenging behaviours dealt with in various intervention programs?

What does EI in Autism look like in NZ; kinds of programs (categories), qualifications of providers, outcome measures, autism specific qualifications, hours attended, child level outcomes; family satisfaction / workforce capacity, family stress / support.

Other topics of interest noted by the delegates:

Concrete proposals needed for biological and genetic research including both biological and behavioural phenotype/genotype relationships and environmental influences; tissue banking

What kind of comparison groups should we be using? Jon Brock agreed to circulate his paper on this.

Work-force concerns for autism research and practice: University/tertiary training of professionals; how can this be developed, improved and focused. Jacqui Roberts and Kate Sofronoff agreed to write a position paper on this.



Australasian Autism Researchers sat around a large table to share ideas and strategies to foster research into ASD.

Conclusion

The final session on Day 2 was devoted to formalizing the network of researchers. It was agreed that we refer to ourselves as the Australasian Autism Research Collaboration (AARC), the peak research body in Australia, and that the 2-day workshop hosted by OTARC marks our inaugural meeting. It was also agreed that AARC exist as a subgroup of the Autism Research Alliance, Australasia (ARAA), which will continue as a listserve.

Further meetings of AARC are anticipated, with the next planned meeting following the Australian Pacific Autism Conference in Sydney (on Sunday August 23).

Cheryl agreed to draft a paper re governance and management of the AARC, including clarifying the ongoing support from OTARC which will facilitate the groups work. She will circulate to the membership for comment prior to the August meeting.

It was agreed that the goals of AARC are to:

- further research in the understanding, detection, prevention and treatment of autism.
- provide forums for the sharing and exchange of research within Australasia.
- encourage and establish collaborative research.
- provide support, encouragement, and a forum for new researchers, including higher degree research students.
- promote and establish international research linkages and collaborations.
- establish practice guidelines in diagnosis, treatment and education.
- seek funding for research.
- establish and maintain a national register/data base
- establish and maintain a website to promote and report on research and projects relevant to ASD.
- foster evidence-based practice in the delivery of services to the ASD community.

These goals can be achieved by:

- identifying any synergies, and potential group collaborations
- delineating strategies for collaborative multi disciplinary research building proposals based on current researcher groups and individuals
- generating larger samples through collaboration and data pooling
- reaching agreement on common basic measures for research projects to facilitate data pooling
- developing a clinical trials group to respond rapidly to current controversies
- developing national guidelines for the raft of current government initiatives (J Wray)
- developing strategies for advocacy and lobbying
- finding funding sources to support the AARC

Last session undertakings and to do list

- The Intervention group resolved to write a position paper on how to establish program fidelity.
- The Biology group proposed the need for a clinical trials rapid response team; set up expert individual or expert subgroup rather than whole group
- Katrina W agreed to co-ordinate an options paper regarding a national register and to identify parent advocates across a few States.
- Jon B agreed to circulate his paper on comparison groups, and to set up website¹.
- Jacqui R and Kate S agreed to write a position paper on University/tertiary training of autism professionals.
- Cheryl D to draft paper re governance and management etc. of AARC
- Margot P² to draft letter to NRMRC/ARC re autism research applications, shortage of expert reviewers, usefulness of AARC etc. and find appropriate pathway to inform funding bodies.
- Murray M³ agreed to circulate a list of published papers and conference papers at regular intervals
- Circulate and link Autism Victoria's position papers, and other similar information from other states.

Next Meeting:

When: Sunday 23rd August, 10am – 3pm

Where: Conference Room 3 at Sydney Children's Hospital, NSW. Enter via the hospital's main entrance off High St Randwick (not the emergency entrance but general hospital foyer) you continue along until you see a sign to the Allied Health department which is on your right. The room is in that section and is sign-posted.

1. Jon has already set up a site on Google: <http://sites.google.com/site/autismresearchaustralia/resources>

2. Margot has drafted letter and circulated to one AARC member from each State for comment

3. Murray has already begun this process

Appendix A

Delegate List

Dr Angelika Anderson	Monash University, Victoria
Professor Edith Bavin	La Trobe University, Victoria
Dr Avril Brereton	Monash University, Victoria
Dr Jon Brock	Macquarie University, NSW
Associate Prof Cheryl Dissanayake	La Trobe University, Victoria
Professor Valsamma Eapen	University of NSW, NSW
Associate Professor Deb Keen	Griffith University, Queensland
Dr Christine Kilham	University of Canberra, ACT
Dr Danuta Loesch	La Trobe University, Victoria
Associate Professor Murray Mayberry	University of Western Australia, WA
Dr Oliver Mudford	Auckland University, New Zealand
Professor Candida Peterson	University of Queensland, Q
Professor Margot Prior	Melbourne & La Trobe Universities, Vic
Associate Professor Amanda Richdale	La Trobe University, Victoria
Dr Nicole Rinehart	Monash University, Victoria
Associate Professor Jacqui Roberts	University of Canberra, ACT
Associate Professor Sylvia Rodger	University of Queensland, Q
Dr Natalie Silove	Children's Hospital Westmead, NSW
Associate Professor Mark Stokes	Deakin University, Victoria
Professor Bruce Tonge	Monash University, Victoria
Dr Katrina Williams	Sydney Children's Hospital, NSW
Dr John Wray	Western Australia Health Dept, WA
Associate Professor Robyn Young	Flinders University, SA

Additional attendees:

Professor Tim Brown,	La Trobe University, Victoria
Professor David Finlay,	La Trobe University, Victoria
Ms Lisbeth Wilks,	La Trobe University, Victoria

Apologies:

Adjunct Assoc Professor Tony Attwood	Griffith University, Q
Associate Professor Verity Bottroff	Flinders University, SA
Dr Kylie Gray	Monash University, Victoria
Associate Professor Jeff Sigafos	Victoria University, Wellington, NZ
Associate Professor Kate Sofronoff	University of Queensland, Q

Appendix B

The forum program

6 April

DAY ONE

8.30am	Registration / tea / coffee
9.00 – 9.10 am	Professor Tim Brown (DVC Research) Welcome and open forum
9.10 - 9.25 am	Professor Margot Prior Goals of the forum
9.25 – 11.00 am	Participant introductions (3-4 minutes – 23 delegates)
11.00 - 11.30 am	Morning tea & networking
11.30 – 11.50 am	Autism in infancy/Early identification: Associate Professor Cheryl Dissanayake
11.50 – 12.10 pm	Intervention/Education: Dr Jacqui Roberts
12.10 – 12.30 pm	Epidemiology: Dr Katrina Williams
12.30 – 1.30 pm	Lunch (on site)
1.30 – 1.50 pm	Biology and Brain Science: Dr Nicole Rinehart
1.50 – 2.10 pm	Plenary Discussion
2.10 - 3.10 pm	Discussion (Topics, topic leader)
3.10 - 3.30 pm	Afternoon tea
3.30 – 4.30 pm	Discussion (Topics, topic leaders)
4.30 – 5.00 pm	Pulling day together (led by Professor Margot Prior)
7.00 – 10.00pm	Dinner (venue Bell City) Guest Speaker: Mrs Olga Tennison

7 April

DAY TWO

9.00 - 9.15 am	Brief overview (Professor Margot Prior)
9.15 – 10.45 am	Reactions; Gaps in Australian research identified in discussion sessions and new directions
10.45 -11.15 am	Morning tea & networking
11.15 am – 12.45pm	Developing a research agenda
12.45 -1.45 pm	Lunch (on Site)
1.45 – 3.00 pm	Pulling it together: Themes; what we are good at, what we need to do? Developing a national research strategy
3.00 – 3.30pm	Conclusion – Findings & report (led by Professor Margot Prior) Afternoon tea available during the session Close