



# Annual Report 2013-2014



Ray David, Child 2009, oil on polycarbonate, 80 x 185 cm

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## ANNUAL REPORT 2013-2014

#### Introduction

We have competed 6 years of operation at the Olga Tennison Autism Research Centre and I am so delighted that our foundation donor, Mrs Olga Tennison, has been honoured this year with an Order of Australia Medal (OAM). This well-deserved award was conferred in recognition "of service to children with Autism Spectrum Disorders and their carers".

We have three new Post Doctoral Research Fellows who have commenced at OTARC within the last year, and they serve to extend our research capacity. Increasing our research staff also enables us to expand our student numbers. I am very proud to have two of my own PhD students, one Clinical Doctoral student and one Clinical Masters student successfully complete their theses. The latter also produced twin girls in the final stages of producing her thesis – evidence that we give birth to much more than research alone at OTARC!

The Autism CRC has completed one year of operation with numerous research projects now underway including the Australian Autism Biobank. The aim in establishing this important resource is to collect phenotypic and genotypic information on Australian children with autism and their parents that will be used to develop tools to facilitate earlier and more accurate

diagnosis of ASD in children. We are one of four data collection sites for the Biobank, which will be an asset of the Autism CRC that will be highly sought after by researchers from around the world to increase our knowledge and understanding of this complex body of conditions.

An exciting development this year has been the adoption of our Social Attention and Communication Surveillance (SACS) approach to early identification of ASD in Tianjin by China's fourth largest city and sister city to Melbourne. The SACS has been incorporated into Tianjin's 7-year Women and Children's Health Plan. The SACS is also being implemented more widely now in Warsaw, Poland – our first international site - and has recently been adopted into the British Autism Study of Infant Siblings (BASIS) in the UK.

We have also been able to expand our research collaborations more locally within the last year through the introduction of five Research Focus Areas (RFAs) at La Trobe University. Our fit within the 'Building Healthy Communities' and 'Understanding Disease' RFAs has spawned three new multidisciplinary research groups, each supported by seed funding. One is exploring animal models of ASD, the second is looking

at telehealth models to disseminate evidence based practice and the third is evaluating a national initiative for ASD.

In closing, I would like to acknowledge the hard work, dedication and passion of all those at OTARC – our staff, students and many volunteers - who make it a joy to work alongside them. I would also like to acknowledge the continued support of our Advisory Committee. We have plenty to keep up busy for another year! A special vote of gratitude goes to all the families and individuals who participated in our research.

Professor Cheryl Dissanayake, PhD MAPS

Director, Olga Tennison Autism Research Centre

# Our Objectives and Achievements Objective 1

#### Facilitate large and/or ongoing research projects

Currently we have over 40 research projects underway at OTARC, including a number of longitudinal studies. Our involvement in the Co-operative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) has increased our research capacity.

The current 'Research Themes and Projects' at OTARC are outlined below, together with details of some specific studies to illustrate our work over the last year. Our achievements are realized in high impact journal publications, conference presentations, and invited addresses, and are a sign of our growing reputation, both nationally and internationally.

### 1. Identification and diagnosis of Autism Spectrum Disorders

Identifying early behavioural signs of Autism Spectrum Disorders in infancy and toddlerhood

Our work in Social Attention and Communication Surveillance (SACS) is now truly international with implementation and data collection in Japan, Poland and China, and about to begin in the UK. The SACS is also incorporated into the Autism CRC, with an implementation due to begin in Perth later this year. We are also studying the barriers to early identification and diagnosis with PhD student Cathy Bent. Our current findings indicate that less than 20 percent of Australian children with ASD are diagnosed under 3 years.

## Identifying biological markers of Autism Spectrum Disorders

We have recently begun to study the relationship between stress, social development and hormonal regulation in children with Autism Spectrum Disorders and William's syndrome. The secretion patterns of the naturally occurring "stress hormone" Cortisol and the "social hormone" Oxytocin in children remains unknown, and we are interested in whether there is an association between these patterns and the development of ASD.

We are one of the four data collection sites for the new Australian Autism Biobank, which is part of the Autism CRC. Data collection will involve blood withdrawal from children aged between 2 and 17 years and their parents for detailed genetic analysis, as well as measurements of head circumference, height and weight. The aim is to investigate whether different types of ASD can be explained by different genes and/or gene combinations. By understanding this, we will be able to learn more about why autism occurs, and facilitate earlier and more accurate diagnosis.

## 2. Behavioural and cognitive development and differences

The work in this area is focussed on developmental differences in behaviour and cognition between children with and without ASD, including typically developing children as well as children with other neurodevelopmental conditions, such as Williams

Syndrome and Fragile X Syndrome. We have also begun to study the contribution of early motor mechanisms to learning, an area led by Research Fellow, Dr Darren Hocking.

## Understanding early learning processes in intellectual development

The association between early social learning and non-social learning processes and later intellectual outcomes in typical and atypical development is poorly understood. As these processes are deeply intertwined in typical development, we are investigating and comparing two atypical populations - children with ASD, who typically have reduced social learning capacity, and children with Williams Syndrome - whose engagement in social learning is usually enhanced. Dr Glacomo Vivanti leads this program of research.

#### **Pretend Play**

In a recent study we compared the emergence of pretend play in children with and without an ASD from 18 to 48 months to establish if the developmental trajectory is the same in both groups. Using both a longitudinal and cross sectional design, Clinical Master student Mahwish Chaudry found no differences in spontaneous play between the groups at 18 months, with deficits in those with ASD becoming more apparent with age. The development of pretend play was related to both their verbal and non-verbal abilities, but not goal directed behaviour. Importantly, however, pretend play did not predict either cognitive development.

#### 3. Related Conditions

## Sleep difficulties Mental health and wellbeing

Associate Professor Amanda Richdale, together with students and colleagues, is involved in a variety of studies of sleep difficulties and anxiety in ASD.

Following on from a pilot study funded by the Australian Wool Innovation (AWI), Associate Professor Richdale and Research Officer Ru Cai, have been working on a survey (also funded by AWI) of sleep and environmental factors in children aged 2-10 years, including children with ASD. They are also examining sleep under two different types of doonas in four 8- to 10-year-old boys.

An analysis of data from the Western Australian Raine data base by Honours student Jacqueline Davis was completed in 2013 (with assistance by Professor Andrew Whitehouse, Telethon Kids Institute and Associate Professor Sue Cotton, University of Melbourne). The results showed that sleep and anxiety (at 2 and 8 years, respectively) and ASD symptoms (at 2 years) are significantly related and predict sleep and anxiety at 8 years of age.

With PhD student Emma Baker, Associate Professor Richdale is also examining the links between sleep, hormones and psychopathology with a specific emphasis on whether circadian rhythm disturbances contribute to sleep disturbances in adults with an ASD. Master of Psychology student, Stephanie Mertins is investigating the relationship between diet, behaviour and sleep in 4 to 11-year old children with and without ASD. Associate Professor Richdale is leading a group of researchers from the Departments of Genetics, Zoology and Psychology at La Trobe University in the project "Investigating the Genetics of Co-morbid Anxiety

and Insomnia in Autism Spectrum Disorder". This project is funded by a grant from La Trobe's Research Focus Area 'Understanding Disease'. We have examined a range of targeted genes reported to be associated with ASD in a fruit fly model and have identified a gene of interest. We are now beginning to examine this gene and its associated behaviour in a mouse model.

Dr Kristelle Hudry and Clinical Doctoral student Kat Crea have almost completed their groundbreaking longitudinal study investigating child and family-related predictors of wellbeing in toddler-aged siblings of children with ASD, from age 2- to 3-years. They found that while many siblings of children with ASD were doing well, a small subset were at increased risk of "acting out" behaviours, such as aggression and hyperactivity, and at increased risk of "holding in" behaviours, such as worry. Further, they found that the more stressed parents were, and the greater the level of behaviour problems in the older sibling, the more likely the younger sibling was to display these acting out and holding in difficulties, especially at age 2 years.

Kat is to present her study to represent the School of Psychological Science at the University's 'Three Minute Thesis' competition. If she wins she will participate as a candidate in the nation-wide competition.

#### 4. Language and Communication

## Language processing and the effectiveness of communication supports

Dr Kristelle Hudry has continued her research program on bilingualism and ASD with Clinical Doctoral students, Lisa Rumney, Nicole Porter and Rebecca Kam, and Honours student Alexandra Woollacott. Their projects focus on the impact of being raised in a bilingual family environment upon the language, social, and cognitive abilities of children with ASD. Some early findings from this research program have recently been prepared by Lisa Rumney and Nicole Porter for publication in their theses, with the work by Rebecca Kam and Alexandra Woollacott continuing. The findings from this research program will contribute to understanding the impact of ASD outside of the context of Western/English-speaking countries.

#### 5. Focus on families

Family adaptation to living with Autism Spectrum Disorder

Families as partners in service delivery

Parents of children with ASD experience high levels of stress, however positive outcomes are also evident. Professor Cheryl Dissanayake, together with Clinical Doctoral student Rebecca McStay, explored the role of child age, parent gender, and family experiences in raising children with ASD. The findings indicate that despite risk and protective factors varying with child developmental stage, mothers of children with ASD reported consistently high levels of stress and reduced quality of life. These levels varied significantly more from

the norm than those reported by the children's fathers.

Given the established levels of parental stress following a diagnosis of ASD in their child, Professor Dissanayake and Dr Jospehine Barbaro are embarking on developing and testing the efficacy of a family support program with CRC scholar and PhD Student Stacey Rabba. Families will be provided with specialised support and guidance to foster parental wellbeing, and to assist with grief/stress associated with the diagnosis.

In another study, we are investigating the contribution, if any, of symptoms of ASD in parents, to parenting their typically developing children. This study is funded by the William and Vera Houston Trust.

#### 6. Interventions across the lifespan

Supporting evidence-based practice Effectiveness of early intervention Predictors of intervention outcomes

A swathe of studies continues to focus on the pre-school children with an ASD enrolled at the Victorian Autism Specific Early Learning and Care Centre. Having established the effectiveness of the Early Start Denver Model (ESDM) implemented within a group-based setting, with significant gains in cognition, particularly in receptive language, both from entry to one year later, as well as in comparison to another matched group of children not receiving the ESDM, we are now planning a research project on the impact of social inclusion on these outcomes.

Professor Dissanayake and Dr Giacomo Vivanti are also undertaking a follow-up study with Clinical Doctoral student Zoe Vinen of those children who received the ESDM to compare their school age outcomes to children who did not receive the ESDM. They also aim to study the predictors of long-term social and cognitive outcomes in these children.

#### Interventions in educational settings

Associate Professor Richdale continues to be involved in a collaborative pilot study of the TOBY Playpad app for iPad, which is an ABA-based intervention for young children with ASD. Professor Andrew Whitehouse (Telethon Kids Institute) is leading the project, with researchers at Deakin and Monash Universities also participating.

#### Interventions with adults

Associate Professor Amanda Richdale and Research Assistant Lahna Bradley have been working on an Autism CRC project to investigate the best way to engage adults with ASD in the longitudinal research being planned for the CRC. This research is been led by Aspect (NSW) and conducted across four states, NSW, Vic, Qld and WA. The report on the findings is expected to be submitted to the CRC in September.

With the arrival of Post-Doctoral Research Fellow, Dr Mirko Uljarevic, PhD student Ru Cai and Associate Professor Richdale have also begun work on the CRC longitudinal project following school leavers with ASD.

#### **Publications**

#### Semester 2, 2013

Barbaro, J., & Dissanayake, C. (2013). Early markers of Autism Spectrum Disorders in infants and toddlers prospectively identified in the Social Attention and Communication Study (SACS). *Autism*, 17(1), 64 - 86. DOI10.1177/1362361312442597

This paper was the most downloaded article in the 2013 edition of 'Autism'.

Duncan, E. & **Vivanti, G.** (2013). Team approach. In Volkmar, F. (Ed). *The encyclopedia of autism and related disorders*. Springer.

Esposito, G. & Vivanti, G. (2013). Gross motor skills. In Volkmar, F. (Ed). *The encyclopedia of autism and related disorders*. Springer.

**Hudry, K.** (2013). Communicative Development Inventories. In F. Volkmar (Ed.), *The encyclopedia of autism spectrum disorders*. Springer.

Richdale, A. L. (2013). Autism and other developmental disabilities. In A. R. Wolfson & H. E. Montgomery-Downs (Eds.) *The Oxford Handbook of Infant, Child, and Adolescent Sleep and Behavior*. Oxford: Oxford University Press.

**Vivanti, G.** (2013). Imitation in autism spectrum disorders: from research to treatment. In D. Riva, S. Bulgheroni & M. Zappella (Eds.). *Neurobiology, diagnosis and treatment in autism - An update* (pp. 161-168). London, John Libbey Eurotext Ltd.

#### Publications (Continued)

**Vivanti, G.** (2013). Imitation of Body Movements. In Volkmar, F. (Ed). *The encyclopedia of autism and related disorders*. Springer.

**Vivanti, G.** (2013). Macrographia. In Volkmar, F. (Ed). *The encyclopedia of autism and related disorders*. Springer.

Vivanti, G., Barbaro, J., Hudry, K., Dissanayake, C., & Prior, M. (2013). Intellectual development in Autism Spectrum Disorders: New insights from longitudinal studies. *Frontiers in Human Neuroscience*, 7, 1-8. DOI 10.3389/fnhum.2013.00354

This paper was the most downloaded article in the 2013 edition of 'Frontiers in Human Neuroscience'.

#### **Semester 1, 2014**

Chandler, F., & Dissanayake, C. (2014). An investigation of the security of caregiver attachment during middle childhood in children with high-functioning autistic disorder. *Autism: The International Journal of Research and Practice*, 18, 485-492. DOI 10.1177/1362361313486205

Gokcen, E., Petrides, K.V., **Hudry, K.**, Frederickson, N., & Smillie, L.D. (2014). Sub-threshold autism traits: The role of trait emotional intelligence and cognitive flexibility. *British Journal of Psychology*, 105, 187–199. DOI 10.1111/bjop.12033

Hocking, D.R., Menant, J.C. Kirk, H.E., Lord, S., Porter, M.A. (2014). Gait profiles as indicators of domain-specific impairments in executive control across neurodevelopmental disorders. *Research in Developmental Disabilities*, 35, 203-14. DOI org/10.1016/j.ridd.2013.10.005

Hudry, K., Chandler, S., Bedford, R., Pasco, G., Gliga, T., Elsabbagh, M., Johnson, M. H., Charman, T., & the BASIS Team (2014). Early language profiles in infants at high-risk for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44, 154-167. DOI 10.1007/s10803-013-1861-4

Lidstone, J. & **Uljarević**, **M**., Sullivan, J., Rodgers, J., McConachie, H., Freeston, M., Le Couteur, A., Prior, M., & Leekam, S. (2014). Relations among restricted and repetitive behaviors, anxiety and sensory features in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8,82-92. http://dx.doi.org/10.1016/j.rasd.2013.10.001

McStay, R., Dissanayake, C., Scheeren, A., Koot, H.M. & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life, and problem behaviour of children and adolescents with autism. *Autism.* 18, 502-510. DOI 10.1177/1362361313485163

Nuske, H. J., Vivanti, G., & Dissanayake, C. (2014). Reactivity to fearful expressions of familiar and unfamiliar people in children with autism: An eye-tracking pupillometry study. *Journal of Neurodevelopmental Disorders*, 6, 14. http://www.jneurodevdisorders.com/content/6/1/14

Richdale, A.L. & Baker, E.K. (2014). Sleep in individuals with an intellectual or developmental disability: Recent research reports. *Current Developmental Disorders* Reports, 1,74-85. DOI 10.1007/s40474-014-0010-x

Tan, X. Y., **Trembath**, **D**., Bloomberg, K., Iacono, T., & Caithness, T. (2014). Acquisition and Generalisation of Key Word Signing by Three Children with Autism. *Developmental Neurorehabilitation*, 17, 125–136. DOI: 10.3109/17518423.2013.863236

**Trembath, D. & Vivanti, G.** (2014). Problematic but predictive: Individual differences in children with Autism Spectrum Disorders. *International Journal of Speech-Language Pathology*, 16, 57-60. DOI 10.3109/17549507.2013.859300

**Uljarević, M., Prior, M.R.**, & Leekam, S.R. (2014). First evidence of sensory atypicality in mothers of children with Autism Spectrum Disorder (ASD). *Molecular Autism*, 5, 26. http://www.molecularautism.com/content/5/1/26

Vivanti, G. & Dissanayake, C. (2014). Propensity to imitate in autism is not modulated by the model's gaze direction: An eye-tracking study. *Autism Research*, 7, 392-399. DOI 10.1002/aur.1376

Vivanti, G., Trembath, D., & Dissanayake, C. (2014). Atypical monitoring and responsiveness to others' goal-directed gaze in Autism Spectrum Disorder. *Experimental Brain Research*, 232 (2), 695-701. DOI 10.1007/s00221-013-3777-9

#### Publications (Continued)

Vivanti, G., & Hamilton A. (2014). Imitation in Autism Spectrum Disorders. In Volkmar, F.R., Paul, R., Rogers, S.J., & Pelphrey, K.A. (Eds). *The Handbook of Autism and Pervasive Developmental Disorders (4th Ed.), Vol.1: Diagnosis, Development, and Brain Mechanisms* (pp. 278-301). Wiley. ISBN: 978-1-118-10702-7

Vivanti, G., Prior, M., Williams, K., & Dissanayake, C. (2014). Predictors of outcomes in Autism Intervention: Why don't we know more? Child and Neurodevelopmental Psychiatry, 2, 1-10. DOI 10.3389/fped.2014.00058

Zachor, D., Curatolo, P., **Vivanti, G**.et al. (2014). Recommendations for early diagnosis and intervention in autism spectrum disorders: An Italian–Israeli consensus conference. *European Journal of Paediatric Neurology,* 18, 107-118. DOI S1090-3798(13)00137-2

#### In Press

**Dissanayake, C.** (online first). Parent mediated intervention for young children with Autism Spectrum Disorder: A commentary. *Evidence Based Child Health*. DOI 10.1002/ebch 1952

Gunn, K., Trembath, D., & Hudry, K. (online first). An Examination of interactions among children with autism and their typically developing peers. *Developmental Neurorehabilitation*. DOI 10.3109/17518423.2013.778348

Jacobs, D. & Richdale, A. (in press). Language and literacy subtypes in young children with a high functioning Autism Spectrum Disorder. In J.Arcuili & J.Brock (Eds). Communication in autism. Trends in language acquisition

research series. Amsterdam: John Benjamins.

McStay, R.L., Trembath, D. & Dissanayake, C. (online first). Stress and family quality of life in parents of children with Autism Spectrum Disorder: Parent gender and the double ABCX Model. *Journal of Autism and Developmental Disorders*. DOI 10.1007/s10803-014-2178-7

Nuske, H., Vivanti, G., Dissanayake, C. (online first). Brief Report: Evidence for Normative Resting-State Physiology in Autism. *Journal of Autism and Developmental Disorders*. DOI 10.1007/s10803-014-2068-z

Nuske, H., Vivanti, G., Hudry, K., & Dissanayake, C. (online first). Pupillometry Reveals Reduced Unconscious Emotional Reactivity in Autism. *Biological Psychology*. http://dx.doi.org/doi:10.1016/j.biopsycho.2014.07.003

Pickles, A., Harris, V., Green, J., Aldred, C., McConachie, H., Slonims, V., Le Couteur, A., Hudry, K., Charman, T., & the PACT Consortium (online first). Treatment mechanism in the MRC Pre-school Autism Communication Trial: Implications for study design and parent-focused therapy for children. *Journal of Child Psychology and Psychiatry*. DOI 10.1111/jcpp.12291

**Richdale, A., Baker, E.,** Short, M., & Gradisar, M. (online first). The role of insomnia, pre-sleep arousal and psychopathology symptoms in daytime impairment in adolescents with high-functioning autism spectrum disorder. *Sleep Medicine*. DOI 10.1016/j. sleep.2014.05.005

Richdale, A. L. & Baglin C. L. (online first). Self-Report and Caregiver-Report of Sleep and Psychopathology in Children with High-Functioning Autism Spectrum Disorder: A Pilot Study. *Developmental Neurorehabilitation*. DOI 10.3109/17518423.2013.829534

**Trembath, D.**, Iacono, T., Lyon, K., West, D., & Johnson, H. (online first). Augmentative and Alternative Communication Supports for Adults with Autism Spectrum Disorders. *Autism.* DOI 10.1177/1362361313486204

Veness, C., **Prior, M.**, Eadie, P., Bavin, E., & Reilly, S. (online first). Predicting autism diagnosis by 7 years of age using parent report of infant social communication skills. *Journal of Paediatrics and Child Health*. DOI 10.1111/jpc.12614

**Vivanti, G.** (in press). Imitation in Autism Spectrum Disorders: From Research to Treatment. In D.Riva, & I. Rapin (Eds). *Neurobiology, Diagnosis, and Treatment in Autism Spectrum Disorders*. Libbey Eurotext

Vivanti, G., & Rogers, S. (in press). Autism and the Mirror Neuron System: Insights from Learning and Teaching. *Philosophical Transactions of the Royal Society B, Biological Sciences*, 369: 20130184. http://dx.doi.org/10.1098/rstb.2013.0184

Vivanti, G., Paynter, J., Duncan, E., Fothergill, H., Dissanayake, C., Rogers, S.J. & the Victorian ASELCC Team (online first). Effectiveness and feasibility of the Early Start Denver Model implemented in a group-based community childcare setting. *Journal of Autism and Developmental Disorders*. DOI 10.1007/s10803-014-2168-9

Vivanti, G., Trembath, D. & Dissanayake, C. (online first). Mechanisms of imitation impairment in Autism Spectrum Disorder. *Journal of Abnormal Child Psychology*, DOI 10.1007/s10802-014-9874-9

#### Conferences

(in chronological order)

Oral and poster presentations and invited keynote addresses given at both national and international conferences by staff and students at the Centre are listed below.

#### 8-10 August

## Asia Pacific Autism Conference 2013 (APAC13), Adelaide

Many OTARC staff and students attended and presented at APAC 2013. We also had an exhibition stand that was very popular with registrants.

**Keynote Symposium 1** 

**Stream: The Early Years** 

Theme: Research and Innovation in Early Identification and Diagnosis: Why is it Important and What Tools are Being Used?

Introduced by: Dissanayake, C.

Speaker: Barbaro, J. The Social Attention and Communication Study (SACS) Pre-School

Theme: Early Screening and Diagnosis

Barbaro, J. Developmental surveillance versus screening for the identification of Autism Spectrum Disorders in infants and toddlers.

**Dissanayake, C.** Early Diagnostic Clinic for Autism Spectrum Disorders: A model for promoting better outcomes.



Theme: Approaches to Play

Duncan, E. & Capes, K. An Augmentative and Alternative Communication (AAC) decision making model in a play-based group environment.

**Theme: Intervention Approaches and Outcomes** 

**Grant, N.** Parents of children with autism and treatment decision making

Hudry, K. Who benefits from early intervention?
Treatment response within the Preschool Autism
Communication Trial (PACT). (Associate Authors:
Slonims, V., Howlin, P., Le Couteur, A., McConachie, H.
& the PACT)

Theme: Exploring cultural values, differences and approaches

Ahmed, N. (Bangladesh, Laos, AUS) Overcoming cultural barriers in autism diagnosis, intervention and integration in the community: Experiences of an autism practitioner from Bangladesh.

**Theme: Language and Communication** 

Ahmed, N. (Bangladesh, Laos, AUS) Does Responsive Interaction Enhance Verbal Communication in Children with Autism and Limited Speech? Findings from Bangladesh.

Trembath, D. A comparative study of the effectiveness of speech generating devices for preschool aged children with ASD.

Theme: The Early Start Denver Model

**Vivanti, G.** Predictors of outcomes in the Early Start Denver Model.

**Zierhut, C.** Early Start Denver Model: Findings from longitudinal follow up and replication studies.

Stream: Health and Wellbeing

**Theme: Mental Health Across the Lifespan** 

Crea, K. Mental health difficulties in toddlers at high-risk for Autism Spectrum Disorders (Associate Authors: Dissanayake, C. & Hudry, K.)

**Stream: The School Years Theme: Learning Supports** 

Richdale, A.L. Reading in HFASD: Comparison with dyslexic and typical peers.

**Keynote Symposium 10** 

Theme: Implications of the DSM 5 – More Affected, More Detected or More Deflected? What are the Connections between Changing Diagnostic Methodologies and Prevalence?

Vivanti, G. DSM 5: Clinical, cultural and research implications

**Keynote Symposium 11** 

Theme: Exploring the Causes of Autism – The Role of Genetics and the Environment. Introduced by: Dissanayake, C.

#### Conferences (Continued)

Asia Pacific Autism Conference 2013 (APAC13), Adelaide - continued

#### **POSTERS**

Rumney, L., Porter, N., Kam, R., Barbaro, J. & Hudry, K. Parental bilingualism in autism spectrum disorders.

Porter, N., Rumney, L., Kam, R., Barbaro, J. & Hudry, K. Language competence in bilingually-exposed children with autism spectrum disorders.

James, C., Richdale A. Treating Sleep Onset Problems in Three Children with Autism Using a Weighted Blanket and Sleep Hygiene.

Trembath, D. Are Children with Autism Really Visual Learners? A Communication and Eye Tracking Study.

Trembath, D. An Evaluation of Keyword Signing for Children with ASD.

#### September, 2013

**Vivanti, G.** The Early Start Denver Model delivered in a group setting: 12 months clinical outcomes. Paper presented at the 10th Autism Europe Congress, Budapest, Hungary

#### October, 2013

Baker, E., Richdale, A. L., Short, M., & Gradisar, M. Sleep and Psychopathology in Adolescents with High Functioning Autism Spectrum Disorder. Paper presented at the Australian Sleep Association Conference, Brisbane

Richdale, A. L. Examining Family Demographics and Environmental Effects on Sleep in Children Aged 2-5 years with and without Autism Spectrum Disorder. Paper presented at the Australian Sleep Association Conference, Brisbane

#### November, 2013

AMAZE / ASD Research Forum, Melbourne

#### **Session 1: Early Presentation and Diagnosis**

**Grant, N.** Features of parent-child interaction style are more strongly associated when children have autism than in typical development.

**Hudry, K.** A longitudinal evaluation of parent-child interaction in the context of heightened risk for ASD.

Bent, C., Dissanayake, C. & Barbaro, J. Age of diagnosis of Autism Spectrum Disorders in Australia.

#### **Session 2: Co-Morbid Conditions**

**Vivanti, G.** Why do many children with ASD have an intellectual disability?

Richdale, A.L. Family demographic and environmental effects on sleep in children aged 2 to 5 years with and without Autism Spectrum Disorder.

Session 3: Physiological processes and socialemotional processing

Nuske, H., Vivanti, G. & Dissanayake, C. Pupillometry reveals reduced unconscious emotional reactivity in autism

#### **Session 4: Intervention**

McStay, R., Dissanayake, C. & Trembath, D. Raising a child with autism: A developmental perspective on family adaptation.

Dissanayake, C. Cooperative Centre for Living with Autism Spectrum Disorders (CRC).

#### March 2014

Dissanayake, C. Early identification of children with Autism Spectrum Disorders: Social Attention and Communication Surveillance. The 3rd International Autism Clinical and Research Collaboration Conference, Children's Hospital of Fudan University, Shanghai, China.



OTARC members and international researchers in Shanghai.



**April 2014** 

#### ISAM Putrajaya, Malaysia

Professor Dissanayake was invited by the Prime Minister of Malaysia to present a talk at 'The International Seminar on Autism, Malaysia 2014', which was jointly organized by the PERMATA Division of Prime Minister's Department, Ministry of Women, Family, and Community Development, Autism Speaks and Universiti Kebangsaan Malaysia. The theme was: "AUTISM IS NOT A TRAGEDY, IGNORANCE IS", with the main objective being to enhance awareness on Autism Spectrum Disorder in Malaysia. The patron of the meeting was the Prime Minister's wife Datin Seri Rosmah Mansor.

The conference was opened by the Prime Minister, Dato' Sri Mohd Najib Tun Abdul Rajak on 22 April, 2014. He announced a new program, the National Permata Kurnia Centre for 300 children with autism (2-6 years) in the capital, Kuala Lumpur, to be

opened in May 2015 under the Permata Division. The Prime Minister and his wife were accompanied by First Ladies from Albania, Republic of Sudan, Republic of Kyrgyzstan, Sri Lanka, and Morocco. Over 1800 delegates attended the two-day meeting with representation from many of the surrounding regions including Indonesia, Thailand, Philippines, Nepal, Bangladesh, and Sri Lanka.

Professor Dissanayake spoke on early identification and intervention for ASD, including parent-mediated intervention. Promoting global knowledge transfer is one of our objectives at OTARC, and participating in regional meetings such as this is important to promote evidence-based practices that serve to foster better outcomes for children with an ASD.

#### 14 - 17 May 2014

IMFAR – International Meeting for Autism Researchers, Atlanta, Georgia, USA

Richdale, A.L. The Impact of Demographics and Sleep Hygiene on Sleep in Children Aged 2-5 Years With and Without Autism Spectrum Disorder (ASD). (poster)

Davis, J., Richdale, A.L. & Cotton, S.M. Do ASD Symptoms at 2 Years Influence the Prediction of Childhood Sleep Problems and Anxiety from 2- to 8-Years? (poster)

**Uljarevic, M., Prior, M.** & Leekam, S.R. Sensory Problems in Parents of Children with Autism Spectrum Disorders (ASD). (poster)

Associate Professor Amanda Richdale participated at the Meet the Experts luncheons for PhD students and Postdoctoral Research Fellows, and co-hosted the Autism Sleep -Special Interest Group (SIG) meeting.

You can read an IMFAR Report on our Blog. http://otarc.blogs.latrobe.edu.au/international-meeting-for-autism-research-atlanta-usa/#more-3440

#### Grants

#### **Onoging Research Grants**

National Health and Medical Research Council
Partnership Grant (2011-2013) – Universal Surveillance
and Early Identification of Developmental Disorders
– V.Eapen, K.Williams, B.Jaludin, C.Dissanayake &
S.Woolfenden.

National Health and Medical Research Council Project Grant (2011-2015) – Prenatal and Early Postnatal Risk Factors in ASD – A.Whitehouse, M.Maybery, C.Dissanayake, M.Hickey & C.Pennell.

#### The Apex Foundation Trust for Autism (2012-2015)

 Circadian Rhythm Dysfunction in Adults with High-Functioning Autism Spectrum Disorder: Evidence from Dim-Light Melatonin Onset – PhD student award to E.Baker, supervised by A.Richdale & A.Hazi.

La Trobe University Research Focus Area 'Building Healthy Communities' (2013-2014) - Strengthening PlayConnect: Specialist playgroups for families of children with autism - Hudry, K., Dissanayake, C. & Sivey, P.

La Trobe University Research Focus Area 'Understanding Disease' Small Project Grants (2013-2014) - Investigating the Genetics of Co-morbid Anxiety and Insomnia in Autism Spectrum Disorder - Richdale, A., Somers, G., Hale, M., Lesku, J., Dissanayake, C. & Kent, S.

**Australian Wool Innovation (2013-2014)** - The influence of bedding, sleep hygiene and environment on sleep in children aged 2 to 10 years - **Richdale**, **A**.

The William and Vera Houston Memorial Trust (2013-2014) - Parenting and Child Outcomes: An exploratory study of the impact of autism symptoms - Dissanayake, C. & Richdale, A.

La Trobe University Faculty of Science, Technology and Engineering 'Near Miss' Grant – Dissanayake, C., Iacano, T., Vivanti, G., & Trembath, D.

National Health and Medical Research Council Project Grant (2013-2015) — Characterization of a novel epigenetic boundary and long range epigenetic modifications specific to FMR1 expansion carriers with behavioural and cognitive disorders — implications for earlier diagnosis and treatment. — H.Slater, D.Godler, D.Amor, C.Dissanayake & Q.Bui.

**Australian Wool Innovation (2013)** - Bedding and sleep quality in children aged 2 to 5 years - **A. Richdale.** 

R E Ross Trust (2012-2013) - Early Diagnostic Clinic for Autism Spectrum Disorders - C. Dissanayake and the EAC Team.

Phyliss Connor Grant (2012-2013) - Early Diagnostic Clinic for Autism Spectrum Disorders - C. Dissanayake and the EDC Team.

The William Buckland Foundation (2012-2015) - Early Diagnostic Clinic for Autism Spectrum Disorders - C. Dissanayake and the EDC Team.

Australian Research Council Linkage Projects Scheme (2012-2016) - Enhancing learning capacity and academic outcomes using novel game technology in primary school children with developmental disabilities - Cornish, K, Gray, K, Hocking, D, Ellis, K, Harcourt, J, McIntosh, K.

#### **New Research Grants**

Playgroup Australia (2014-2015) - Strengthening PlayConnect: Expert Advice and Current Service Evaluation - Hudry, K., Nadachowski, W. & Dissanayake, C.

National Health and Medical Research Council Early Career Fellowship (2014-2016) - Improving Treatment Outcomes for Children with Autism: Translating Intensive 1:1 Treatment into a Group-Based Community Model - Trembath, D.

Menzies Foundation (2014) - The Menzies Foundation Symposium on Early Identification, Diagnosis, and Intervention in Autism Spectrum Disorders and Keynote Lecture at the Australasian Society for Autism Research (ASfAR) Conference - Barbaro, J.

La Trobe University Research Focus Area 'Building Healthy Communities' (2014-2015) - Translating Autism Research Excellence to a Regional Service though Telehealth - Iacono, T., Hudry, K., Hulme-Chambers, A., Erickson, S., Trembath, D. & McConnachie, S.

Macquarie University Research Development Grants (2014-2015) - The role of oxytocin in modulating anxiety and social behaviour in neurodevelopmental and anxiety disorders - Porter, M., Hocking, D., Wong Q., Williams, M., Rapee, R., Dissanayake, C., Kent, S.

Autism CRC Core Program 1 (2014-2017) - Project 1.001RC, Base Resources Project - Whitehouse, A., Dissanayake, C., Eapen, V. & Heussler, H.

Autism CRC Core Program 1 (2014-2015) - Project 1.002RC, Creation of Autism Biobank Project - Whitehouse, A., Dissanayake, C., Eapen, V. & Heussler, H.

Autism CRC Core Program 1 (2014-2017) - Project 1.005RC, Developmental Surveillance for ASD. Dissanayake, C. & Barbaro, J.

Autism CRC Core Program 3 (2014-2017) - Project 3.012RC, Base Resources Project. – Richdale, A., Falkmer, T., Lennox, N. & Troller, J.

Autism CRC Core Program 3 (2014) - Project 3.017RC, Optimisation of Recruitment Project. – Costley, D., Clarke, T., Richdale, A., Falkmer, T., & Sofronoff, K.

Autism CRC Core Program 3 (2014) - Project 3.016RC, Unique ASD Profile School Leavers. - Richdale, A., Falkmer, T., Lennox, N. & Troller, J.

A complete list of grants can be found at http://www.latrobe.edu.au/otarc/research/grants

#### **OTARC** Meetings

#### **Research Seminars**

OTARC, staff and students meet monthly to hear about and discuss the latest research. Presentations are given by OTARC staff and students, as well as external invited guests.

#### Lab Meetings

OTARC students meet monthly with the Laboratory Manager, Carmela Germano, and relevant staff, to address their ongoing work and research needs.

#### **Staff Meetings**

The formal staff meetings which used to be held monthly are now held fortnightly, given our increase in research capacity and other service engagements. Informal staff meetings occur frequently through each week as required to discuss administration and research ideas, directions and needs. This enables us to foster our collaborative research initiatives around particular projects.

#### The OTARC Advisory Committee

This committee (see Page 41) meets three times each year to assist in guiding the direction and operation of the Centre.

## Objective 2

#### Facilitate collaboration with other research centres, both nationally and internationally

Our international and national collaborations continue to grow as the Centre expands and also as a result of hiring international scholars. In addition, the commencement of the Autism CRC has resulted in a number of new projects with colleagues from Curtin University, University of Western Australia, University of New South Wales and the University of Queensland. We also continue to attract new visitors to the Centre, including an increasing number from the Asia-Pacific region. In addition, our own staff visit other researchers and research centres as indicated below.

#### **International Collaborators**

**Dr Sander Begeer**, Developmental Psychology, VU University Amsterdam, The Netherlands

**Professor Tony Charman**, Centre for Research in Autism and Education, Institute of Education, University of London, UK

**Dr Mayada Elsabbagh**, Department of Psychiatry, McGill University, Montreal, Canada

**Professor Jonathan Green**, School of Medicine, University of Manchester, UK

**Dr Teodora Gliga**, Centre for Brain and Cognitive Development, Birkbeck, University of London, UK

**Professor Pat Howlin**, Institute of Psychiatry, King's College, London, UK

Professor Mark Johnson, Centre for Brain and Cognitive Development, School of Psychology, Birkbeck College, London, UK **Professor Emiko Kezuka**, Gunma Prefectural Women's University, Japan

**Dr Joanna Kwasiborska-Dudek**, Speech Therapist (Adesse) and Lecturer, Department of Speech Therapy, Academy of Special Education, Warsaw, Poland

**Professor Ann Le Couteur**, Institute of Health and Society, Newcastle University, UK

Professor Sue Leekam, Chair of Autism Research, The Wales Autism Research Centre, Cardiff University, UK

**Dr Liu**, Director of Child Health, Tiangin Women and Children's Health Centre, Tiangin, China

**Dr Iliana Magiati**, Department of Psychology, National University of Singapore, Singapore

Professor Beth Malow, Dr Blythe Corbett and Dr Suzanne Goldman, Kennedy Center, Vanderbilt University. Nashville. USA

**Professor Helen McConachie**, Institute of Health and Society, Newcastle University, UK

Professor Filippo Muratori, Scientific Institute Stella Maris, University of Pisa, Calambrone, Italy

**Dr Greg Pasco**, Centre for Research in Autism and Education, Institute of Education, London, UK

**Professor Andrew Pickles**, Institute of Psychiatry, King's College, London

Professor Sally Rogers, MIND Institute, University of California. Davis in Sacramento, USA

**Dr Kimberley Schreck**, School of Behavioral Sciences & Education, Pennsylvania State University, Harrisburgh, USA

**Dr Vicky Slonims**, Guy's and St Thomas' Hospital, London

Professor Sook Whan Cho, Sogang University, South Korea

**Dr Margaret Souders**, University of Pennsylvania School of Nursing, Philadelphia

**Professor Elizabeth Starr**, Faculty of Education, University of Windsor, Ontario Canada

**Dr Laurie Vismara**, MIND Institute, UC Davis in Sacramento, USA

**Dr Ming Wai Wan**, School of Medicine, University of Manchester, UK

Associate Professor Chongying Wang, Director of the Center for Behavioural Science, Medical School, Nankai University, Tianjin, China

**Dr Kent Williams**, Nationwide Children's Hospital, Columbus, Ohio, USA

#### **National Collaborators**

Ms Kate Bowen, Liverpool Hospital, Sydney

Professor Valsamma Eapen, Chair of Infant, Child and Adolescent Psychiatry, University of New South Wales

**Professor Torbjorn Falkmer**, School of Occupational Therapy and Social Work, Curtin University

**Dr Michael Gradisar**, Faculty of Social and Behavioural Sciences, School of Psychology, Flinders University

**Dr Evan Kidd**, Department of Psychology, The Australian National University

**Professor Murray Maybery**, University of Western Australia

**Dr Mark Nielsen**, Department of Psychology, University of Queensland

Dr Jess Paynter, AEIOU Foundation, Queensland

**Dr Melanie Porter**, Department of Psychology, Macquarie University

**Dr Michelle Short**, Centre for Sleep Research, University of South Australia

Associate Professor Leanne Togher, Faculty of Health Sciences, University of Sydney

Associate Professor Julian Trollor, Chair of Intellectual Disability Mental Health, Head, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, University of New South Wales

Professor Andrew Whitehouse, Telethon Kids Institute, University of Western Australia

#### **Victorian Collaborators**

Dr Minh Bui, University of Melbourne

**Dr Susan Douglas**, Department of Linguistics, University of Melbourne

**Dr David Godler**, Professor Howard Slater & Associate Professor Lesley Bretherton, Murdoch Children's Research Institute, University of Melbourne

**Dr Diane Jacobs**, Department of Speech Pathology, Australian Catholic University

**Dr Jordy Kaufman**, Swinburne Brain Sciences Institute, Swinburne University of Technology

Associate Professor Lesley Stirling, Department of Linguistics, University of Melbourne

**Dr Cathy Marraffa, Professor Katrina Williams** and **Professor Jill Sewell** at the Royal Children's Hospital, Centre for Community Child Health and Department of Developmental Medicine

Ms Karen McKinnon, Ms Chris Stocco and Ms Kathleen Franks, Autism Partnerships

#### Collaborators at La Trobe University

**Dr Edith Bavin**, School of Psychological Science, La Trobe University

**Dr Matthew Hale**, School of Psychological Science, La Trobe University

**Dr Alana Hulme Chambers**, School of Social Work and Social Policy, La Trobe University

Professor Teresa Iacono, Head of La Trobe Rural Health School, La Trobe University

Associate Professor Stephen Kent, School of Psychological Science, La Trobe University

**Dr John Lesku**, Department of Zoology, La Trobe University

**Dr Danuta Loesch**, School of Psychological Science, La Trobe University

**Associate Professor Seng Loke**, Engineering and Mathematical Sciences, La Trobe University

**Dr Peter Sivey**, School of Economics, La Trobe University

**Dr Greg Somers**, Institute of Molecular Science, La Trobe University

**Dr Torab Torabi**, School of Computer Science, La Trobe University

#### Visitors to our Centre













Professor Alan Reiss, Professor Emiko Kezuka, Dr Elisa Hill, Dr Joanna Kwasiborska-Dudek, Ms Joanna Granich and Professor James Reha,

#### **July 2013**

Professor Kyung-Sook Lee from Hanshin University, South Korea, discussed further research and implementation of SACS in South Korea with Dr Josephine Barbaro.

Assistant Professor Saqib Ali from the Department of Information Systems, College of Economics and Political Science, Sultan Qaboos University, Sultanate of Oman met with Professor Cheryl Dissanayake and Dr Elfriede Ihsen to discuss OTARC's involvement in developing research strategies and diagnostic and treatment services for ASD in the Sultanate of Oman.

**Dr Paul Swan** from Australian Wool Innovation visited Associate Professor Amanda Richdale to discuss a research project to evaluate bedding options for children.

**Dr Joanna Kwasiborska** from Poland spent time at OTARC and the Margot Prior Wing to undertake further training on the Early Start Denver Model and to discuss her findings on the SACS-Poland.

#### August 2013

Professor Tony Charman (Chair of Clinical Child Psychology, King's College, London, UK) - visited OTARC and participated in discussions about research with OTARC staff and students.

**Dr Elisa Hill** from the University of Melbourne spoke at our monthly seminar. Her presentation was entitled "Autism in the gut."

**Jenni Montgomery** from the Australian Bureau of Statistics met with Associate Professor Amanda Richdale to discuss employment of adults with ASD.

#### September 2013

Professor Emiko Kezuka from Gunma Prefectural Women's University in Japan spent two weeks at OTARC working on a collaborative project on social attention with Professor Cheryl Dissanayake and Dr Josephine Barbaro. They also discussed data collected as part of the Social Attention and Communication Surveillance project implementation in Tanaka, a small region in Gunma.

**Dr Valentina Postorino** visited from the Istituto di Ricovero e Cura a Carattere Scientifico (I.R.C.S.S.) Children's Hospital 'Bambino Gesu', Rome. Dr Postorino worked with Dr Giacomo Vivanti to design cross-cultural studies for data collection in Australia and Italy.

#### October 2013

Shannon Eeles, CISCA
Debra Goldfinch, Irabina
Robyn Hawkins, Little Souls Taking Big Steps,
Goldcoast
Anne Houghton, RMIT Lecturer in Early Childhood
Education
Anna Rigoni, Principal Northern School for Autism
Christine Stocco, Autism Partnerships
Sylvia Walton, Former La Trobe Chancellor, now on
OTARC Advisory Committee

These visitors formed part of a specially organized tour

of the Victorian Autism Specific Early Learning and Care Centre (ASELCC) and OTARC.

Professor Ann LeCouter visited from Newcastle University in the UK to co-facilitate the ADOS-2 course run by Dr Kristelle Hudry from 30th September to 3rd October. Professor LeCouter is Professor of Child and Adolescent Psychiatry, and an expert in the field of ASD diagnosis, and was one of the developers of another important diagnostic tool, the Autism Diagnostic Interview – Revised (ADI-R). Whilst here for the ADOS course, Professor Le Couteur very generously gave of her time to speak to staff and students of OTARC and participated in an episode of Inside the Lab with Dr Hudry and Amanda Golding.

#### December 2013

Professor James M. Rehg from the School of Interactive Computing at the Georgia Institute of Technology visited. He is the Director of the Center for Behavior Imaging, co-Director of the Computational Perception Lab, and Associate Director of Research in the Center for Robotics and Intelligent Machines. Professor Rehg presented a talk on Behavior Imaging in the Study of Autism.







Adjeng Sukesmi, Karmela Eka Putri and Sri Dianti

#### Visitors to our Centre continued

#### February 2014

Jana Goldberg joined OTARC for three months to complete her research for a Masters degree at the Department of Special Education, San Diego State University in California under the supervision of Professor Laura Hall. During her stay in Melbourne, Jana worked with Professor Cheryl Dissanayake and Dr Josie Barbaro to investigate behavioural differences between children who met criteria for ASD at 24 months of age, but no longer did so at follow-up at 48 months, and those who continued to meet criteria for ASD at 48 months.

#### **April 2014**

Joanna Granich from the Telethon Kids Institute, University of Western Australia visited OTARC and the Victorian Autism Specific Early Learning and Care Centre (ASELCC). She was interested in learning about the ESDM program offered at the ASELCC and the ASD Early Assessment Clinic at OTARC. She spoke with Ed Duncan, Dr Giacomo Vivanti, and Dr Josephine Barbaro.

**Jessica Reeve** from Macquarie University NSW visited Dr Darren Hocking to collaborate on a research project.

#### May 2014

Visitors from Indonesia: Sri Dianti, Head of Education Division Karmela Eka Putri, Program Manager Adjeng Sukesmi, Treasurer These visitors are from a school for about 25 children with Autism Spectrum Disorder, which is located in Bogor (about 60 km south of Jakarta), West Java Province, Indonesia.

The school is operated by a family-initiated not-for-profit organisation – The Special Family Foundation Indonesia, incorporated in 2005. They were accompanied by **Dr Hugh Stewart**, Director of International Programs, the Rotary Club of Flemington, which sponsored their stay in Melbourne.

Professor Allan Reiss from Stanford University, USA, gave a special presentation entitled 'Shifting Sight Lines in Developmental Neuropsychiaty: Frome DSM to Brain Disease' during his visit to La Trobe University. Professor Reiss was accompanied by his wife, Dr Lynne Huffman, Associate Professor of Paediatrics, also at Stanford University. Dr Darren Hocking hosted Professor Reiss' tour of the OTARC research facilities and the ASELCC during their visit.

Yagmur Ozturk arrived to study at OTARC for six months. She is a second-year PhD student in the Psychological Science and Education at the University of Trento, Italy. She has a Bachelor's degree in Psychology from the University of Istanbul and a Master degree in Cognitive Neuroscience from the University of Trento. Yagmur's project focuses on stress of mothers and fathers of children with ASD using behavioral and physiological measures.

#### OTARC Folk Out & About

#### Mayoral Mission to China

Professor Cheryl Dissanayake and OTARC's Senior Advisor, Operations and Projects, Mr Wojciech Nadachowski, travelled to China in March 2014. They joined the Lord Mayor of Melbourne, Robert Doyle, and his team on a Mayoral Mission to visit Melbourne's sister city Tianjin. The reason for the mission was to build on and support the work already undertaken with the team in Tianjin (see Objective 6) by establishing a Tianjin-Melbourne Autism Centre of Excellence, for which an MOU was signed on 27 March 2014 with the proposed partners being La Trobe University, Nankai University and the Tianiin Women and Children's Health Centre. OTARC will act as a knowledge partner in this venture. A Round Table was also held at Nankai University (see photo) at the School of Medicine with all partners represented, including the Lord Mayor. Professor Dissanayake spoke to the group about the joint work already undertaken to promote the early identification of ASD in Tianjin using the SACS. It is hoped that through the mission, funds will be allocated by the Tianjin Government to establish the proposed Autism Centre of Excellence.



### Dr Nusrat Ahmed visits the Central Asian Autism Network in Tajikistan

Dr Nusrat Ahmed, ASD Specialist at the Victorian Autism Specific Early Learning and Care Centre and the Early Assessment Clinic, was invited to the three-day Central Asian Forum "Autism Problems and Solutions" that was held from 5th to 7th February in Dushanbe, Tajikistan. The forum was jointly supported by The Association for Civil Society Development (ARGO) Kazakhstan and USAID. The Central Asian Autism Network (CAAN) is a parent-led initiative and consists of groups in three countries of Central Asia: Tajikistan, Kazakhstan and Kyrgyzstan.

At the forum, Dr Nusrat shared her experience of working with children with ASD in Bangladesh and Australia and spoke of recent advancements in early screening and diagnosis of ASD and early intervention for children with ASD and their families.

Dr Nusrat also participated on policy dialogue with representatives of the Ministry of Health and Education (MOH), doctors, teachers, specialists and parents from Tajikistan, Kazakhstan and Kyrgyzstan. The results of the forum have led to long-term commitments of cooperation from the MOHs and WHO, for the promotion and improvement of early screening and diagnosis of ASD, as well as early intervention programs for children with ASD and their families.



Training at the Central Asian Autism Network.

## Objective 3

Foster and support a National Research Network investigating the cause and management of ASD.



Our involvement in the Autism CRC has brought two post doctoral fellows to OTARC, Dr Heather Nuske and Dr Mirko Uljaravic. We also have two new PhD students (Stacey Rabba and Ru Cai) working on CRC projects with us as well as two new Research Assistants (Melanie Muniandy and Lahna Bradley). We are working closely with our national colleagues in building capacity in early behavioural developmental surveillance for ASD, in collecting genotypic and phenotypic data of affected children and their parents. and in engaging adults with ASD in research as well as researching the unique profile of school leavers with an ASD. In addition, together with our Western Australian colleagues, we are developing a Graduate Certificate in Identification and Diagnosis of ASD to be rolled out at the University of Western Australia in 2015 and at La Trobe University in 2017. OTARC will host the inaugural CRC Scholar Meeting at La Trobe University on December 3.

More details about the CRC are available at www.autismcrc.com.au



The Australasian Society for Autism Research (ASfAR) is a member based organization devoted to advancing knowledge about Autism Spectrum Disorders (ASDs) through research and scholarship. The membership currently exceeds 200, with new members joining weekly.

OTARC will host the second biennial ASfAR research conference in Dec (4 - 5) at La Trobe University alongside the inaugural CRC scholar event on Dec 3 and a CRC Board Meeting on Dec 4. We have secured recognized international speakers including Professor Cathy Lord, Dr Andy Shih and Professor Patricia Howlin.

More details about ASfAR are available on the website: asfar. org.au

#### **Executive Committee**

Professor Katrina Williams (Chair)
Professor Cheryl Dissanayake (Co-chair)
Dr Trevor Clark (Secretary/Treasurer)
Professor Deb Keen
Associate Professor Andrew Whitehouse
Associate Professor Mark Stokes
Dr Jon Brock
Ms Clare Holmes (postgraduate student member)
Ms Sandra Devaraj (Secretariat)

## Objective 4

Conduct campaigns to improve the public profile of autism research, thereby attracting additional research funds via grants and donations.

## Talking ASD Research: Inside the Lab

This year we increased our digital presence in a new and exciting form by launching a talk show that focusses on news and developments in ASD research. These episodes are available on our blog (www.otarc. blogs.latrobe.edu.au), with accompanying show notes, documents and links available on each episode's blog post.

For each episode of 'Inside the Lab' selected OTARC staff discuss current issues in ASD research and/ or practice with at least one external contributor. For several of this year's episodes we have invited rearchers from around the world to give us their inside knowledge on questions they are focusing on. Other episodes feature parents, teachers, clinicians, and other community-based professionals who help us to understand the impact of research as well as to ascertain their priorities. By using a 'talk show' format we hope to make this information more accessible.

## Inside the Lab – Episode 1: Separating Autism and Intellectual Disability

Dr's Giacomo Vivanti and Cynthia Zierhut discuss the boundaries of autism and intellectual disability and the impact of intervention on the expression of each in young children.

## Inside the Lab – Episode 2: Stakeholder driven research.

Dr Kristelle Hudry, Ms Amanda Golding (AmaGol Services, Victoria) and Professor Ann Le Couteur (Newcastle University, UK) discuss recent news and developments in Autism research. Topics covered include the Autism Diagnostic Observation Schedule (ADOS), the Autism Research Policy Hub developed by the Wales Autism Research Centre in Cardiff, issues facing adults, stakeholder driven research, the Autism CRC, and a database for children with autism spectrum disorder living in the north east of England.

#### Inside the Lab - Episode 3: Autism in China

Professor Cheryl Dissanayake, Dr Josephine Barbaro and Associate Professor Chongying Wang (Nankai University, Tianjin, China) discuss the state of autism in China and the implementation of early identification using the SACS in Tianjin, while also comparing the SACS with other tools such as the M-CHAT and CHAT-23 used for screening purposes elsewhere. Related topics include training medical professionals in Tianjin, the tension between research and practice in the developing and developed world, the influence of cultural differences and the one-child policy on identification, public awareness, and the need for Global Knowledge Transfer.

## Inside the Lab – Episode 4: Research into Early Interventions

Dr Kristelle Hudry, Dr Giacomo Vivanti, Dr John McEachin (Autism Partnerships Australia) discuss the development and trends of research into early intervention. Topics include the neurodiversity vs intervention debate, barriers to research on interventions, the historical tendency to focus on high functioning autism, the lack of understanding about how children learn, and the challenges of implementing randomised control trials in community settings.

#### Inside the Lab - Episode 5: Focus on Adults

Associate Professor Amanda Richdale, Dr Janine Mangiviona (Clinical Psychologist, Melbourne) and Dr Debra Costley (Autism Spectrum Australia – ASPECT) discuss the developments in research focusing on adults with ASD, findings from ASPECT's 'We Belong' study, the shortage of clinical services for adults, challenges for diagnosis, influence of co-morbid conditions, and the importance of relationships, social connections and support for the ability to gain and keep employment, and to live independently. Further discussions focus on greater end-user engagement and the Autism CRC.

#### **OTARC Podcasts and Blog**



In addition to launching 'Inside the Lab', we have also increased dissemination of autism research using podcasts via iTunes U, with over 79,000 downloads to date. As a result, we have been featured twice on the iTunes U homepage.

We also disseminate our research findings and other news about ASD research and services in our OTARC Blog, which can be accessed via out website. It incorporates a number of articles and staff interviews, as well as our quarterly Newsletter 'Another Piece', which now attracts 5000 subscribers.

The 10 most popular articles downloaded from our Blog were:

- 1. Why do many children with ASD have an intellectual disability? (by Giacomo Vivanti)
- 2. Frame of Mind exhibition.
- Why is learning difficult for children with ASD? (by Giacomo Vivanti)

- 4. New show looking at developments in autism research. Inside the Lab Episode 1.
- A family's experience of diagnosis and participating in research in SACS.
- Early identification of Autism Spectrum Disorders: Why it's important and why we need to have this conversation with parents (by Dr Josephine Barbaro)
- Choosing a school for a child with ASD. (by Professor Margot Prior)
- 8. Are gluten free diets helpful as a treatment for ASD? (by Dr Catherine Marraffa, Royal Children's Hospital)
- Emotional Reactions of children with ASD. (by Heather Nuske)
- Autism Spectrum Disorder in Girls (by Dr Rucha Joshi)

In addition, a blog post written for Open Forum by Dr Nancy Sadka was ver popular. Its title is 'Bound Together: Research shows that children with Autism are attached to their parents'.

#### "Ask a Researcher" Service

Our Ask a Researcher online service continues to be popular. Questions typically come from parents and professionals.

The following questions and associated answers were published in our newsletter, because of their potential public interest.

- Are gluten and casein-free diets helpful as a treatment for Autism Spectrum Disorder? – by Dr Catherine Marraffa
- Behaviour Changes during a Fever by Dr Elfriede Ihsen
- Should I use melatonin to aid my daughter's sleep?
   by Associate Professor Amanda Richdale
- Can a child with ASD manage using more than one language? by Dr Kristelle Hudry
- Do Children with ASD "hear voices"? by Dr Elfriede Ihsen.

#### Media Activities

We also advocate for research by using print, radio, television and social media. The number of our FACEBOOK 'friends' increased to 1465 this year, and we have many followers on Twitter.

The following OTARC staff were interviewed during the year:

#### **July 2013**

 Professor Cheryl Dissanayake was interviewed about the OTARC Autism Research Forum streaming to La Trobe University, Bendigo campus, on Breakfast Radio by Fiona Parker (594 ABC Western Victoria - Bendigo)

#### August 2013

 Professor Dissanayake was interviewed by Anna Salleh for the 'ABC News in Science' article Genetic 'signature' highlights autism risk

#### September 2013

 Dr Jospehine Barbaro was interviewed by Heather Jacobs for an article on the SACS study for Australia Unlimited - Understanding Autism

#### October 2013

 Associate Professor Amanda Richdale was interviewed by Kate Hagan for an article entitled Screen time link to insomnia in young children that appreared in The Melbourne Age, Sydney Morning Herald and Essential Mums  Associate Professor Amanda Richdale was interviewed by Perth Radio Noongar on sleep, TV and computer use in young children.

#### November 2013

- Professor Cheryl Dissanayake for MOJO News -Alana Mitchellson reports, More resources needed for the Autistic. This feature also included interviews with Murray Dawson-Smith (AMAZE), Amanda Golding and Meredith Ward (AFSA).
- Associate Professor Amanda Richdale was interviewed by Paula Goodyer from the Sydney Morning Herald for the article Television can be a sanity-saver for parents, but how much is too much for young children?.
- Dr Josephine Barbaro was interviewed by Richard Stubbs from 774 Melbourne Radio, about her research in the SACS program.

#### December 2013

- Professor Cheryl Dissanayake was interviewed by Kimberley Gillan from the NineMSN - Health program for a feature on Love hormone Oxytocin makes kids with autism more social.
- Professor Cheryl Dissanayake was interviewed by John Ross for The Australian for the article Bacteria hope for action on autism. She warned that the findings would fuel advocates of diet therapies for autism, "for which there is still no evidence base".

- Professor Cheryl Dissanayake commented on the treatment and reporting of Probiotics a potential treatment for Autism? in the AUS/SMC – Australia Science Media Centre - Round Up
- Dr Josephine Barbaro was interviewed by Michael Rowland and Beverly O'Connor for ABC Breakfast TV about her technique for identifying ASD in children as young as 12 months - Eye contact, gestures used to help detect autism in babies.

#### January 2014

 Dr Josephine Barbaro was interviewed by Shivali Nayak for ABC News Networks - Researchers implement program in China that allows for early detection of autism.



 Dr Josephine Barbaro took part in La Trobe University's 'Big FAT Ideas' - Transforming the Early Identification of Autism.

#### February 2014

 Professor Cheryl Dissanayake was interviewed by Clare Kermond for The Sunday Age - EXTRA - on the popularity of Lego clubs for children with ASD - Fairfield Lego club Inside the Brick helps children with autism to build bridges.

#### March 2014

 Associate Professor Amanda Richdale was interviewed by Kaitlyn Opie for the Sunraysia Daily about the influence of bedding, sleep hygiene and environment on sleep - Study into Sleep: Parents asked to take online survey.

#### May 2014

- Associate Professor Amanda Richdale was interviewed for Health Naturally Magazine about the influence of bedding, sleep hygiene and environment on sleep - Your Child's Sleep is Important.
- Associate Professor Amanda Richdale and others contributed to an online article (edited by Leigh Haye) for the Australian Scholarships Group website. Autism. What is it?

#### June 2014

- Professor Dissanayake was interviewed for NineMSN Autism could be caused by higher hormones in the womb.
- Professor Dissanayake was interviewed by Channel Nine News about a study reporting a link between stress during pregnancy and symptoms of autism in the child.

#### **Donations**

A total of \$534,761.00 was received in donations.

### **Organisations**

The Quality of Life Foundation (via the Fishing Rod Foundation)

KD Johns and Co Pty Ltd (via the Fishing Rod Foundation)

The Carman Family Trust (via the Fishing Rod Foundation)

SP Charitable Foundation (via the Fishing Rod Foundation)

Autistic Family Support Association Taj Bear Foundation

#### **Individuals**

Olga Tennison Wendy Kozica Sylvia & Robin Walton Bequest from the Estate of Mr Giacinto Gilberti Maryon Walters Anonymous Carmelo Imbesi

### Everyday Hero fundraisers

This year several of our students and friends raised funds for OTARC via Everyday Hero.

Cathy Bent, a OTARC PhD Candidate, participated in a Half Marathon in October 2013 and raised \$605.00 Donors:

- Prof Cheryl Dissanayake
- Miss Eleanor Bent
- Mrs Mary Bent
- Mr Peter Bent
- Lucy Daley
- Cathy Bent
- Catherine Murphy
- Tanya Kilgower
- Miss Jillian Crane
- Dr Elfriede Ihsen



Josie Toscano, a Friend of OTARC, participated in the City2Sea run in late 2013 and raised \$1640.00 Donors:

- Ms Tessa Dobson
- Mrs Leanne Gelemanovic
- Mrs Tania Vescio
- Ms Catherine Wade
- Ms Imogen Caruso
- Mr Christopher Grieco
- Mrs Cathy Sala
- Mrs Susan Conduit
- Miss Avril Hill
- Dr Elfriede Ihsen
- Mrs Julia Agrimi
- Prof Cheryl Dissanayake
- Mr Vince Tarallo
- Miss Teresa Vescio
- Ms Josephine Mercuri
- Ms Lucy Sacino
- Miss Kiara Grieco
- Mrs Tamara Vescio
- Ms Pina Scicluna
- Ms Emma Zito
- Mrs Nicky Vejanovski
- Mr Peter Vescio

Amelia and Andrew, Friends of OTARC, celebrated their engagement in late 2013. Instead of presents they asked thier guests to make a donation to OTARC. They raised \$3239.00

#### Donors:

- Mr Ralph Tarallo
- Mrs Deborah Johnson
- Mr Andrew Johnson
- Mrs Sarah Evans
- Mrs Christine Paterson
- Mrs Lark Bushby
- Mr David McCarthy
- Ms Lisa Cusmano
- Mrs Carol Haves
- Miss Samantha Greaves
- Mr Nicholas Maxsted
- Miss Gemma McKechnie
- Miss Stephanie Ringwood
- Mr Jeremy Payne
- Mr James Trethewie
- Mrs Jill Smith
- Mr John Knoll
- Mr Dave Harry
- Mr Andrew Paterson
- Mr Geoff Saunders
- Mr Nicholas Hill

OTARC sends our heartfelt appreciation to all the donors who supported Cathy, Josie, Amelia and Andrew's fundraising events.

#### Volunteering at OTARC

OTARC's database features 184 people who are willing to help volunteer in various capacities at OTARC. They are contributing their knowledge and skills in data entry, event planning, research support, and data verification. We utilise volunteers throughout the year for a variety of activities.

We are grateful to the following volunteers who helped in the planning and execution of the July 2013 OTARC Autism Research Forum and other activities at La Trobe University, Bundoora.

Peter Johansen Kenzo Low Lachlan West Melanie Muniandy Matthew Digby Joanne Ferraro Christine Antoniou Roseanne Currie Parise Gentikoglou Shakuntla Gondalia Perry Varol Alara Karayalcin Nicole Young Heather Nuske Emma Baker Megan Clark Megan Grant Kat Crea Cathy Bent



Matthew Digby and Megan Clark helping at the Research Forum in 2013.

Airlie Hamlyn
Ayesha Maharaj
Katherine Bastin
Catherine Van Remmen
Tim Walker
Carla McEnery
Jackie Maya
Jessica Day
Oda Steensaeth
Courtney Daly
Reuel Del Rosario
Nathasia Brail
Lily Qiao Li
Aarabi Raveendiran

Anna-Maria Pertile
Amber Yu Shi
Mahwish Chaudry
Rebecca Kam
Parise Gentikoglou
Joanne Ferraro
Christina Antoniou
Matthew Digby
Akanesi Akapusi
Alanie Angelucci
Elena Dierickx
Jenny Bott
Daniel Berends

Yogi Khosugi

## Objective 5

### Provide opportunities for student based research and early career mentoring programs

In 2013/14 we had 20 students (Honours, Masters, Doctoral, and PhD candidates) undertaking their research at the centre. Twelve students successfully completed their studies in the last twleve months.

#### Postgraduate students

#### **PhD Candidates**

**Emma Baker** - The role of melatonin in sleep disorders in individuals with an Autism Spectrum Disorder.

Cathy Bent - What are the barriers and enablers to the early identification of Autism Spectrum Disorders in Australia?

Megan Clark - An investigation of school age outcomes of children diagnosed with an Autism Spectrum Disorder at 24 months.

**Stacey Rabba** - Parental support following early diagnosis.

**Kitty Wan** - Investigating cortisol and oxytocin in young children with Autism Spectrum Disorders.

#### **Doctor of Clinical Psychology Candidates**

**Katherine (Kat) Crea** - Longitudinal study into the mental health and emotional development in toddlers at high risk for Autism Spectrum Disorders by virtue of having an older sibling with the diagnosis.

**Megan Grant** - Wellbeing in parents around the time of child ASD diagnosis.



**Rebecca Kam** - Investigating the effects of bilingual exposure on learning and development in children with Autism Spectrum Disorders.

**Nicole Porter** - The impact of dual language exposure on language and communication in children with Autism Spectrum Disorders.

**Zoe Vinen** - School-aged outcomes of children who received early intervention using the ESDM.

#### **Doctor of Clinical Neuropsychology Candidate**

Peter Fanning - Understanding Intellectual Disability in Autism Spectrum Disorders and idiopathic Intellectual Disability.

**Kavi Jayasinghe** - Concept formation, repetitive and sensory behaviours, and stress-response in children with an Autism Spectrum Disorder.

#### **Masters of Clinical Psychology Candidates**

**Stephanie Mertins** - Diet and Autism Spectrum Disorder.

#### **Honours Candidates in 2014**

Claire Ellul - Mapping the 2 year developmental trajectories of children attending the Victorian ASELCC.

Ashlee Hancock - A longitudinal follow-up on the diagnostic outcomes of children seen at La Trobe's Early Assessment Clinic for Autism Spectrum Disorders.

**Jackie Maya** - Parental coping and acceptance of a recent ASD diagnosis in their young child.

**Deniz Özbilgin** - The interplay between motor control and social cognitive outcomes in children with ASD.

**Danielle Smith** - Identifying the predictive factors of outcomes in the Early Start Denver Model 24 months post-treatment.

**Danielle Soliman** - The influence of restricted behaviours, anxiety and intolerance of uncertainty on sleep in adults with ASD.

Alexandra Woollacott - Parental bilingualism and childhood ASD: Impacts on synchrony during parent-child interaction.

#### Successful Completions in 2013 - 2014

#### **PhD Candidates**



Rucha Joshi - A longitudinal study of gender differences in the early development of girls and boys with an Autism Spectrum Disorder from infancy to their early childhood years, with a specific emphasis on the developmental profiles of girls.



Heather Nuske - Emotional reactivity in young children with an Autism Spectrum Disorder (aged 2-5 years), using eye tracking technology.

#### **Doctor of Clinical Psychology Candidates**

**Rebecca McStay** - A developmental perspective on family adaptation to a child with an Autism Spectrum Disorder.

**Lisa Rumney** - The effects of non-native language use on parent-child interaction style in dyads with Autism Spectrum Disorders.

#### **Masters of Clinical Psychology Candidates**

**Mahwish Chaudry** - A longitudinal investigation of developmental changes in pretend play in children with an Autism Spectrum Disorder.

Natalie McKay - Factors associated with educational placement of children with Autism Spectrum Disorder during or following Early Intensive Behavioual Intervention (EIBI).

Successful Completions continued

#### **Honours Students 2013**

**Suzana Cunha** - Bilingualism and Autism Spectrum Disorder.

Sandra D'Souza - Predictors of outcomes in from age 2 to 4 years in children with an Autism Spectrum Disorder.

Susana Medina - Sleep in Autism Spectrum Disorder.

**Janette Rees** - Emotional development and wellbeing in high-risk siblings of children with an Autism Spectrum Disorder.

**Veronica Rose** - Visual attention and Key Word Sign acquisition in children with Autism Spectrum Disorder.

**Jacqueline Uren** - Sleep and Psychopathology in Autism Spectrum Disorder.

**Nicole Young** - From Social Referencing to Social Learning.

## Visiting early career researchers and postgraduate students

We also provide the opportunity for early career researchers and postgraduate students from overseas to come and work in our Centre. Over the past year we had the pleasure of welcoming one post doctoral fellow and two postgraduate students.

Dr Valenina Postorino.
Ms Jana Goldberg
Ms Yagmur Ozturk (still with us until November)

See Visitors to our Centre, Pages 16 - 17





Dr Valenina Postorino. Ms Jana Goldberg



Ms Yagmur Ozturk

## Objective 6

## Foster knowledge transfer to practitioners within the field

We have engaged in numerous activities throughout this year to transfer knowledge to practitioners in the field, and to the community in general.

#### ADOS Training with Dr Kristelle Hudry and Professor Ann Le Couteur

#### **January 21-25**

Dr Kristelle Hudry has continued to run training courses, twice per year, on the Autism Diagnostic Observation Schedule – 2nd edition (ADOS 2). The ADOS 2, considered the gold-standard observational assessment for the diagnosis of Autism Spectrum Disorders, provides a rigorous, evidence-based method of coming to a diagnostic decision. ADOS 2 courses are run for researchers and medical/allied health professionals, and the demand for places on Dr Hudry's ADOS courses has grown steadily since they were first offered at OTARC in 2011. Waitlist numbers far exceed our capacity to offer places on each course.

Recent courses were held in September 2013 and January 2014. In September, we were thrilled to have an invited international trainer to co-facilitate the course – Prof. Ann Le Couteur, a Child and Adolescent Psychiatrist from Newcastle University in the UK, and one of Dr Hudry's research collaborators. Prof. Le Couteur's visit allowed us to double the number of trainees on this ADOS course and provided the



opportunity for research and clinical trainees to benefit from the extensive experience of an international leader in lifespan ASD diagnosis.

From January, Dr Cherie Green started working with Dr Hudry as an ADOS Junior Trainer, an initiative to begin building capacity for ADOS 2 training in Australia. Dr Green already has extensive experience with use of the ADOS in different clinical and research contexts and with individuals of different ages and levels of ability. She also has experience with teaching and supervision and so makes an excellent addition to what we hope will be a growing team of ADOS trainers in Australia,

During 2013, Dr Hudry also began to offer professional development sessions for clinicians and researchers who have already completed initial ADOS training, providing

the opportunity for ongoing supervision and support in the refinement of administration and observational coding skills. To date, the monthly ADOS Coding Meetings have been attended primarily by OTARC staff and students who use the ADOS in their research. However, a number of external researchers and clinicians from local services have become regular attendees, valuing the opportunity for ongoing supervision and networking which is offered via attendance at these monthly sessions.

For more information go to http://www.latrobe. edu.au/otarc/services/professional-training-anddevelopment/ados-2-training-and-supervision

#### 2013 OTARC Research Forum

On July 26, 2013 we held a free whole-day forum for our research participants (parents/professionals/ people with ASD) to tell them about our recent research findings and to introduce them to our staff and students. This forum was held in special recognition of the people who have already assisted in our research, and for those who are prepared to do so in the future.

Professor Cheryl Dissanayake gave the introductory address including some general information about research at OTARC. Other OTARC staff and students also presented some of their research results. In the afternoon, Professor Cheryl Dissanayake and Dr Giacomo Vivanti, and Dr Cathy Marraffa from the Royal Children's Hospital, addressed some of the common myths about ASD. This was followed with a Question and Answer session in which all staff, as well as Dr Marraffa, participated. Judging from the audience participation in this and the other sessions, the interest in ASD research and the quest for answers is unabated.

The forum was attended by close to 200 registrants and was video-conferenced to the La Trobe Bendigo Campus. Social media (Facebook; Twitter) was used to share key messages throughout the day. We thank our students and staff, as well as the volunteers who assisted us to host this event.

## Early Identification Training in China

Professor Cheryl Dissanayake, Dr Josephine Barbaro and Dr Giacomo Vivanti travelled on the second Group Mission to Tianjin, China in November 2013 (funded by the Australia-China Science Research Fund). They have now trained 600 early childhood practitioners to monitor children at risk of ASD in the second year of life using the SACS. Practitioners also attended a presentation on early intervention for children with ASD.

Melbourne and Tianjin have a close sister-city relationship, which is an important factor in facilitating collaborations to share and develop knowledge. Our collaborators in Tianjin are Associate Professor Wang, Director of the Centre for Behavioural Science at Nankai University, and Dr Liu, Director of Child Health at the Tianjin Women and Children's Health Centre. Our joint research based on a pilot implementation of the SACS is showing that our approach to early identification of autism in Tianjin is working. Therefore this approach has now been incorporated into the Tianjin 7-year Women and Children's Health Plan. Tianjin is the first city in China to monitor all children born annually (100,000) for ASDs from 12- to 24-months of age.

## Early Identification Training in Bangladesh

Dr Josephine Barbaro went to Dhaka, Bangladesh, where she trained nurses and childcare workers in 'Autism Diagnosis and Intervention'. The event was organised by the Department of Public Health Hospital Administration, NIPSOM in Dhaka. Dr Barbaro's trip was sponsored by the Non Communicable Disease Control Program (NCD), DGHS, Bangladesh and Ankur International.



While in Dhaka, Dr Barbaro stayed with the family of Dr Nusrat Ahmed (a member of the OTARC team). Dr Barbaro and Dr Nusrat Ahmed are seated at the centre.

#### New ASD Undergraduate Subject

August 2013 saw the beginning of a very exciting development for OTARC and for ASD in Australia. Drawing on the expertise of our research team. PSY3ASD: Understanding and Treating Autism Spectrum Disorders was launched by La Trobe University and offered through the School of Psychological Science. Coordinated by Dr Kristelle Hudry, this is the first, undergraduate semester-long subject dedicated to ASD in Australia. Lectures were taught by various members of the OTARC team of researchers and staff - Dr Josephine Barbaro, Dr Giacomo Vivanti, Dr Cherie Green, Associate Professor Amanda Richdale, and Dr Nancy Sadka, as well as Professor Dissanayake and Dr Hudry. Lectures were delivered to 340 students at La Trobe's Bundoora campus and, via video-conferencing, Bendigo and Albury-Wodonga campuses. Fortnightly tutorials were facilitated by OTARC postgraduate students Lisa Rumney and Heather Nuske at Bundoora, by Tim Godber in Bendigo, and by Dr Sharon Hanna in Albury-Wodonga. Students enrolled in this new subject were from various disciplinary backgrounds, including Psychological Science, Occupational Therapy, Health Science. Law and Education.

The aim of this new subject was to give students an appreciation of the many different faces and facets of ASD, as well as familiarizing them with ASD research and practice in Australia. Lecture and tutorial topics included:

 The history of our understanding of ASD - from Leo Kanner's first case studies to the recently-published diagnostic manual, the DSM-5;



- Early identification and diagnosis of ASD;
- Genetic and neuro-biological features of ASD, as well as behavioural presentation across the lifespan;
- Various models of intervention support for preschoolers and school-aged children with ASD;
- Impact of ASD and adaptation to life beyond school, including commonly co-occurring conditions such as sleep difficulties, anxiety, gastro-intestinal problems;
- Impacts of ASD on the family, highlighting the important need for support for the whole family living with ASD.

Student feedback on the subject was very positive, and we plan to run PSY3ASD again in Semester 2 2015. Enrolments are currently available only to students at La Trobe University. However, we hope to explore options for extending the accessibility of PSY3ASD to interested students at other Universities and to professionals working in the field.

#### Talks & Workshops

#### 2013

July 16 - College of Neuropsychologists (Vic) seminar – Associate Professor Amanda Richdale "Autism Spectrum Disorder: An update from a life span perspective."

July 22 – AMAZE – Dr Josephine Barbaro "How to critically evaluate the evidence for interventions for Autism Spectrum Disorders".

August 8 – Early Childhood Intervention Network, Moreland City – Dr Elfriede Ihsen "The Olga Tennison Autism Research Centre and recent developments in Autism Spectrum Disorders."

August 16 - The College of Educational and Developmental Psychologists (Perth, WA) one-day workshop - Associate Professor Amanda Richdale, co-presented with Dr Sarah Blunden – "Treating behavioural sleep problems in children: What psychologists need to know."

August 21 – Presentation for the La Trobe University Alumni and Advancement (Victorian State Library, Melbourne) – Professor Cheryl Dissanayake: "Research at the Olga Tennison Autism Research Centre: Who are we and where are we at in 2013?"

August 29 - RMIT Psychology colloquium - Associate Professor Amanda Richdale - "Supporting Tertiary Students with Autism Spectrum Disorder: Student Issues and Staff Support." September 17 – Austin Hospital Early Childhood Intervention Network – Dr Elfriede Ihsen "The Olga Tennison Autism Research Centre and recent developments in Autism Spectrum Disorders."

October 7 - Alfred Infant Mental Health Group -Professor Cheryl Dissanayake - "Research at the Olga Tennison Autism Research Centre: Who are we and where are we at in 2013?"

#### 2014

February 13 - Menzies College, La Trobe University - Associate Professor Amanda Richdale and Ms Ru Cai "Workshop on students with ASD".

May - La Trobe University - Hallmark Program Guest Speaker Presentation - **Dr Josephine Barbaro** "Early identification of Autism Spectrum Disorders: 10 years of longitudinal research."

May - Webinar panel organized by the Mental Health Professionals Network - Associate Professor Amanda Richdale - "Working Together to Support a Child with Autism Spectrum Disorder Experiencing Sleep Disturbance"

June 13 - Developmental Medicine Annual Seminar, Royal Children's Hospital, Melbourne - Associate Professor Amanda Richdale, "Promoting sleep in the child with Autism Spectrum Disorder."

#### Other Initiatives

#### Early Assessment Clinic for Autism Spectrum Disorders

Thanks to the generous grants from the R.E.Ross Trust, the William Buckland Foundation and the Phyllis Connor Memorial Trust we have seen over 200 families with a child identified as 'at risk' of developing ASD. We continue to assess two children per week. The team comprises Dr Josephine Barbaro, Ms Katherine Pye, Dr Nusrat Ahmed and Dr Nancy Sadka, who is our Intake Officer. The majority of children are referred to us by paediatricians and allied health professionals. The mean age of children assessed at the clinic is 27 months (range 12 – 35 months), with 73% of referrals meeting criteria for an ASD (ratio: 3 boys to 1 girl). Nearly all of the remaining children have special needs, such as developmental and/or language delay, with less than 2% developing typically. More than 40% of children meeting criteria for an ASD have a relative with ASD.



### The Victorian Autism Specific Early Learning and Care Centre: The Margot Prior Wing

Over the last 12 months, the Victorian Autism Specific Early Learning and Care Centre (ASELCC) has continued to reinforce its standing as a premium provider of care and intervention to toddlers and young children with ASD. We also remain committed to supporting the ASD community through research and capacity building.

The recent publication of the paper "Effectiveness and Feasibility of the Early Start Denver Model Implemented in a Group-Based Community Childcare Setting" in the *Journal of Autism and Developmental Disorders*, with authors from both OTARC and ASELCC, underlines the strength of the collaborative partnership between the two Centres located within the La Trobe University's Community Children's Centre. This landmark paper is the first to provide evidence supporting the use of the Early Start Denver Model (ESDM) with toddlers and young children with ASD in a childcare setting. We are in the unique position of having three internationally certified ESDM trainers and therefore continued to provide

specialized ESDM training to professionals, students and parents in the use of the model. We also provide support to the ASD community through workshops and seminars on the ESDM.

As a disability service provider the Victorian ASELCC is working to ensure that the service remains sustainable within the National Disability Insurance Scheme (NDIS) service model. We therefore believe that it is critical that we continue to build on the research about the outcomes of delivering the ESDM. One of our primary research aims involves understanding and overcoming current barriers to social inclusion in intervention settings. Having recently designed, created and successfully implemented the first electronic ESDM data collection system (in partnership with La Trobe University's Computer Science and Engineering department), we believe that the service is well placed to successfully broaden its research objectives to better suit an NDIS marketplace.

#### Other Initiatives continued

#### Raising Children Network

OTARC staff continue to work with colleagues from the Parenting Research Centre to create, write and review content for the Raising Children Network - Autism site. Working together, we can ensure that the relevant information is up-to-date, evidence-based, and of a high standard.



#### **Play Connect**

OTARC have partnered with Play Connect, a federally funded program under the Helping Children With Autism Initiative, to evaluate their service to families of young children with an ASD, and to train their playgroup facilitators.





Left: La Trobe University Vice Chancellor Professor John Dewar opened the 'Frame of Mind' exhibition

Right: Professor Cheryl Dissanake, Mrs Olga Tennison and Dr Ray David share their thoughts on the exhibtion.

#### World Autism Awareness Day (WAAD)

OTARC and the La Trobe University Museum of Art (LUMA) celebrated World Autism Awareness Day this year by hosting 'Frame of Mind', an art exhibition which was opened on April 2 by La Trobe University's Vice Chancellor, Professor John Dewar. The exhibition at Writers Block Café at the Borchardt Library featured the work of artist Dr Ray David who is on the autism spectrum. The La Trobe Community enjoyed exposure to Ray's inspirational works throughout April and May. Whether you were sitting at Writer's Block Café, visiting our blog Another Piece, or receiving an email from OTARC, you could share your thoughts about Ray David's evocative paintings.

Each work was accompanied by a QR code. If the viewer had an iPhone or Android smartphone with a QR code reader, scanning the QR code gave access to the blog page of each artwork, featuring an image of the work and an explanation of the back story and influences.

We are very grateful to Ray David because he has made his work available for sale through OTARC, and donated 40% of the purchase price to OTARC's research.

#### WAAD at Luna Park

We also participated at the exhibtion organised by AMAZE at Luna Park, where we distributed information about ASD, OTARC and ASD services associated with OTARC, the Early Assessment Clinic and the Autism Specific Early Learning and Care Centre. Thank you to the many students and staff who attended and helped with the display.

#### Appointments

#### **Professor Cheryl Dissanayake**

- Co-Chair, La Trobe University Research Focus Area 'Understanding Disease' (June 2013-);
- Co-Chair, Executive Committee of the Australasian Society for Autism Research (ASfAR; December 2012-);
- Member, Strategic Advisory Committee of the Victorian Autism Specific Early Learning and Child Care (2010 -);
- Convenor, AMAZE's ASD Research Group (2003-);
- Member, Research and Development Committee, Autism CRC (2013-)
- Member, Australian Autism Biobank Operations Committee, Autism CRC (2014-)
- Member, Editorial Board of the Australian Educational and Developmental Psychologist (2012);
- Member, Editorial Board of Frontiers in Developmental Psychology (2011-).
- Section Editor Current Developmental Disorder Reports (2013-)

#### **Dr Kristelle Hudry**

Member, AMAZE (Autism Victoria) Accreditation Board (2013).

#### **Associate Professor Amanda Richdale**

- Chair, EPIC Early Intervention Board of Management (2013-);
- Member, Committee for the APS Intellectual &/or Developmental Disabilities and Psychology Interest Group (2012-);
- Member, Editorial Board of Research in Autism Spectrum Disorders (continuing);
- Member, Autism Victoria (Amaze) ASD Research Group (continuing);
- Co-editor (with Associate Professor Kyle Johnson, Oregon Health & Science University, Portland, Oregon) of a new book Advances in Autism: Sleep Disorders (In preparation).

#### **Dr Giacomo Vivanti**

- Member, Editorial Board of the Journal of Autism and Developmental Disorders (2013-);
- Scientific Consultant, Italian Department of Health Committee to establish the Italian Guidelines on ASD Diagnosis and Treatment (continuing);
- Scientific Consultant, Autism Europe International Association for the Advancements of Rights of Persons with Autism (continuing);
- Scientific Consultant, Neuro-Engineering Group, University of Pisa, Italy (continuing);
- Scientific Consultant, Stella Maris Scientific Institute, University of Pisa, project on early diagnosis and predictors of treatment outcomes in the Tuscany region, Italy (continuing);
- Member, Editorial Board for Autismo e Disturbi dello Sviluppo (Italian journal of Autism and Developmental Disorders) (continuing);
- Member, Editorial Board for Disabilita' e Disturbi dello Sviluppo (Disability and Developmental Disorders) (continuing).

#### **OTARC Operations & Projects**

Since 2012, La Trobe University has been undertaking 'Future Ready', an extensive strategic overhaul of the university's vision, objectives and operations. During that time OTARC has likewise worked diligently to prepare for its future. Much of the administrative and communication infrastructure we have developed was aimed at responding to future needs and proved a good fit with the University's 'Future Ready' plans. In particular, as OTARC continues to increase its research activities and outputs, there has been pressure on the operational front to enable and resource staff and students to progress their work to the highest standards. Some of the more significant developments this year have been:

- extending the functionality of our online database platform 'salesforce.com' by:
- rolling out a customised application for all staff and students to manage their research projects;
- continuing to support the participation of 110 Maternal and Child Health Care Centres in the SACS-R study throughout Melbourne;
- commencing to support Autism CRC projects in Core Programs 1 & 3.
- expanding the dissemination and reach of our research findings



Throughout the year OTARC has enjoyed strong support from many business units within La Trobe University. Primarily the School of Psychological Science continues to provide us with significant administrative assistance. Alumni and Advancement, Marketing and Engagement, Digital Marketing, La Trobe's Learning & Teaching,

Research Services and Commercialisation have helped us shepherd many projects that are important to meeting our objectives. Many of the achievements listed throughout the Annual Report are due to the energetic support of these La Trobe units, and we are very grateful for it.

#### The OTARC Laboratory

In late 2013, the OTARC laboratory space expanded to include more testing rooms and offices. We now have separate office space for our students and volunteers, as well as separate offices for our research assistants and Laboratory Manager. We also have a second waiting area to greet families and individuals. We acknowledge all those who generously donate their time to be involved as participants in OTARC's research studies.

Our OTARC Laboratory Manual, providing information about our procedures and processes, is proving useful to students and staff alike. Our Research Participant Registry is a key resource at OTARC. It assists us to achieve quality communication with our research participants as well matching them appropriately to relevant research studies.



## The Financial Report of the Olga Tennison Autism Research Centre For the Period Ending 30th June 2014

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Revenues		Ending June 30 2014 Actual \$	Ending June 30 2013 Actual \$	Ending 30 June 2012 Actual \$	Ending 30 June 2011 Actual \$
Revenues					
Commonwealth Grants - DEEWR		17,363	0	21,703	42,201
State Government Grants		0	0	0	243,847
Research Revenue		384,136	63,549	83,498	127,280
Investment Revenue	Interest on monies held	43,161	46,481	102,754	78,236
Commercial Revenue		53,218	42,714	46,904	29,587
Other Grants and Donations		644,876	659,761	580,498	520,636
Other Revenue		1,500	0	21,960	12,379
Internal Revenue/Transfers		9,567	189,111	100,000	114,011
Total Revenue		1,153,821	1,001,616	957,317	1,168,184

## The Financial Report of the Olga Tennison Autism Research Centre \_\_\_\_\_\_ For the Period Ending 30th June 2014

### Expenditure

Expenditure		Ending June 30 2014 Actual \$	Ending June 30 2013 Actual \$	Ending 30 June 2012 Actual \$	Ending 30 June 2011 Actual \$
Expenses					
Total Employee Benefits and on costs		1,028,532	995,534	825,637	446,440
Academic		570,614	670,098	626,685	379,149
Casual - Academic		193,589	281	281	57,051
General		187,913	114,167	114,167	34,125
Casual - General		109,000	83,921	83,921	32,846
Other salary related		-32,584	-6,562	584	-56,730
Total Non Salary Expenditure		144,748	88,746	227,877	102,822
Infrastructure Related	Maintenance, services	34,170	12,507	20,217	21,799
Depreciation		11,544	11,546	10,581	6,790
Professional Fees	Consultancies, etc	395	13,412	13,113	656
Student Related	Scholarships, Stipends, Training	22,222	5,361	48,258	41,665
General Operating	General Admin Costs	44,022	13,664	14,724	14,056
Staff related	Travel, Accommodation, Entertainment	51,805	27,462	29,686	19,874
Financing costs		0	0	-8	0
Other Expenses Sundry Items		6,847	4,794	4,454	1,380
Internal Expense Transfers		-26,257	0	86,854	-3,399
Total Expenses		1,173,280	1,084,280	1,053,514	549,262
Net Operating Result		-\$19,459			

Olga Tennison Autism Research Centre Balance as at 30th June 2014 -Reported in Cost Centre 9105

LTU Foundation (Fund 105831) 586,661 OTARC (Fund 107159) 600,064 \$1,186,725 **Consolidated Balance** 

## Staffing and Centre Personnel

#### Staff

Professor Cheryl Dissanayake, Director

Associate Professor Amanda Richdale, Principal Research Fellow

Dr Elfriede Ihsen, Research Fellow

Dr Josephine Barbaro, Postdoctoral Research Fellow

Dr Giacomo Vivanti, Research Fellow, ASELCC/OTARC

Dr Kristelle Hudry, Lecturer, Developmental Psychology, School of Psychological Science

Dr Darren Hocking, Postdoctoral Research Fellow

Dr Heather Nuske, Postdoctoral Research Fellow

Dr Mirko Uljarevic, Postdoctoral Research Fellow

Ms Katherine Pye, Speech Pathologist, Early Assessment Clinic/ASELCC

Dr Nusrat Ahmed, Early Autism Specialist

Dr Nancy Sadka, EAC Intake Officer

Ms Ru Cai, Research Officer

Ms Melanie Muniandy, Research Assistant

Ms Lindsay Pamment, Research Assistant

Ms Rachel Yeo, Research Assistant

Ms Lanha Bradley, Research Assistant

Mr Wojciech Nadachowski, Senior Advisor, Operations & Projects

Ms Lisbeth Wilks, Administrative Officer

Ms Carmela Germano, Laboratory Manager

Mr Lachlan Burnside, Database Officer

Ms Alex Aulich, Adminstrative Officer

#### **Academic Adjuncts**

Dr Naomi Bishop, Department of Microbiology, La Trobe University

Dr David Trembath, Senior Lecturer, School of Allied Health Sciences, Griffith University.

Dr Cynthia Zierhut - MIND Institute, University of California, Davis in Sacramento, USA.

#### **Honorary Members**

Ms Amanda Golding, Amagol Consulting/Autism Noticeboard Mr Mike Burnside. Salesforce

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Associate Professor Elizabeth Johnson, Acting Dean of Faculty of Science, Technology and Engineering, La Trobe University

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**Dr Catherine Marraffa**, Senior Paediatrician Developmental Medicine, Royal Children's Hospital, Melbourne

Mr Tony Stein, Asia Pacific Cloud Delivery Executive, IBM - Community Representative

Ms Lia Castorini, Autism Victoria 'AMAZE'

Ms Emma Baker, PhD candidate, Student representative for OTARC, La Trobe University



The Olga Tennison Autism Research Centre (OTARC) was established in 2008 as a joint initiative of La Trobe University and Autism Victoria. This was made possible with a private donation by Mrs Olga Tennison in 2007. The Centre is named after her to acknowledge her generosity.

Our mission within the Centre is to advance knowledge of the nature and causes of Autism Spectrum Disorders (ASDs), as well as to develop and study evidence-based strategies for supporting children and families affected by an ASD.



Our Patron is Professor David De Kretser (AC, AO, MD 1969, HonLLD 2006) Monash University. Professor Kretser was Governor of Victoria from 2006-2011.

OTARC is situated in the School of Psychological Science within the Faculty of Science, Technology and Engineering (FSTE) at La Trobe University in Melbourne, Australia.

