

# Chair of Intellectual Disability Mental Health Progress 2009 - 2014

**Never Stand Still** 

Medicine

Department of Developmental Disability Neuropsychiatry

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# The Highest Attainable Standard of Mental Health and Wellbeing for People with an Intellectual or Developmental Disability

Vision of Associate Professor Trollor, Inaugural Chair Intellectual Disability Mental Health, 3DN Strategic Plan, 2013-2015

# **Executive Summary**

The UNSW Chair of Intellectual Disability Mental Health (Chair IDMH) is unique in being the only academic unit of its kind in Australia. The Chair IDMH commenced at UNSW with funding from NSW Department of Family and Community Services, Ageing, Disability and Home Care (ADHC) in February 2009. The Chair IDMH established the Department of Developmental Disability Neuropsychiatry, or 3DN, within the same year. Over the past five years the Chair IDMH has developed 3DN into a highly regarded centre of expertise, capacity development, research, and advocacy in the field of intellectual disability mental health (IDMH).

The University of New South Wales (UNSW) provides an excellent setting for the Chair IDMH position. It offers both the physical infrastructure and a rich collaborative network of disability scholars, which enhance the work of the Chair. The location of the Chair at UNSW has enabled liaison and collaboration with leading Australian academics within the School of Psychiatry, the Faculty of Arts and Social Sciences (such as, the Social Policy Research Centre and the Schools of Education and Social Work), the Faculty of Science, (which includes Neuroscience Research Australia and the Dementia Collaborative Research Centre (DCRC)). Furthermore, UNSW have recently been awarded a Chair in Intellectual Disability and Behaviour Support (Chair IDBS) which will develop additional capacity in the complex space between mental health and behaviour.

The Chair IDMH and 3DN have demonstrated a rich engagement with ID in the fields of teaching, research, policy and practice, and clinical work and have established a reputation for outstanding contributions to government, industry and non-government sectors. More information on the future work envisioned by the Chair IDMH can be found in 'Chair IDMH Work Plan and Strategic Vision 2015 – 2019' on our website This paper will outline the rapid progress made by the Chair IDMH and 3DN over the last five years, 2009 – 2014.

# Introduction

# Intellectual Disability and Mental Health- The Imperative for the Chair

A significant minority (about 2%) of Australia's population have an ID (Australian Institute of Health and Welfare, 2003). People with an ID experience very poor physical health and mental health compared to the general population. The prevalence of mental disorders is at least two to three times higher in people with ID compared to the general population (Bouras & Holt, 2010; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Stewart L. Einfeld et al., 2006). Predisposition to mental ill health is apparent across the lifespan, including in children, younger people and adults (Dekker & Koot, 2003; Stewart L. Einfeld et al., 2006; Emerson & Hatton, 2007). At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind (Bouras & Holt, 2010; Cooper et al., 2007; Stewart L. Einfeld et al., 2006; S. L. Einfeld & Tonge, 1996). For example, the common mental disorder schizophrenia is over-represented two to four times and has an earlier onset in people with an ID compared to the general population (Cooper et al., 2007; S. L. Einfeld & Tonge, 1996; Morgan, Leonard, Bourke, & Jablensky, 2008). Predisposition to mental ill health continues into late life as illustrated by the higher rates of dementia in older persons with an ID compared to the general population (Cooper, 1999).

Vulnerability to mental disorders in people with an ID is conferred by a variety of biological. psychological, and social risk factors. Specific genetic conditions associated with ID can increase the risk of psychopathology (Tonge & Einfeld, 2003), as can developmental brain abnormalities and pharmacological treatments and their side effects (Kastner, Walsh, & Fraser, 2001). People with an ID are also at increased risk of a range of physical health conditions which may increase the risk of mental ill health (Cooper, 1999; O'Hara, 2008; Scheepers et al., 2005). The presence of an ID usually affects a person's coping skills and autonomy, creating greater susceptibility to stress, and thereby increasing psychological vulnerability (Janssen, Schuengel, & Stolk, 2002). Further risk arises from the reduced opportunities to engage in a range of life choices, and restricted social networks that people with an ID often experience. Other social factors which impact mental health include poverty, a higher likelihood of contact with the criminal justice system, negative experiences during schooling, and financial and emotional strain within the family (Chan, Hudson, & Vulic, 2004; Emerson, 2007; Vanny, Levy, Greenberg, & Hayes, 2009). Furthermore, people with an ID experience higher rates of physical and sexual abuse (McCarthy, 1996; McCarthy & CQSW, 1996) which can further magnify their vulnerability to mental ill health. This complex set of vulnerabilities underscores the need for comprehensive research, interventions and changes in practice across multiple disciplines and in recognition of this, the Chair IDMH has developed projects and forged links across the sectors relevant to mitigating this vulnerability.

Many people with an ID experience major barriers when trying to access mental health services. The development of accessible mental health services for people with an ID in Australia lags behind internationally accepted practice (Evans et al., 2012). The experience of family, carers and consumers is that mainstream mental health services do not readily accommodate the needs of people with an ID. The initiatives of the Chair IDMH speak directly to the adjustments required within the mental health sector to address this issue.

# Background of the Chair IDMH

In 2008, the Department of Family & Community Services, Ageing, Disability & Home Care (ADHC) sought to establish a University Chair in Intellectual Disability and Mental Health within a Faculty of Medicine. The goal of the Chair was to "increase workforce capacity to deliver appropriate and effective services to people with an intellectual disability and a mental health issue" (Service Description Schedule (SDS), ADHC 2008). The activities to be undertaken by the Chair were to include, "leading, facilitating, undertaking and supporting the development and delivery of courses in mental health and intellectual disability" and "to lead the development of a research program in relation to people with an intellectual disability and mental health issues to address knowledge deficits within the Australian and international context" (SDS, ADHC 2008). The School of Psychiatry within UNSW Medicine was awarded the contract and appointed Associate Professor Trollor to the position of Chair in Intellectual Disability Mental Health in February 2009. A brief profile of Associate Professor Trollor is provided at Appendix A.

# An Academic Department

Associate Professor Trollor established the Department of Developmental Disability Neuropsychiatry, or 3DN in 2009. 3DN remains unique in Australia, being the only academic unit with a specific focus on intellectual disability and mental health. This makes it the national leader of services, workforce and research initiatives in IDMH. The evolution of 3DN has been rapid, and it is now a highly regarded centre of excellence. 3DN has aligned its work under the key domains of: Building Capacity, Research and Consultancy. Projects in each of these areas are described in some detail in the body of this proposal and in greater depth on 3DN's website <a href="http://www.3dn.unsw.edu.au/">http://www.3dn.unsw.edu.au/</a>. 3DN is actively engaged with the sector and this is evidenced by regular presentations and workshops on capacity building, multiple and ongoing submissions and reports advocating on the issue, and numerous publications in peer-reviewed journals (a list of which can be found in <a href="https://www.adn.unsw.edu.au/">Appendices B and C</a>).

3DN provides a dynamic work environment which employs staff from a variety of disciplines. Staff profiles can be found also on 3DN's website. 3DN is host to undergraduate and postgraduate students from diverse backgrounds, specialist and general psychiatry trainees on placement from Local Health Districts (LHDs) across New South Wales and placements from highly skilled staff from the disability sector. 3DN has attracted personal visits from internationally acclaimed academics, including: Professor Eric Emerson (United Kingdom), Professor Tony Holland (United Kingdom), Associate Professor Andre Strydom (United Kingdom), Baroness the Professor Sheila Hollins (United Kingdom), Professor Michael Kopelman (United Kingdom), Professor David Bunce (United Kingdom), Professor Alan Reiss (United States), Professor Luis Salvador-Carulla (Spain, now relocated to Australia) as well as lead intellectual disability academics and clinicians from all over Australia. We consider this a measure of esteem for 3DN as a centre of excellence with an ever growing reputation.

Over the course of these five years of rapid development, 3DN has attracted grant and project funding to the value of \$10,863,329 from a variety of sources including: the Australian Government, NSW State Government, and Australia's leading grant bodies such as the National Health and Medical Research Council (NHMRC) and the Australian

Research Council (ARC) (see <u>Appendix D</u> for a summary). 3DN's broad array of workforce, teaching and research projects will be discussed in some detail herein and can also be found on the <u>website</u>. In addition, the Chair IDMH plays a leadership role in one of the major components (Program 3.2) of the \$31M "Living with Autism Spectrum Disorders" Cooperative Research Centre (Autism CRC) established in 2013.

Throughout the remainder of this document, the term 'Chair IDMH' (or Chair) refers to the work undertaken by the Chair IDMH and 3DN.

# Establishing Stakeholder Links

The Chair IDMH values well-formed stakeholder links with consumers, carers, academics, government and non-government sectors and considers these essential to the work of the Department. The University of New South Wales Guiding Principles of mutual respect, collegiality, teamwork and high service standards (<u>Blueprint To Beyond UNSW Strategic Intent: 2011</u>) have provided the backdrop for the Chair's collaborative approach. The highlights of these stakeholder links and their purpose are outlined in Table 1.

The Chair IDMH's strategy in relation to stakeholder links includes establishing strong links in the following groups: advisory links, capacity building links, mentoring links, governance links and advocacy links. These are essential for the Chair's success and include:

- The formation of high calibre international collaborations which have ensured the work of the Chair is harmonised with international work of the highest standards and which have provided the Chair with insights into service, educational and policy developments which enable more rapid progress to be made in Australia.
- Meetings with senior figures in the Australian Government Department of Health in order to examine options for action to improve mental health in people with an ID at a national level.
- Periodic meetings and representations to NSW State Government Ministers for Mental Health and Ageing and Disability and their respective Departments, to provide briefings, advice, and to lobby for action in policy and service development. This has included the provision of expert legal advice to the Disability Services Minister via the Crown Solicitor and advice on revision of disability and health legislation and policy.
- Consultancy with the National and the NSW Mental Health Commissions.
- The development of links with all key professional associations (such as Health Workforce Australia (HWA) and the Royal Australia and New Zealand College of Psychiatrists (RANZCP)) in order to inform them of work in the area of ID mental health and to foster interdisciplinary approaches.
- Partnership with consumer and advocacy organisations which has ensured that the work of the Chair is appropriately aligned with sector expectations, especially regarding the key principles for clinical practice and person-centred approaches.

The table below outlines the active stakeholder links the Chair IDMH has established. These demonstrate the powerful, cooperative and interdisciplinary framework that has been built and sustained by the Chair IDMH.

STAKEHOLDER	STAKEHOLDER ROLE	SPECIFIC INPUT	
STAKEHOLDEK	STAKEHOLDER ROLE	SPECIFIC INFO	
INTERNATIONAL			
Professor Nick Bouras and staff of the Estia Centre, Institute of Psychiatry, London	Mentor Capacity Building	<ul> <li>Educational strategy consultations.</li> <li>Visits for some NSW IOP ID mental health fellows.</li> <li>Invited as authorship of future book chapter.</li> </ul>	
Baroness the Professor Sheila Hollins, London, UK	Mentor Capacity Building	<ul> <li>Capacity building strategy consultations.</li> <li>3DN hosted a visit and address as part of the RANZCP Sydney Congress.</li> <li>3DN acts as Australian distributor of Books Beyond Words by Prof Hollins.</li> </ul>	
Cambridge Intellectual & Disabilities Research Group (CIDDRG), Professor Tony Holland, Cambridge University, UK	Mentor Capacity Building	<ul> <li>3DN nominated Prof Holland for RANZCP travelling professorship.</li> <li>Chair sponsored Keynote for AADDM conference.</li> </ul>	
Professor Eric Emerson and the Health Observatory, Lancaster University, UK	Advisory & Collaboration	<ul> <li>Policy consultations.</li> <li>Engaged as a CI for successful NHMRC Partnerships for Better Health Grant.</li> </ul>	
Professor Angela Hassiotis and A/Prof Andre Strydom, University College London, UK	Advisory	Consultation for ageing studies.	
Professor Frans Ewals, Erasmus Medial College Rotterdam, Netherlands	Capacity Building	<ul> <li>3DN hosted specialty ID physician trainees.</li> </ul>	
PROFESSIONAL ASSOCIATIONS			
Australian Association of Developmental Disability Medicine (AADDM)	Partnership	<ul> <li>3DN has engaged in joint health advocacy with Australian Government.</li> <li>Chair appointed as Vice-President of AADDM.</li> </ul>	
Royal Australian and New Zealand College of	Capacity Building	<ul> <li>Chair has engaged RANZCP in a variety of initiatives including consultation and</li> </ul>	

Australian Association of Developmental Disability Medicine (AADDM)	Partnership	<ul> <li>3DN has engaged in joint health advocacy with Australian Government.</li> <li>Chair appointed as Vice-President of AADDM.</li> </ul>
Royal Australian and New Zealand College of Psychiatrists	Capacity Building	<ul> <li>Chair has engaged RANZCP in a variety of initiatives including consultation and launch of "The Guide."</li> </ul>
Royal Australian College of General Practitioners	Capacity Building	<ul> <li>Consultation for educational initiatives and "The Guide".</li> </ul>
Australian Psychological Society	Capacity Building	<ul> <li>Consultation regarding educational initiatives, "The Guide" and policy initiatives.</li> </ul>
Professional Association of Nurses in Developmental Disability Australia	Capacity Building	<ul> <li>Consultation regarding educational initiatives and "The Guide", presentations at National Conferences.</li> </ul>
The Association of	Capacity Building	<ul> <li>Consultation regarding educational</li> </ul>

STAKEHOLDER	STAKEHOLDER ROLE	SPECIFIC INPUT
Psychologists in		initiatives and "The Guide".
<b>Developmental Disability</b>		
Services		

# **AUSTRALIAN GOVERNMENT**

Professor Jane Halton, Secretary, Department of Health	Capacity Building	<ul> <li>Consultations for development of strategy for work of Chair, and to lobby for inclusion of people with an ID in all mental health initiatives.</li> </ul>
Department of Health Mental Health Services Branch, Primary Care Service Section	Capacity Building	<ul> <li>The formation of a working group on IDMH which has led to funding of the National Round Table and "The Guide". Continuing dialogue regarding ID mental health initiatives through regular meetings.</li> </ul>
Health Workforce Australia	Capacity Building	<ul> <li>Consultation regarding mental health workforce strategy and submissions relating to standards relating to people with ID.</li> </ul>

# **NSW GOVERNMENT**

NSW Minister for Ageing, Disability and Homecare	Capacity Building	<ul><li>Meetings to represent the Chair's work and progress key initiatives.</li><li>Ministerial launch of e-Learning platform.</li></ul>
Agency for Clinical Innovation, Intellectual Disability Network	Capacity Building	<ul> <li>Foundation member and serving on the Executive, and as Co-Chair of the Research and Development Subcommittee.</li> </ul>
NSW Minister for Mental Health	Capacity Building	<ul><li>Meetings to lobby for policy and service development.</li><li>Ministerial launch of e-Learning platform.</li></ul>
NSW Health, Mental Health and Drug and Alcohol Office	Capacity Building Advisory Collaborative	<ul> <li>Regular meetings to progress key initiatives in workforce capacity, services and policy.</li> </ul>
NSW Health MH-Kids	Capacity Building	<ul> <li>Regular meetings to progress key initiatives in workforce competencies.</li> </ul>
NSW Health Justice Health	Capacity Building	<ul> <li>Assisted with capacity building strategy in cognitive disorders; regular presenter at national conferences and educational program.</li> </ul>
Corrective Services NSW	Capacity Building	<ul> <li>Educational program, research and engagement in National Round Table and The Guide.</li> </ul>
NSW Health, Health Education and Training Institute	Capacity Building	<ul> <li>Meetings to progress the alignment of e- Learning platform.</li> <li>Seed funding for e-Learning module development.</li> </ul>

STAKEHOLDER	STAKEHOLDER ROLE	SPECIFIC INPUT
Department of Attorney General and Justice, Law Reform Commission	Capacity Building	<ul> <li>Consultation and written submissions relating to legislation for people with cognitive disorders.</li> </ul>

#### **SECTOR AGENCIES**

NSW Institute of Psychiatry	Capacity Building	<ul> <li>Serving on the NSW Institute of Psychiatry Board.</li> <li>Key member of ID mental health fellowships Committee.</li> <li>Overseeing clinical and research elements of trainee applications and mentorship of all ID mental health fellows.</li> </ul>
Clinical Innovation and Governance, NSW Department of Family & Community Services, Ageing, Disability and Home Care (ADHC)	Governance Advisory Collaborative Capacity Building	<ul> <li>Regular meetings to discuss strategic direction of Chair's work; regular reporting of progress.</li> </ul>
Queensland Centre for Intellectual and Developmental Disability, University of Queensland	Capacity Building Joint Advocacy	<ul> <li>Joint health advocacy and educational work; partnership in national initiatives such as The Guide and the National Round Table</li> </ul>
NSW Mental Health Commission	Capacity Building	<ul> <li>Comprehensive briefings and written submissions regarding ID mental health reform and clinical service development; advice to Commission regarding consultation strategy with people with ID.</li> </ul>
National Mental Health Commission	Capacity Building	<ul> <li>Consultation regarding capacity building in ID mental health; submissions for content for reports;</li> <li>Key stakeholder in National Round Table.</li> </ul>
National and NSW Council for Intellectual Disability	Partner	<ul> <li>Partner in key health advocacy initiatives, and in the development of inclusive research, training and policy.</li> </ul>
NSW Ombudsman	Capacity Building	<ul> <li>Chair sits on Adult Disability Deaths review advisory committee and advises re Ombudsman's activities in ID health.</li> </ul>
The Public Guardian New South Wales	Capacity Building	<ul> <li>Consultation regarding key Chair initiatives; presentations at OPG staff training days.</li> </ul>

#### Work of the Chair IDMH to Date

Over this first five years, 2009 – 2014, the work of the Chair IDMH has been strategically planned under the three domains of: Building Capacity, Research and Consultancy.

# **Building Capacity**

This domain of the Chair's work aims to improve the accessibility of mental health services for people with an ID through education and workforce projects. Significant progress has been demonstrated in the following broad project areas, each elaborated upon below:

- i) excellence in IDMH education,
- ii) the development of an IDMH Workforce and;
- iii) enhancing partnerships.

#### **Excellence in IDMH Education**

The Chair IDMH has provided leadership at a national level in the development of IDMH training and education strategies to achieve excellence in IDMH Education. Exemplar projects include:

- Survey of Staff Attitudes, Confidence and Learning Needs in IDMH. 222 mental health staff employed within the then-South Eastern Sydney Illawarra Area Health Service (SESIAHS) completed the survey. Detailed results of the survey are published in a Report to the then-Office of the Senior Practitioner (Mental Disorders in Intellectual Disability Survey and Training Workshops: 2011). The survey revealed that a high proportion of workers believed that their current level of training in intellectual disability mental health was inadequate. They reported generally low levels of confidence and a positive desire for further education in the area.
- IDMH Training Modules- A workshop package A ten module curriculum was created covering five fundamental and five advanced training topics in IDMH. These were delivered in a series of two day workshops to 92 clinicians at NSW Health sites. The 10 modules were:
  - 1. Introduction to Intellectual Disability
  - 2. Mental Disorders in Intellectual Disability Introduction
  - 3. Mental Disorders in Intellectual Disability Communication and Assessment
  - 4. Agencies Involved in Supporting People with Intellectual Disability
  - 5. Mental Disorders in Intellectual Disability Management
  - 6. Challenging Behaviour
  - 7. Legal and Ethical Considerations
  - 8. Lifespan and Transition Issues
  - 9. Personality Disorders, Forensic, and D&A Issues
  - 10. Mental Disorders in Other Developmental Disabilities Specific Vulnerabilities

Evaluation of the workshops revealed that on average participants rated their improvement on all learning outcome measures as "good". Participants also reported

very high levels of satisfaction with both workshops (Mental Disorders in Intellectual Disability Survey and Training Workshops: 2011).

# E-Learning Resource www.idhealtheducation.edu.au



An e-Learning site was developed which provides effective and accessible training in IDMH. This resource was jointly launched by both the Minister for Mental Health, Hon. Kevin Humphries and Minister for Disability Services Hon. John Akaja in July 2013. The site has been designed to house modules accessible to professionals, carers and consumers. Funding awarded for the project has enabled us to develop a comprehensive suite of modules for mental health professionals, and to commence work on developing modules for carers. Seven months after the launch of the site, there were more than 4,300 registered users of the site. The modules have been written to reflect an evidence-based approach to person-centred clinical practice. The entire e-Learning platform was subject to usability and independent expert review before it was formally launched. The data from the evaluations was analysed, which indicated that users were very satisfied with the modules and the interface. This was presented at the 48th Annual Australasian Society for Intellectual Disability Conference in November 2013.

- This was a two part project which included: (1) an audit of curriculum content at UNSW Medicine and (2) the development of innovative content for the curriculum. The audit process indicated a lack of specific ID content in the medicine curriculum, and identified available background material to inform the development of enhanced content. The second part of the project involved the development of two lectures; scenario based learning sessions; assignment options and exam content. The lecture content includes co-presentation by the Chair, a consumer with an ID, and a parent who has had the experience of losing a young child with an ID and caring for an adult son with an ID. This material has been particularly engaging for medical students as they become aware of the impact of disability on the lives of individuals and families.
- Leading National Audits of Medical and Nursing Curricula National audits of medical and nursing schools are being undertaken by the Chair IDMH. This project builds a profile of the content related to the health and well-being of people with an ID, will develop a national network of ID health curriculum champions, and with future funding will develop minimum content and a toolkit for its implementation. This project has engaged numerous parties including the Council of Medical Deans of Australia and New Zealand, and the Council of Deans of Nursing and Midwifery Australia and New Zealand.
- Presentations and Workshops in IDMH
  The Chair and 3DN staff members have delivered over 100 presentations to the mental health and disability sector with a specific focus on building capacity in IDMH. These have included presentations or workshops for international, national, NSW and local audiences. Many of these presentations are to trainee psychiatrists, psychiatrists, mental health nurses and case managers within the public and private health systems, and a substantial proportion are focussed on education and training in the disability sector. A

summary of all presentations provided by the Chair IDMH and 3DN staff are provided in Appendix C.

#### Other Innovation in Teaching and Education

- The Chair has developed IDMH materials for teaching in the NSW Institute of Psychiatry Master's Program and in the UNSW Masters of Forensic Mental Health Program.
- The Chair has collaborated with A/Prof Beth Kotze, MH-Kids, to produce examination content for the RANZCP exams. This has included the production and editing of an examination station in which trainees are asked to critique a mock interview with a person with intellectual disability.

#### Other Teaching Contributions

- The Chair has contributed to education in IDMH by delivery of invited lectures and webinars with professional bodies such as the Mental Health Professionals Network (MHPN), the Australian Psychological Society, Professional Association of Nurses in Developmental Disability Australia (PANDDA), and the Association of Psychologists in Developmental Disability Services (PsychDD).
- o The Chair was appointed to the Board of the NSW Institute of Psychiatry in 2011.

#### The Development of an IDMH Workforce

In the development of a workforce strategy for IDMH, work has focussed on long-term strategies to build capacity in the public and private mental health sectors. Exemplar projects include:

#### Creating a National Guide for Mental Health Professionals

To improve the quality of mental health care for people with an ID, funding was obtained from the Australian Government Department of Health to develop Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers (The Guide). The Guide outlines the principles which underpin practice, the core components of service provision and the reasonable adjustments for inclusive practice for all elements of the mental health service system. Development of The Guide was informed by literature searches, a series of stakeholder surveys, focus groups and consultations with a Core Reference Group. An initial draft of The Guide was also reviewed at the National Roundtable on the Mental Health of People with Intellectual Disability in May 2013. The final text was approved by the Australian Government Department of Health in January 2014, and The Guide will be officially launched by the RANZCP President at the Congress in May 2014.

#### The Formation of an RANZCP Special Interest Group

The Chair IDMH has been a key catalyst in the formation of a new Special Interest Group in Intellectual and Developmental Disability within the RANZCP (SIGPIDD). The Chair has actively sought to promote workforce capacity, training and education in the agenda of this group through regular participation in the Executive, and through leadership of a specific subcommittee with this focus. The SIGPIDD has made a dynamic contribution to the RANZCP through (1) development of components in the new

competency based training, (2) provision of high quality content for Congress and (3) provision of advice to the RANZCP regarding ID/DD policy and legislative issues. The formation of the SIGPIDD has also allowed a portal for liaison with similar groups which exist within other professional organisations such as the Australian Psychological Society and the Paediatric & Child Health Division of the Royal Australasian College of Physicians.

#### Specialist IDMH Trainees

The Chair IDMH has mentored/supervised five NSW Institute of Psychiatry Fellows in Intellectual Disability Mental Health to completion. An additional Fellow is currently undertaking training and there are three more applicants for remaining positions. These positions are for advanced trainees who obtain an in-depth exposure to ID mental health, usually over a period of one year. During their Fellowship, trainees are richly immersed in a variety of training settings across the Sydney metropolitan area. Trainees concurrently obtain skills in a related area such as neuropsychiatry, forensic psychiatry, child and adolescent psychiatry or consultation-liaison psychiatry.

- The Development of a Training Framework
  - The Chair has developed a training curriculum for specialty IDMH training. This training curriculum is the only such curriculum in Australia and one trainee's experience of it has been formally described in a peer-reviewed publication. It is intended that this curriculum will be used as a basis for a formal proposal to the RANZCP for training in IDMH when this area is recognised as a sub-specialty.
- Basic Psychiatry Trainees Additionally, the Chair has supervised six basic psychiatry trainees in an ID mental health term, each for a period of six months. Half of these rotations have been funded by the South Eastern Sydney Local Health District (LHD) and half by a successful application to the Australian Government's Special Training Program fund. This experience gives trainees a fundamental exposure to clinics and training resources in IDMH across the LHD.
- Training Needs Analysis of the NSW Public Mental Health Workforce A state-wide survey has been undertaken which document the attitudes, confidence and training needs of public mental health workers in IDMH. Analysis of the survey is underway and will inform the development of competencies for NSW mental health staff in IDMH. Early indicators are that staff have positive attitudes towards people with an intellectual disability and demonstrate a willingness to incorporate people with an ID into their work. However, they lack skills and confidence in this area. This work dovetails with the competency and e-Learning work of the Chair.
- Competencies in IDMH for the NSW Mental Health Workforce
  The Chair is undertaking a multipart project which develops and implements
  competencies in IDMH for the NSW mental health workforce. Phase 1 (a Delphi
  consensus) is complete, and items for inclusion in a competency framework have been
  selected. Subsequent work will focus on the framework for presentation of
  competencies, field testing of a competency manual, and the implementation of the

competencies across public mental health services in NSW. These competencies will be the first of their kind in Australia, and a rarity internationally.

#### ■ IDMH Forensic Capacity

Several consultations have taken place with the Justice and Forensic Mental Health Network CEO, Clinical Director and the Director of Training around development of capacity in forensic ID mental health. This has resulted in: (1) construction of a specific forensic IDMH Fellowship experience and (2) commitment by the Justice and Forensic Mental Health Network CEO to fund the development of a clinical pathway in forensic IDMH.

#### Enhancing partnerships: the Chair of Intellectual Disability and Behaviour Support

The Chair IDMH's capacity to enhance partnerships is demonstrated in the successful tendering for the Chair in Intellectual Disability Behaviour Support (IDBS) at UNSW Australia. The Chair IDMH led the UNSW tender application process in March 2013 together with Associate Professor Kristy Muir, which resulted in the award to UNSW Australia of funding for a Chair in Intellectual Disability Behaviour Support (Chair IDBS) by the NSW Department of Family and Community Services (FACS), Ageing, Disability and Home Care (ADHC). The primary goal of the new Chair IDBS is to expand the body of knowledge and increase workforce capacity in the delivery of appropriate and effective services to people with an intellectual disability with complex and challenging behaviour. The synergy between the Chair IDMH and Chair IDBS will ensure increased capacity in the sector through education, training and other complimentary initiatives. The rich network of disability scholars at UNSW will ensure the development of enduring collaborations with the Chair IDBS.

#### Research

The Chair IDMH has built a long-term research program which will mature further over the coming five years. The research program is underpinned by a strategy which involves:

- The conduct of ethical research which engages people with ID and their carers.
- Emphasis on translational projects which both identify and propose solutions to the overrepresentation of mental disorders in people with an ID.
- The growth of 3DN as a centre of academic excellence in IDMH.
- Collaboration with fellow academics in the 'disability research hub' at UNSW to expand opportunities and partner in key cross-disciplinary research projects.
- Mentoring junior researchers in IDMH, and sponsoring higher degree students in this field.
- Involving clinical IDMH Fellows in research activities and making IDMH an attractive and engaging area of opportunity for young scholars and clinicians.

The Chair IDMH has been highly successful in research, project and other funding, securing over \$10M in research, project and other funding since commencing in 2009. This includes over \$5.6M from nationally competitive research grants such as National Health and Medical Research Council (NHMRC) and Australian Research Council (ARC) grants; \$2.1M from research funding sources; and \$2.7M of other funding sources. In addition, the Chair IDMH has been awarded \$450,000 from the Cooperative Research Centre for Living with Autistic

Spectrum Disorders (Autism CRC), a \$31M partnership between industry and the Australian Government which involves collaborations with multiple universities across Australia in a program of research and capacity (see Key Research Collaborations in Table 2 below and also <a href="Appendix D">Appendix D</a>: Summary of Funded Project (2009 – Present)).

Significant progress in the development of research capacity in the following domains is elaborated upon below:

- i) establishing academic collaborations,
- ii) leadership of key research programs,
- iii) specific developmental and related disorders,
- iv) other research programs,
- v) successfully supervising higher degree and research students to completion,
- vi) obtaining other research awards,
- vii) partnering with stakeholders in nationally competitive research grant success and,
- viii) contributions to IDMH research capacity building.

#### **Establishing Academic Collaborations**

Academic collaboration is instrumental to the rapid development of research capacity in IDMH. Above and beyond the key stakeholder relationships outlined in Table 1, the Chair IDMH has successfully developed local, national and international academic collaborations. The most significant active collaborations are listed below in Table 2. The Chair IDMH's strategy in relation to academic collaborations networks includes:

- The formation of high calibre international collaborations.
- The formation of academic links with lead Australian academics in the field of disability health, which has enabled success in competitive grant schemes such as Australian Research Council and National Health and Medical Research Council.
- Consultation regarding areas of specific interest (ageing and ID, Fragile X related disorders) with international leaders in their fields.

**Table 2. Key Research Collaborations** 

COLLABORATOR GROUPS	RESEARCH DOMAINS
UNSW Faculty of Arts and Social Sciences Professor Eileen Baldry and Dr Leanne Dowse	<ul> <li>Intellectual disability, psychiatric disorders and the criminal justice system.</li> <li>Indigenous offenders with cognitive disabilities.</li> </ul>
UNSW Social Policy Research Centre, A/Prof Karen Fisher	<ul> <li>Workforce capacity &amp; policy.</li> </ul>
UNSW 3DN, Dr Liz Evans, Dr Anjali Bhardwaj La Trobe University Rural Health School, Faculty of Health Sciences, Prof Teresa Iacono Monash University Centre for Developmental Disability Health Victoria, Dr Jenny Torr	<ul> <li>Ageing and dementia in Intellectual Disability.</li> </ul>
Professor Randy Hagerman and the MIND Institute, University of California Davis, USA; Monash University Developmental Neuropsychology,	<ul><li>Fragile X Disorders.</li></ul>

#### **COLLABORATOR GROUPS**

#### **RESEARCH DOMAINS**

**Prof Kim Cornish**;

Murdoch Children's Research Institute, Genetics Education and Health Research, Prof Sylvia Metcalfe;

**Hunter Genetics, Dr Anna Hackett;** 

Monash University School of Psychology and

Psychiatry, Faculty of Medicine, Prof Nellie Georgiou-Karistianis

Dementia Collaborative Research Centre, and Centre for Healthy Brain Ageing, University of New South Wales, Scientia Prof Henry Brodaty AO, and Scientia Prof Perminder Sachdev AM; Assoc. Prof Wei Wen, School of Psychiatry

- Dementia in Intellectual Disability.
- Ageing in the general population.
- Genetics of ageing and age-related disorders.

Genetics of Age-Related Disorders.

- Neuroimaging in ageing and dementia.
- National Ageing Research Institute, Prof David Ames;

  QIMR Berghofer Medical Research Institute, Prof Nick

  Martin and A/Prof Margie Wright;

**EUroDisco Twin Consortium led by Prof Tim Spector, Institute of Psychiatry London** 

University of Adelaide School of Medicine: Prof Bernhard Baune,

Garvan Institute, Sydney, Prof Leslie Campbell, Prof Katherine Samaras, Prof Sam Breit, A/Prof David Brown Cooperative Research Centre for Living with Autistic Spectrum Disorders: Curtin University, Griffith university, La Trobe University, Mater Medical Research Institute, Queensland University of Technology, University of Queensland University of Western Australia, AEIOU Foundation, Autism Queensland, Autism Spectrum Australia, Queensland Department of Education, Training and Employment

- Neuroinflammation.
- Metabolic and cardiovascular factors in brain ageing.
- Autism Research Program including improving health, mental health and social participation.

#### Leadership of Key Research Programs

A complete list of funded research project are summarised in <u>Appendix D</u>. Exemplar projects include:

This research links the administrative datasets of health and disability sectors to build a detailed profile of the mental health of people with ID and to examine the relationship between mental health and patterns of service use across disability and health system. The feasibility of linkage was demonstrated with ambulatory mental health (MH-AMB) and disability data (DSMDS) in a representative sample of the NSW population and linkage has now been extended to a state-wide linkage between the DSMDS and inpatient mental health admissions and emergency department presentation data. These linkage projects will have substantial benefit in the understanding of the mental health and service use profiles of people with ID. Future linkage will allow examination of the impact of service enhancements and reform in IDMH.

- Strategies To Better Support People With ID At Risk Of Offending: UNSW Faculty of Arts and Social Sciences academics (Eileen Baldry, Leanne Dowse, and others), Justice Health, ADHC and other partners have collected a multiagency linked data set of individuals who have experienced contact with the criminal justice system as offenders. The Chair IDMH is currently investigating the mental health profile of those with cognitive disorder in this sample.
- Indigenous Australians with Cognitive Disabilities: An ARC Linkage grant (Baldry, Trollor, Dowse, Dodson and others) was awarded to develop a new focus on aboriginal people with cognitive disabilities. This innovative research examines data related to aboriginal offenders and also collects qualitative data obtained from fieldwork in metro, rural and remote indigenous communities. This work has substantial bearing on the understanding of the individual and service system factors associated with offending and re-offending in aboriginal people with cognitive disabilities, and on the planning of appropriate supports for these highly vulnerable populations.
- Healthy Ageing and Dementia in People with Intellectual Disability: Older people with an intellectual disability are at high risk of a range of health and mental health conditions including dementia. The rapid ageing of this population (which proportionately eclipses the expansion in the general elderly population) highlights the need for a more detailed understanding of the health and mental health of this group, and the impact of the ageing process on service use and carers. There are two formal studies being conducted in this area:

The Successful Ageing in Intellectual Disability (Sage-ID) Study is led by the Chair IDMH. The investigator team is diverse (see Table 2), and includes key collaborations with the UNSW Dementia Collaborative Research Centre and UNSW Centre for Healthy Brain Ageing, as well as Monash University and La Trobe University. The study is funded from a number of sources including HACC/FACS, the NSW Institute of Psychiatry, and the Dementia Collaborative Research Centres. Sage-ID has completed data collection, and cleaning for Wave 1, and is seeking funding for Wave 2. This study:

- Has established a cohort of 122 older people with ID (aged 40+ years, with any cause and level of severity of ID) and their carers for longitudinal study across two states (NSW and Victoria).
- Has a quantitative component about the person with ID which will deliver information about: (1) the health, mental health, cognitive and behavioural profiles of elders with ID; (2) the service use and support needs of elders with ID; (3) the performance of dementia screening instruments in a diverse group of people with ID; (4) the experiences of trauma and life events in people with ID; and (5) the feasibility of cognitive testing in elders with ID.
- Has a quantitative component about the carer of the person with ID which will deliver information about carer health and mental health, carer burden and coping style, and carer quality of life.
- Has a qualitative component which features focus groups with both carers and professionals. These groups have produced rich data sets which examine (1) carer and professional experiences as they care for or support a person with ID as they age or develop dementia; (2) examine issue of transition of care arrangements and (3) highlight the gaps in supports and services for elders with ID and their carers.

Is a longitudinal study, which, with further funding, will (1) deliver the capacity to test robustness & validity of screening instruments for dementia; (2) allow the development of improved understanding of the precursors and predictors of dementia and cognitive decline in elders with ID; (3) allow the development of recommendations for cost-effective screening for dementia and cognitive decline in people with ID; and (4) allow the development of appropriate service models for dementia and cognitive decline for people with ID and their carers.
And,

The Improving Service Delivery for Younger Onset Memory and Related Disorders (INSPIRED) Study is an NHMRC funded study which is the first comprehensive study of younger onset dementia (YOD) in Australia. As a Chief Investigator, the Chair IDMH is involved in all aspects of the study and specifically leads the intellectual disability components of the work. The needs of people with younger onset dementia (< 65 years of age) are poorly understood. The study comprises of two parts. The first is a quantitative study which examines the prevalence of YOD. This aims document the number of people with YOD, the aetiology of their dementia, the accuracy of the diagnosis, and their pathways to diagnosis and care. This information will help policy makers and service providers identify key priority areas, and to work with this population more effectively. The second component of the study examines the needs of people with YOD and their carers through in depth interviews and focus groups. This information will help identify the health and support service needs of this population, and will inform the development of training packages for health professionals working with people with YOD.

#### Specific Developmental and Related Disorders

The Chair IDMH is involved in research into specific disorders related to intellectual and developmental disability. These include:

- Fragile X Related Disorders
  Trollor is a CI on an ARC Discovery Grant, 'Are neurobehavioural and neuromotor signatures associated with FMR1 Gene expansion?' This research project examines the motor and neuropsychiatric profile of carriers of the premutation of the Fragile X gene. This work involves extensive collaboration with NSW and Victorian colleagues (see Table 2).
  - Autism Spectrum Disorders (ASD)

    The Autism CRC is an Australian Commonwealth Government Initiative in partnership with industry and key stakeholders. It provides the world's first national, cooperative research effort focussed on Autism, and has a budget of over \$31M over eight years. The Chair IDMH is involved in 'Program 3' of the research which aims to identify best practice in physical and mental health management, and improve opportunities for people with ASD to successfully transition to post-school life and participate in higher education and employment. This initiative will inform the basis for a focus on adults with ASD in the proposed work plan of the Chair over the next five years.

#### **Other Research Programs**

The Chair IDMH has an active role as a Chief Investigator in two large NHMRC funded studies, the *Sydney Memory and Ageing Study (MAS)* and the *Older Australian Twins Study (OATS)*. The MAS study is a large study which examines the predictors of cognitive decline and dementia in an elderly cohort who were non-demented at baseline. The OATS project is a large study of the genetic and environmental influences on ageing and age-related disorders in the elderly.

# Successfully Supervising Higher Degree and Research Students to Completion

Since taking up the role, the Chair IDMH has successfully supervised to completion six PhD (two full supervision, four co-supervision) students, two Honours students and seven UNSW Medicine Independent Learning Project students. Details for the completed PhD and Honours theses are listed below:

#### PhD Thesis Completions

- 'Grey matter morphological changes in late life using magnetic resonance imaging technique', Haobo Zhang, Psychiatry, Faculty of Medicine, University of New South Wales, Thesis (PhD) 2011; main supervisor.
- 'Cardiovascular risk factors for falls in older people', Wong, Kwok Wai Alfred, Clinical School - Prince of Wales Hospital, Faculty of Medicine, University of New South Wales, Thesis (M.D) 2011; co-supervisor.
- 'Diffusion tensor imaging in the early diagnosis of Alzheimer's disease'. Lin Zhuang, Psychiatry, Faculty of Medicine, University of New South Wales, Thesis (PhD), 2012; co-supervisor.
- 'Genetic and environmental influences on neuropsychological functioning in later life: the older Australian twins study', Teresa Lee, Psychiatry, Faculty of Medicine, University of New South Wales, Thesis (PhD) 2013; co-supervisor.
- 'Genetic and environmental influences on brain structure and biochemistry in the elderly: data from the older Australian twins study', Seyed Amir Hossein Batouli, Psychiatry, University of New South Wales, Thesis (PhD) 2013; main supervisor.
- 'Morphological Analysis of Cerebral Cortex based on Magnetic Resonance Imaging in the Elderly', Tao Liu, University of Technology, Sydney, Thesis (PhD) 2013; co-supervisor

#### Honours Thesis Completions

- 'Prevalence and functional significance of microbleeds in an elderly healthy population using susceptibility weighted imaging', Adam Seruga, BSc(Med)Hon program, 2009; cosupervisor.
- 'Heritability of Excessive Daytime Sleepiness and associated inflammation and in Older Australian Twins', Tanya Duckworth, Psychology (Hon) Program, CQ University Australia, 2013; co-supervisor.

#### **Obtaining Other Research Awards**

 The Chair IDMH has supervised three successful Research Fellowships from the NSW Institute of Psychiatry: Dr Liz Evans, and Ms Rachael Birch (first and second Fellowship awards).

#### Partnering with Stakeholders in Nationally Competitive Research Grant Success

- NHMRC Partnerships for Better Health project Improving the Mental Health Outcomes of People with Intellectual Disability
  - The Chair IDMH led a successful application for an NHMRC Partnerships for Better Health grant which will commence in 2014. This project has secured funding of \$2.3M for four years to collaborate with key mental health, disability, education, justice and consumer agencies to undertake the following work:
  - Create an annualised linkage of administrative minimum datasets of our partners to enable a detailed examination of mental health profiles and service utilisation, patterns of cross-sector service provision including specific gaps, the impact of recent service initiatives for people with ID, and to enable comprehensive development of ID mental health services in NSW.
  - Analyse Commonwealth and State mental health policy to determine the current representation of people with ID and to establish strategies which will enhance ID mental health policy.
  - Engage with stakeholders including consumers and support persons (including family and non-family carers), to inform improved recognition of mental ill health, accessibility of mental health services and mental health policy for people with ID across the lifespan.

This project is due to commence in mid-2014 and will develop an evidence base that will guide the development of clinical services and policy for people with ID and mental illness at both a Commonwealth and State level to meet the fundamental right of people with ID to access quality mental health support.

#### Contributions to IDMH Research Capacity Building

The Chair IDMH has made the following contributions:

- As Joint Co-Chair of the Research and Development Subcommittee of the Intellectual Disability Network of the Agency for Clinical Innovation, the achievements have been:
  - i. Undertaking an audit of ID research and research capacity in NSW (the final report is available on the <u>ACI website</u>).
  - ii. Shortlisting research priorities in IDMH.
- As member of the NSW Mental Health Commission's Research Advisory Committee, the Chair IDMH has provided advice on capacity in research and IDMH research to the NSW Mental Health Commission which will directly inform the Commission's strategic plan.
- Reviewed grants in IDHM for large granting bodies including Australian Research Council (ARC), National Health and Medical Research Council (NHMRC) and Alzheimer's USA.

# Consultancy

Significant progress has been made under this strategic priority of Consultancy, which involves both the work undertaken by the Chair IDMH with government and policy makers and the direct clinical capacity that has been developed by the Chair IDMH. Key and exemplary submissions in the following areas are provided below:

i) legislative reviews,

- ii) workforce and capacity building,
- iii) policy,
- iv) direct ministerial advice and consultation and
- v) clinical services.

A comprehensive list of our representations in these areas can also be found on our website.

#### Legislative & Legal

The following submissions have been made:

- Submission to the Draft Disability Inclusion Bill, 2014
- Submission to the Review of the NSW Disability Services Act 1993, 2013.
- Expert legal report on matter for the NSW Disability Services Minister, 2012
- Submission to the Review of the NSW Mental Health Act 2007, 2012.
- Submission to the Senate Committee on the (Draft) Human Rights Bill, 2012.
- Chair IDMH contribution to the NSW Law Reform Commission consultation related to people with cognitive disability, 2011.

#### Workforce & Capacity Building

The following submissions and reports have been made:

- Report for the NSW Mental Health Commission: Clinical Services Planning for Adults with ID & Co-occurring Mental Disorders, 2013.
- Chair IDMH and CID Submission to the National Mental Health Commission National Mental Health & Suicide Prevention Report Card, 2012.
- Correspondence to Mental Health Workforce Advisory Committee & Health Workforce Australia on National Mental Health Practice Standards & Competencies, 2012.
- Submission to NSW Health on the draft NSW Mental Health Services Competency Framework, 2012.
- Submission on Proposed Draft National Mental Health Roadmap, 2012.
- Report to Office of Senior Practitioner: Mental Disorders in ID Survey & Training Workshop, 2011.
- Submission to the Senate Inquiry into Mental Health Reform, 2011.
- Chair IDMH and ADHC Joint Submission to the National Partnership Agreement on Supporting National Mental Health Reform, 2011.
- Chair IDMH contribution to ADIDD Submission to NSW Legislative Council Inquiry into Services Provided or Funded by ADHC, 2010.
- Chair IDMH contribution to CID and AADDM Position Statement, 2010.

#### Policy

The Chair has made the following reports and submissions:

- Accessible Mental Health Services For People with an Intellectual Disability: A Guide for Providers, Launch May 2014.
- Chair IDMH contribution to CID Communique from the National Roundtable on the Mental Health of People with Intellectual Disability, 2013.
- Correspondence to Healthcare Management Advisors (HMA) on proposed National Mental Health & Suicide Prevention Report Card, 2012.
- Chair IDMH and CID submission to the National Mental Health Commission National Mental Health & Suicide Prevention Report Card, 2012.

- Submission on Proposed Draft National Mental Health Roadmap, 2012.
- Submission to the Senate Inquiry into Mental Health Reform, 2011.
- Chair IDMH and ADHC Joint Submission to the National Partnership Agreement on Supporting National Mental Health Reform, 2011.

#### **Direct Ministerial Advice and Consultation**

The Chair IDMH also makes regular representations and provides advice to Government on the issue of mental illness and accessibility of services to people with an ID, such as:

- Three direct representations with the Secretary of the Australian Commonwealth Government Department of Health, Professor Jane Halton (2012, 2013, 2014).
- Written representations to the current Australian Commonwealth Government Minister of Health, Hon Peter Dutton.
- To the former Australian Commonwealth Government Minister for Mental Health, Hon Mark Butler.
- To the former Australian Commonwealth Government Shadow Minister for Mental Health, Hon Concetta Fierravanti-Wells.
- Annual direct representation to the former and current NSW State Government Minister's for Disability Services (Hon Andrew Constance and current, Hon John Ajaka).
- Annual direct representation to the NSW State Government Minister for Mental Health, Hon Kevin Humphries.
- Provision of direct advice to the NSW State Mental Health Minister, Hon Kevin Humphries office as required on legislative and related matters related to people with cognitive disability.

#### **Clinical Services**

Also under the scope of the Consultancy domain are the contributions and leadership that the Chair IDMH regularly makes to clinical services. This includes:

Tertiary consultations through the Clinic for the Assessment of Neuropsychiatric Disorders in Intellectual Disability (CANDID)

CANDID is based on a tertiary clinic model, and provides an outpatient service which supports specialists working with people with intellectual disability. The clinic provides second opinions in complex cases or situations where there is lack of consensus. It has received referrals from the public mental health sector, forensic mental health services and from private specialists. The clinic is an important training resource for psychiatry trainees and Intellectual Disability Mental Health Fellows. The clinic has also contributed to cross sector capacity building by hosting ADHC regional behavioural support staff.

#### Community Clinic

The Chair IDMH supervises a secondary clinic model embedded within the NSW South Eastern Sydney Local Health District (LHD) with the aim of improving service provision of the local mental health team for people with ID. This clinic is primarily staffed by the ID Mental Health Fellow, with input from the Chair and review of cases as required.

Community Outreach Model of Service Provision (MRID.Net)

The Chair IDMH was part of the successful South Eastern Sydney Local Health District tender for NSW Ministry of Health Funded ID health service pilot. This pilot, MRID.net, involves extensive collaboration between leaders of this pilot program and NSW Ministry of Health, NSW Department of Family and Community Services (Ageing Disability and Home Care), the Agency for Clinical Innovation - ID and Transition Networks, the NSW Department of Education & Communities, Aboriginal Medical Services, GP Rural and Urban Divisions and a variety of non-government agencies, including The Disability Trust. The model has attracted extra funding of psychiatrist trainee positions from the Australian Government, and uses an outreach and technology based model to improve existing health care services through consultations, support and training for health and disability professionals and service providers.

#### Additional Consultations

The Chair IDMH provides additional consultation capacity through the following initiatives:

- Consultation to LHDs for complex cases.
- Phone consultation service for NSW mental health clinicians regarding complex cases.
- Consultation to inpatient services of the Prince of Wales Hospital.
- Consultation service to the inpatient facilities of Eastern Suburbs Mental Health Service.
- Participation in the General Adult Psychiatry on call roster for general mental health in Eastern Suburbs mental health service.

# **Concluding Remarks**

The Chair IDMH has established a unique academic unit in Australia which is tasked with building capacity in a much needed field. The past five years have seen substantial gains in the sector which have far exceeded the initial scope proposed for the Chair by the funder. The Chair is committed to improving the mental health and wellbeing of people with an ID and has a clearly articulated strategy and work plan to achieve this over the coming years. The next five years will see substantial maturation of the Chair's program, with clear translational benefits for people with an intellectual disability, their carers, those providing both mental health and disability services and for multiagency capacity building and cooperation. The continued work of the Chair IDMH will help ensure that this vulnerable population group is no longer marginalised and does not continue to fall through the gaps. It will ensure that this population is proactively included in health and social services policy and practice, and that potential is maximised for individuals with ID to lead a contributing life.

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#### APPENDIX A: About the Current Chair IDMH

Associate Professor Trollor is the current and inaugural Chair of Intellectual Disability Mental Health at UNSW Australia. He is a neuropsychiatrist within South Eastern Sydney Local Health District, where he leads clinical service development, supervises specialist trainees and provides direct clinical services to people with ID. At UNSW he has dedicated himself to building initiatives to improve access to mental health services for people with intellectual and developmental disabilities. He is overseeing State government funded training positions for psychiatry trainees in ID mental health and contributes to the mental health component of a NSW Health sponsored specialist ID/DD health pilot. He is committed to ID health reform and policy development, and believes that such developments should be firmly based on data and that this data is actively sought and derived from multiple sources, such as epidemiological studies, administrative datasets and the lived experience of people with ID and their carers.

Trollor has been at the forefront of National and International developments in ID over the past five years. Trollor has been awarded career total funding of over \$14M, including nationally competitive research grants totalling over \$9M, other research funding of over \$2M and other projects of over \$3M. The national grants he currently holds include an Australian Research Council (ARC) Linkage grant, an ARC Discovery grant, an NHMRC Partnership for Better Health grant and two NHMRC Project grants. Trollor provides supervision to higher degree students (5 completed PhDs, 6 current PhDs; 1 completed Master's, and 1 current Master's) and he trains and mentors ID and mental health psychiatry trainees (5 completed and one current).

Trollor understands the importance of working across sectors to improve access to mental health services and supports for people with ID.

# **APPENDIX B: Peer Reviewed Publications and Reports**

The following provides a list of all peer reviewed publications, policy and legislative review submissions, and other written submissions prepared by the Chair and 3DN since commencement in 2009. In summary, the Chair has published 108 peer reviewed publications (including published abstracts and book chapters), and he and his team have been highly proactive in contributing to policy and legislative developments in both disability and disability health. Peer reviewed publications have been diverse and reflect the neuropsychiatry background of the Chair. An expanded publication focus specific to intellectual and developmental disability will be possible from 2014 onward as the intellectual and developmental disability research program matures.

#### 3DN Peer Reviewed Publications

- 1. Batouli, S.A.H., Sachdev, P.S., Wen, W., **Trollor, J.N.**, Wright, M.J., Ames, D. Heritability of brain volumes in older adults: The Older Australian Twins Study. *Neurobiology of Aging*, 2014; *35*(4), 937.e935–937.e918.
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#### 3DN Book Chapters

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#### 3DN Publications, Reports and Submissions (Other)

- 2014 Submission to NSW Department of Family & Community Services on the Exposure Draft of the *Disability Inclusion Bill 2014*.
- 2013 Submission to the NSW MH Commission on for clinical services for adults with an intellectual disability. *Clinical Services Planning for Adults with an Intellectual Disability (ID) and Co-occurring Mental Disorders*.
- 2013 Submission to the Review of the NSW Disability Services Act 1993.
- 2013 Update on Intellectual Disability Mental Health Data Linkage Project; CIG Newsletter January 2013.
- 2013 Submission to NSW MH Commission. Engagement strategy for consultation with people

with an intellectual disability.

occurring mental ill health

- 2012 Submission to the Review of the NSW Mental Health Act 2007.
- 2012 Submission to the National Mental Health Commission on the proposed National Mental Health & Suicide Prevention Report Card
- 2012 Submission to Senate Committee Inquiry into the Exposure Draft of Human Rights and Anti-Discrimination Bill 2012.
- 2012 Submission to the Department of Health on the Proposed Draft Mental Health Roadmap.
- 2012 Submission to the Healthcare Management Association (AMA) on the proposed National Mental Health & Suicide Prevention Report Card

  Title: "Dual diagnosis: The importance of a national report card that describes and
  - Title: "Dual diagnosis: The importance of a national report card that describes and measures the experiences and outcomes of Australians with an intellectual disability and mental illness"
- 2012 Submission to Mental Health Workforce Advisory Committee and Health Workforce
  Australia on the proposed changes to the National Mental Health Practice Standards and
  the development of National Common Health Competencies

  Title: Discussion Paper on the needs of people with an intellectual disability and co-
- 2012 Submission to NSW Health on the draft NSW Mental Health Services Competency Framework
- 2011 Submission to the Senate Standing Committees on Community Affairs Inquiry into Commonwealth Funding and Administration of Mental Health Services
- 2011 Joint Submission (with ADHC) to National Partnership Agreement On Supporting National Mental Health Reform.
- 2011 Intellectual Disability Mental Health Data Linkage Project Article for OSP June 2011
- 2011 Howlett, S. "Falling through the gaps the unmet mental health needs of people with intellectual disability" retrieved from:

  <a href="http://blogs.crikey.com.au/croakey/2011/12/20/falling-through-the-gaps-the-unmet-mental-health-needs-of-people-with-intellectual-disability/">http://blogs.crikey.com.au/croakey/2011/12/20/falling-through-the-gaps-the-unmet-mental-health-needs-of-people-with-intellectual-disability/</a>
- 2011 Submission to the ADHC Reference Group on Offenders with ID.
- 2010 Intellectual Disability Mental Health Workshops Attract Interest Article for OSP Newsletter Oct 2010
- 2010 Intellectual Disability Mental Health Workshops Attract Interest Article for AADDM Oct 2010
- 2010 Submission to NSW Legislative Council Inquiry into Services Provided or Funded by ADHC
- 2010 'Position Statement on the Health of People with Intellectual Disability' Joint Statement by 3DN, NSW CID & AADDM.

# APPENDIX C: Chair IDMH and 3DN Presentations (2009 – present)

The Chair IDMH and 3DN staff have been highly productive in presenting their work to diverse national and international audiences. The Chair IDMH has consistently been invited to provide keynote presentations, an indication of the high degree of interest in the activities of the Chair IDMH, particular within national forums.

Note: \*denotes capacity building presentations in IDMH. Unless otherwise specified, presentation was by the Chair IDMH.

#### International Keynote Presentations

- The Expanding Family of Fragile X Associated Disorders, Trollor J., Birch R. Symposium. 9th Congress of the International Neuropsychiatric Association, Chicago, Illinois, USA, 26 September 2013
- 2. Dementia in People with Intellectual Disability. 8th International Congress of the International Neuropsychiatry Association (INA), Chennai India, 16 18 September 2011
- 3. Is Intellectual Disability Mental Health Core Business for Neuropsychiatry? 8th International Congress of the International Neuropsychiatry Association (INA), Chennai India, 16 18 September 2011
- 4. Making Sense of ADHD Symptoms in Adults with Intellectual Disability. INA Congress, Lima, Peru June 2010.
- 5. Adult ADHD: A Lifespan Perspective. World Congress of Internal Medicine 2010, Melbourne, March 2010.
- 6. Does inflammation affect cognition in the elderly? International Neuropsychiatric Association Conference 2009, Kobe, Japan, September 2009.

#### International Presentations (Other)

- 7. Doubly Disadvantaged: Addressing stigma experienced by people with coexisting mental illness and intellectual disability in the Human Services sector. Ponzio, V., Trollor J. 5th International Stigma Conference: Together Against Stigma: Changing how we see mental illness, Ottawa, Canada, June 4-6, 2012
- 8. Glucose disorders exert a detrimental effect on total brain volume in the elderly: a 2-year prospective MRI study. Samaras, K., Lutgers, H., Wen, W., Campbell, L., Baune, B., Brodaty, H., Trollor, J., Sachdev, P. 15th International & 14th European Congress of Endocrinology, Florence, Italy, May 5-9, 2012
- 9. The burden of disease in elderly people with IFG. Lutgers, H., Campbell, L., Baune, B., Brodaty, H., Trollor, J., Sachdev, P., Samaras, K. 15th International & 14th European Congress of Endocrinology, Florence, Italy, May 5-9, 2012
- Enhancing clinician confidence, assessment ability and management of mood disorders in adults with an Intellectual Disability workshop convened at RANZCP Congress, Auckland, New Zealand, May 2010
- 11. Mental Health Services for People with Intellectual Disability in Australia and New Zealand: Conceptual Framework, Current Status and Future Goals symposium convened at RANZCP Congress, Auckland, New Zealand, May 2010
- 12. Mental Health Services for People with an Intellectual Disability: A Human Rights Perspective on Service Provision and Development. RANZCP Congress, Auckland,

- New Zealand, May 2010
- 13. Challenging Behaviour and Neuropsychiatric Disorders in People with Intellectual Disability RANZCP Congress, Auckland, New Zealand, May 2010
- Neuropsychiatry and Intellectual Disabilities symposium convened at RANZCP Congress, Auckland, New Zealand, May 2010
- 15 Successful Ageing in Intellectual Disability, Bhardwaj, A., IASSID 2013 Conference, Tokyo Japan, 23 August 2013
- Cognitive and neuropsychiatric features of fragile X-associated tremor ataxia syndrome (FXTAS): A systematic review. Birch, R. C., Cornish, K. M., Hocking, D. R., & Trollor, J. N. 1st International Conference on the FMR1 Premutation: Basic Mechanisms and Clinical Involvement, Perugia, Italy, 2013

# **National Keynote Presentations**

- 17. \*Improving the mental health of people with an intellectual disability presentation on maintaining wellbeing in people with intellectual disability, 2013 Special Olympics Asia Pacific Games "Our Time to Shine" Health Symposium, New Castle, 1 December 2013
- \*Accessible mental health services for people with intellectual disability: Implications for disability service providers, Trollor, J. Keynote speaker. Mental Health & Intellectual Disability, Untangling the knots and working together for better personal outcomes, Metro North BIS 14th Symposium Sydney 27 August 2013
- \*Understanding and Addressing Mental Health Inequalities in People with Intellectual Disability, Ageing, Mental Health and Intellectual Disability forum "Ageing and Intellectual Disability: Staying well & included", Bendigo, February 2013
- 20. \*Building Capacity in Intellectual Disability Mental Health "You've Got to Pick a Pocket or Two", Trollor, J., 23rd PANDDA Conference: Great Expectations, Sydney, 27 November 2012
- 21. \*Improving the Mental Health of People with Intellectual Disability. Australian Association of Developmental Disability Medicine (AADDM) 2012 Conference, Sydney, March 8-10, 2012
- \*Intellectual Disability Mental Health Update and Intellectual Disability Mental Health Building Capacity Across Sectors, Trollor J., Invited Presentation, ADHC Annual Training Day, Sydney, 28 November 2011
- 23. \*Mental Disorders in People with Intellectual Disability & A Criminal Justice System Perspective, Australian Custodian Medical Officer's Conference, Sydney, Coogee, November 20, 2011
- 24. \*Improving the Mental Health of Adults with Intellectual Disability presented at 2010 BIS Training Course, Sydney, November 2010.
- 25. \*Challenging Behaviour and Mental Disorder in Intellectual Disability: The Case for Integrated Service Provision. Presented at 45th ASSID Conference, Brisbane, October 2010.
- 26. \*TSC and Mental Health in Adulthood presented to Australasian Tuberous Sclerosis Society's Seminar Day, Randwick, August 2010.
- 27. \*Mental Health Services for People with an Intellectual Disability: A Human Rights Perspective on Service Provision and Development presentation to the Office of the Public Guardian, Sydney, July 2010
- 28. \*Challenging Behaviour and Mental Disorder in Intellectual Disability: The Case for Integrated Service Provision, Trollor J., Keynote Presentation, PSYCHDD Conference

- 2009, Sydney, 2 November 2009
- 29. \*New Horizons in Mental Health Care for People with an Intellectual Disability. Association of Doctors in Developmental Disability Annual Conference, Westmead, October 2009.
- 30. \*Challenging Behaviour and Mental Disorder in Intellectual Disability: Separable or Inseparable? 20th Annual PANDDA Conference and AGM, Sydney, August 2009.

#### **National Invited Presentations**

- 31. Accessible Mental Health Services for People with an Intellectual Disability, Trollor, J., National Disability Services NSW State Conference, Sydney, 10 & 11 February 2014
- \* Intellectual Disability and Justice Health Practical Guidance, Trollor, J., 2013 Australasian Medical Officers Conference 'Safety First', Sydney, 23 & 24 November 2013
- 33. \*Intellectual Disability Mental Health (IDMH): Building Workforce Capacity in the Public Mental Health Sector, Trollor, J. Invited presentation. Sutherland Hospital Mental Health Grand Rounds, Sutherland Hospital, Sydney, 10 October 2013
- 34. \*Metabolic and Inflammatory Factors, Centre for Healthy Brain Ageing (CHeBA) Research Day, Trollor J., Samaras, K., CheBA, UNSW, Sydney 8 October 2013
- 35. \*Intellectual Disability Mental Health (IDMH): Building Workforce Capacity in the Public Mental Health Sector, Trollor J., NSW Health Mental Health Program Council Meeting 13-03, Sydney, 6 September 2013
- 36. \*Intellectual Disability Mental Health (IDMH) Building Workforce Capacity in the Forensic Mental Health Sector, Trollor J., Justice Health & Forensic Mental Health Network, NSW Ministry of Health, Sydney, 15 August 2013
- 37. \*Intellectual Disability Mental Health (IDMH) Building Workforce Capacity in the Public Mental Health Sector, Trollor, J., CAC Clinical Advisory Council, Mental Health and Drug & Alcohol Office, NSW Ministry of Health Sydney, 26 July 2013
- 38. \*Local Initiatives Addressing Mental Health Inequalities in People with Intellectual Disability, Trollor J., Florio T., Clinical Council Meeting, Mental Health Centre, St George Hospital, Kogarah, Sydney, 28 February 2013
- \*Making Sense of ADHD Symptoms in People with Intellectual Disability, Trollor, J.,
   Sydney, 14 December 2012
- 40. \*Management of mental illness in people with ID: focus on psychotropic medication, Trollor, J., ADHC Psychologists Presentation, Rosebery, Sydney, 3 December 2012
- 41. Intellectual Disability, Trollor, J., Florio, T., SESLHD Mental Health Clinical Council Meeting, District Office Kogarah, Sydney, 22 November 2012
- 42. \*Fragile X: One Gene, Three Syndromes, The Royal Australian and New Zealand College of Psychiatrists (RANZCP) 2012 Congress "Cells, Circuits and Syndromes", Hobart 20–24 May 2012
- 43. \*Improving the Mental Health of People with Intellectual Disability, Current Status and Potential Role of the SIGPIDD. Trollor, J., Johnson, K. The Royal Australian and New Zealand College of Psychiatrists (RANZCP) 2012 Congress "Cells, Circuits and Syndromes", Hobart 20–24 May 2012
- 44. Forum on Intellectual Disability and Mental Health in Young People aged 14 to 24 years, Trollor, J., University of Wollongong, 3 November 2011
- 45. \*Making Sense of ADHD Symptoms in People with Intellectual Disability, Trollor J., Invited Presentation, ADHD Interest Group, Academic Forum Children's Hospital, Sydney, 13 October 2011

- \*Why is Dementia Common? Priorities for Translational Research. National Dementia Research (DCRC) Forum 2011, Sydney, September 22-23, 2011
- 47. Neuropsychiatry and Intellectual Disability, Trollor J., RANZCP Head Quarters, Sydney, 25 August 2011
- 48. \*People with Intellectual Disability in the Criminal Justice System, Trollor J., Statewide Disability Services Meeting, Long Bay Correctional Complex, Sydney, 17 June 2011
- 49. \*Mental Health and Intellectual Disability: An interdisciplinary panel discussion Webinar convened by Mental Health Professionals Network Ltd, Sydney June 2011
- \*The Place of People with Intellectual Disability in Mental Health Reform & Key Issues and Launch of an RANZCP endorsed Position Statement. Trollor, J., Tomasic, M. The Royal Australian & New Zealand College of Psychiatrists (RANZCP) 2011 Congress, Darwin, 29 May 2 June 2011
- 51. \*Chair IDMH Progress and Proposals, Trollor J., Office of the Senior Practitioner Executive Meeting, Sydney, 17 January 2011
- \*Intellectual Disability and Crime, Ellis A., Trollor J., Justice Health Educational Series, Invited Speaker, Sydney, 2 December 2010
- \*Mood Disorders in Adults with Intellectual Disability: Presentations and Pitfalls presented to the Australian Psychological Society, Sydney, November 2010.
- 54. \*Intellectual Disability Mental Health: Focus on Management; Initiatives and Ageing: Progress and Proposals, Trollor J., Office of the Senior Practitioner Executive Meeting, Sydney, 11 October 2010
- \*Mood Disorders in Adults with Intellectual Disability: Presentations and Pitfalls. Presented at 45th ASSID Conference, Brisbane, October 2010.
- 56. \*Hypothetically Speaking; guest panellist at the 45th ASSID Conference, Brisbane, October 2010
- 57. \*Ageing and Cognitive Decline in Intellectual Disability Trollor J. Lecture for the SES LHD Psychiatric Trainee Teaching Sessions, September 2010
- 58. \*Improving the Mental Health of Adults with Intellectual Disability presented to Nepean Hospital Department of Psychological Medicine Academic Meeting, September 2010
- 59. \*Human Rights Issues for people with Intellectual Disability and Mental Health. Forum on Mental Disorders in Children & Adolescents with an Intellectual Disability for clinicians, educators and other professionals. Sutherland, September 2010
- 60. \*Improving the Mental Health of Adults with Intellectual Disability presented to Mental Health Priority Taskforce, Sydney, August 2010.
- \*Developments and Initiatives in Intellectual Disability Mental Health presentation to Mental Health Clinical Advisory Council, June 2010
- \*The Ageing Patients with a Developmental Disability Ageing and Cognitive Decline in Intellectual Disability. Presentation to Aged Care Psychiatry, May 2010
- \*Mental Health Services for People with Intellectual Disability what should shape Service Provision & Development? Hunter New England Area Health Service, May 2010.
- \*Diagnosing ADHD in Adults: Discerning the Wood from the Trees ADHD Across the Lifespan - a comprehensive approach to assessment and treatment, including implications of the new NHMRC Guidelines Conference, Macquarie University, March 2010
- \*Adult ADHD: Contentious Issues in diagnosis and treatment- Part 2 presented to NSW Department of Justice Health, Long Bay Jail, Malabar February 2010.

- \*The older person with an intellectual disability. Presentation to Aged Care Assessment Team, Prince of Wales Hospital, February 2010.
- 67. \*Chair IDMH Development and Research, State Wide Behaviour Intervention Service, Invited presentation, Trollor J, Ryde, Sydney, January 2010
- 68. \*Adult ADHD: Contentious Issues in Diagnosis and Management. Long Bay Gaol, Sydney, September 2009.
- \*Vagus Nerve Stimulation: Emerging treatment or flash in the pan? Country Psychiatrists Association of New South Wales 22nd Annual Conference, Port Macquarie, April 2009
- 70. \*Ageing and Intellectual Disability. Country Psychiatrists Association of New South Wales 22nd Annual Conference, Port Macquarie, April 2009

#### **Other Presentations**

- 71. Chair IDMH Presentation, Trollor, J., FACSAR Knowledge Transfer Seminar Series, FACS Analysis and Research, Family and Community Services, Sydney, 18 February 2014
- 72. Linking Disability and Mental Health Data: Improving Mental Health Outcomes for Persons With An Intellectual Disability. Howlett, S. ASID Conference, Sydney, NSW, 2013
- \*Meeting the Needs of Marginalised Population Groups in the Health System: People with Intellectual Disability and Co-occurring Mental Illness, Govett, J., Howlett, S., Kremser, T., Trollor, J. The Royal Australian and New Zealand College of Psychiatrists (RANZCP) 2013 Congress "Achievements and Aspirations", Sydney 26-30 May 2013
- 74. Successful Ageing in Intellectual Disability (SAge-ID), Bhardwaj, A., Turner, B., ASID 2013 Conference, Sydney, 6 November 2013
- 75. An analysis of the capacity of the mental health workforce in NSW, Govett, J., ASID 2013 Conference, Sydney, 8 November 2013
- 76. Linking Disability And Mental Health Data: Improving Mental Health Outcomes for Persons With An Intellectual Disability, Howlett, S., ASID 2013 Conference, Sydney, November 2013
- 77. Building mental health workforce capacity in the area of intellectual disability mental health. Govett, J. et al. The Australasian Society for Intellectual Disability Annual Conference, Sydney, November, 2013
- 78. Mental health in older adults with intellectual disability and their family carers: The Successful Ageing in Intellectual Disability Study. Bhardwaj, A, B & Turner, B, R. ASID conference, Sydney, November 2013
- 79. Intellectual disability mental health: educating the workforce, Kremser T., ASID 2013 Conference, Sydney, 8 November 2013
- 80. Meeting the needs of marginalised population groups in the Health System: People with intellectual disability and co-occurring mental illness, Govett, J., RANZCP 2013 Congress, Sydney, 29 May 2013
- 81. Intellectual Disability Mental Health: Using data to improve Mental Health Outcomes for People with ID, Howlett, S., RANZCP 2013 Congress, Sydney, 29 May 2013
- 82. Intellectual disability mental health: Educating the workforce, Kremser, T., RANZCP 2013 Congress, Sydney, 29 May 2013
- 83. Intellectual Disability Mental Health: Using data to improve Mental Health Outcomes for People with ID. Howlett, S. RANZCP Congress Sydney, NSW, 2013

- \*Psychiatric Illness And Behavioural Disorders In Adults With Autism: Essential Management Skills For The Psychiatrist, d'Abrera, C., Franklin, C., O'Brien,G., Trollor, J. Psychotropic Medication Use in Adults with Autistic disorder: Principles, The Royal Australian and New Zealand College of Psychiatrists (RANZCP) 2013 Congress "Achievements and Aspirations", Sydney 26-30 May 2013
- 85. \*Accessible Mental Health Services for People with ID: A guide for Providers, National IDMH Roundtable on the Mental Health of People with Intellectual Disability, Canberra, 21-22 May 2013
- 86. Online learning, Kremser, T., ACI Workforce and Capacity subcommittee meeting invited presentation, Sydney, 23 July 2012
- 87. Intellectual Disability Mental Health Data Linkage: A NSW Pilot Project, Howlett, S. AADDM 2012 Conference, UNSW, Sydney, 9 March 2012
- 88. Intellectual disability mental health: Educating the workforce, Kremser, T., AADDM 2012 Conference, UNSW, Sydney, 9 March 2012
- 89. \*Healthy Minds, Healthy Brains, Trollor, J., Community forum Embracing Life and Ageing Forum, Sydney, 30 October 2012
- 90. Successful Ageing in Intellectual Disability (SAge-ID), The SAge-ID Study and tools to diagnose dementia in older adults with intellectual disability. Evans, E., Presentation to the Ageing, Disability and Home Care (ADHC) Non-Government Organisation Agency Meeting Day, Sydney, 24 August 2011
- 91. \*Is challenging behaviour in people with intellectual disability core business for psychiatrists. Trollor, J., Evans, E. The Royal Australian & New Zealand College of Psychiatrists (RANZCP) 2011 Congress, Darwin, 31 May 2011
- \*Intellectual disability mental health: a survey and a workshop. The Royal Australian & New Zealand College of Psychiatrists (RANZCP) 2011 Congress, Darwin, 31 May 2011
- 93. \*Neuropsychiatry and Intellectual Disability. The Royal Australian & New Zealand College of Psychiatrists (RANZCP) 2011 Congress, Darwin, 31 May 2011
- 94. Screening for dementia in people with Intellectual Disability, Evans, E., PsychDD Conference, Sydney, November 2011
- 95. Mowat-Wilson syndrome, Evans, E., 14th Scientific Meeting of the Society for the Study of Behavioural Phenotypes, Brisbane, October 2011
- 96. An examination of neuromotor and brain 'signatures' in FMR1 premutation carriers, Birch R., Fragile X Research Symposium, Brisbane, 4 October 2011
- 97. Is challenging behaviour in people with intellectual disability core business for psychiatrists?, Trollor, J., Evans, E., RANZCP Congress, Darwin, June 2011
- 98. Inflammatory Remarks about Ageing. School of Psychiatry Academic Meeting, June 2010
- 99. Intellectual Disability Mental Health: Attitudes, Confidence and Learning Needs of Mental Health Staff, Kremser, T., Psych DD Conference, Sydney, 26 November 2010
- 100. The Predictors and Correlates of Cognitive Decline in Elders with ID: Introducing the Successful Ageing in ID Study Protocol, Evans, E., National Dementia Research Forum, Surfers Paradise, September 2010
- 101. The Predictors and Correlates of Cognitive Decline in Elders with ID: Introducing the Successful Ageing in ID Study Protocol. Evans, E. Trollor, J., Poster presented at the National Dementia Research Forum, Surfers Paradise, September 2010

102. The Tuberous Sclerosis Complex (TSC) & Mental Health in Adulthood, Evans, E., Trollor, J., Australasian Tuberous Sclerosis Society's Seminar Day, Randwick, Sydney, August 2010

# APPENDIX D: Summary of Funded Projects (2009 – Present)

The following is a list of research and capacity building projects for which the Chair IDMH has received funding, either as Sole, Lead or Chief Investigator. This demonstrates the capacity of the Chair IDMH in raising the profile of this issue and in generating external funding for the work of the Chair IDMH.

#### Nationally Competitive Research Grants

- NHMRC Project Grant APP1060524; 2014-2017, Total Funding \$713,447. Defining the Role of Inflammation in Depression during Ageing (Baune, Cohen-Woods, **Trollor**, Reppermund)
- 2. NHMRC Partnership Project APP1056128; 2013-2017, Total funding \$2,308,058 NHMRC funding \$1,133,558, Partner contribution \$1,174,500. Improving the Mental Health Outcomes of People with Intellectual Disability (**Trollor**, Emerson, Lenroot, Dowse, Fisher, Johnson, Dean)
- 3. NHMRC Project Grant Application APP1045325; 2013-2016, \$912,023. The Older Australian Twins Study (OATS) of healthy brain ageing and age-related neurocognitive disorders (Sachdev, Wright, Ames, **Trollor**, Wen, Baune, Lee, Crawford)
- 4. NHMRC Project Grant / Seed funding; 2012; \$181,265. Genetic and environmental contributions to amyloid burden in older Australians: a PiB-PET imaging study of twins (Slavin, Rowe, Wen, **Trollor**)
- 5. The Mason Foundation Medical & Scientific Research Grant; 2011; \$49,801. Alzheimer's Disease: Caring for the carers health and wellbeing of rural families supporting elders with intellectual disabilities showing signs of Alzheimer's Disease (Iacono, Torr, **Trollor**)
- NHMRC Project Grant APP1008267; 2011-2013; \$715,350. Improving Service Provision for Early Onset Dementia: The INSPIRED Study (Draper, Cumming, Loy, Quine, Trollor, Withall)
- 7. ARC Discovery Project ID DP110103346; 2011-2013; \$400,000. Are neurobehavioural and neuromotor impairments associated with FMR1 gene expansion? (Cornish, Metcalfe, **Trollor**, Georgiou-Karistianis, Wen, Jansek, Fielding, Bradshaw, Delatycki, Hackett)
- 8. ARC Linkage Projects Scheme Project ID LP100200096; 2010-2013; \$384,000. Indigenous Australians with mental health disorders and cognitive disabilities in the criminal justice system (Baldry, Dowse, **Trollor**, Dodson, Indig)

#### Research Consultancies and Projects

- 1. HETI & MRID.net; 2013-2014; \$36,015. Mental health crises in people with an intellectual disability: an e-Learning module (**Trollor**)
- 2. Agency for Clinical Innovation ACI; 2013-2014; \$47,000. Understanding mental illness in people with intellectual disability: an e-Learning resource for carers project (**Trollor**)
- Dept of Health and Ageing; 2013; \$136,669. Accessible Mental Health Services for People with ID: A Guide for Providers' Project (Trollor)
- 4. Ageing, Disability and Home Care ADHC; 2012; \$150,000. Renewal of Registered Nursing Curriculum (**Trollor**)
- 5. NSW Ministry of Health, MH Kids; 2012; \$216,456. Core competencies for staff working in the field of Intellectual Disability and Mental Health Project (**Trollor**)

- 6. NSW Ministry of Health; 2012; \$228,760. Intellectual Disability Mental Health Data Linkage Project (**Trollor**)
- 7. NSW Ministry of Health; 2012; \$219,463. Online Training and Education in Intellectual Disability Mental Health Project (**Trollor**)
- 8. Ageing, Disability and Home Care ADHC; 2011; \$413,814. Mental health and carer support in elders with intellectual disability (**Trollor**)
- 9. Ageing, Disability and Home Care ADHC; 2011; \$20,000. AADDM 2012 conference support (**Trollor**)
- 10. Ageing, Disability and Home Care ADHC; 2011; \$90,000. Mental illness in people with intellectual disability: an online resource for psychiatrists and psychiatry trainees (**Trollor**)
- 11. CETI; 2011; \$19,678. Online education resource for Psychiatrists and Psychiatry trainees: mental disorders and intellectual disability (**Trollor**)
- Ageing, Disability and Home Care ADHC; 2010; \$149,811. A Pilot Study of the Feasibility of Creation of a De-Identified data set of disability and Health Service Delivery for Persons with intellectual disability (**Trollor**)
- 13. Ageing, Disability and Home Care ADHC; 2010; \$155,989. Training and Teaching Initiative in Adult Intellectual Disability Mental Health (**Trollor**)
- 14. Dept of Health and Ageing (via DCRC); 2010; \$38,000. Contract research: Profile, correlates and predictors of cognitive decline in fragile X Premutation carriers (**Trollor**, Wen, Hackett, Rogers, Cornish)
- 15. Dept of Health & Ageing (via DCRC); 2010; \$39,663. The SA-ge ID Study: The predictors and correlates of cognitive decline in people with intellectual disability: a questionnaire study (**Trollor**, Torr, Iacono, Brodaty, Sachdev, Schofield, Mowat, Crawford, **Evans**, Wen)
- Dept of Health & Aging (via DCRC); 2010; \$37,538. Predictors and correlates of cognitive decline in people with intellectual disability (Trollor, Torr, Iacono, Brodaty, Sachdev, Schofield, Mowat, Crawford, Evans, Wen)
- 17. IMET; 2010; \$7,556. Mental illness in people with intellectual disability: an online resource for psychiatrists and psychiatry trainees (**Trollor**)
- 18. Ageing, Disability and Home Care ADHC; 2009; \$45,028. A training curriculum for IDMH in Adults (**Trollor**)
- 19. University of New South Wales; 2005; \$20,000. Faculty Research Grant (Trollor).

#### Other funding

- 1. Ageing, Disability and Home Care ADHC; 2013-2015; \$700,000. Additional funding for the Chair in Intellectual Disability and Mental Health (**Trollor**, Mitchell)
- 2. Ageing, Disability and Home Care ADHC; 2013-2016; \$1,997,945. Establishment of a new Chair in Intellectual Disability and Behavioural Support (**Trollor**, Muir)
- 3. Cooperative Research Centre for Living with Autism Spectrum Disorders: To date **Trollor** in receipt of \$450,000 in direct funding.