



# Research and Development Subcommittee: *Future Strategy*

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

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# Research Initiatives

- <http://www.3dn.unsw.edu.au/>
- 'latest news' presentation 27<sup>th</sup> February 2014

# Key Questions

- Where does Research fit within the purpose and priorities of ACI and the ID Network?
- What are the key challenges?
- How should priorities be determined?

**HEALTH SERVICES ACT 1997**

Signed at Sydney this 7<sup>th</sup> day of DECEMBER 2009

**AGENCY FOR CLINICAL INNOVATION**

DETERMINATION OF FUNCTIONS



Carmel Tebbutt  
**Minister for Health**

**Role**

The role and purpose of the Agency is to work with other public health organisations to improve healthcare for patients and the public by rapidly developing and spreading new ways of caring for patients which represent evidence based best practice.

The Agency will develop and support the implementation of standards for care and treatment of people with specific diseases and conditions commonly presenting to NSW public health services, to enhance and improve the effectiveness, safety and cost effectiveness of that care and treatment.

The standards will be developed using the expertise of NSW Health's doctors, nurses, allied health professionals, managers, and the wider community including patients and carers, industry and the academic world.

Subject to the annual performance agreement of the Agency under section 126 of the Act, the initial work program of the Agency is to focus on development and implementation of standards for the care and treatment of heart attack, hypertension, cataracts, diabetes, kidney disease, stroke, lung disease, hip fracture, delirium, severe infection, management of severe chronic back pain, management of degenerative joint disease, dementia, severe chronic disease, the undertaking of hysterectomies, and supporting implementation of standards for interventional cardiac procedures.

## Functions

- (1)(a) In respect of unexceptional surgical interventions, and common diseases or syndrome treatment modalities encountered in NSW public health services to work with area health services and other public health organisations, their clinicians and managers, and other appropriate individuals and organisations:
  - (i) to identify, review, and, where appropriate, modify or enhance; or
  - (ii) to research and prepare,  
  
standard evidence-based clinical protocols or models of care guidelines which will reduce inappropriate clinical variation and enhance and improve the effectiveness, safety and cost-effectiveness of the patient care that clinicians provide; and
- (b) to support area health services and other public health organisations in ensuring the implementation of those standard evidence-based protocols or models of care guidelines.
- (2) To investigate, identify, design, cost and recommend for implementation on a state-wide basis, changes in clinical practice, including the content and method of such practice, which will reduce inappropriate clinical variation and enhance and improve the effectiveness, safety and cost-effectiveness of the patient care that clinicians provide.
- (3) To support appropriate clinician networks, taskforces and clinical practice groups to assist in undertaking the Agency's functions and to involve patients, carers and other members of the community in the work of the Agency.
- (4) To provide advice to the Department of Health and public health organisations on matters relating to changes in clinical practice which will enhance and improve the effectiveness, safety and cost-effectiveness of the patient care in the public health system.
- (5) To report to, and advise, the Director-General of the Department of Health and Minister for Health on matters in respect of the exercise of its functions and to prepare an annual report to the Minister on its progress.

# *ACI Statement on research:*

- *“...the ACI is committed to supporting scientifically excellent health and medical research, where the research is consistent with the strategic priorities of the ACI and will enable system-wide improvements in patient experiences and outcomes. “*

# ACI ID Network: Purpose

- To improve the care and health of people with intellectual disability across all ages by **providing clinical leadership, research and education as essential elements** to enhance the capacity of primary and secondary health services.

# ACI ID Network Priorities

- To develop links and collaborate with relevant individuals and organisations, to provide a coordinated statewide approach in clinical leadership to improve healthcare for children, young people and adults with intellectual disability, with a particular focus on those with chronic, complex health needs and mental health co-morbidities.
- To develop specific initiatives to implement change such as standardised treatment protocols, models of care and service benchmarks.
- To provide a forum for clinical leadership in which clinicians, relevant government and non-government groups and consumers determine together through interagency agreements and partnerships the future directions for healthcare for people with intellectual disabilities across their life span.
- To improve education, research and safety and quality service provision underpinned by evidence through liaison with ACI partners and other organisations.



# R & D Aim (from TOR)

- To improve the health of people with intellectual disability in NSW by actively facilitating the development of research capacity and research networks.

# Key Questions

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# Key Challenges

- Growing Researchers
- Finding Funding
- Participants
  - Recruitment
  - Diversity
- Inclusive/Participatory Research
- Translating findings into benefit

# Knowledge Translation Frameworks

[http://www.who.int/ageing/publications/knowledge\\_translation.pdf](http://www.who.int/ageing/publications/knowledge_translation.pdf)

- Promoting Action on Research Implementation in Health Services (PARIHS) framework
- Ottawa Model of Research Use (OMRU) framework
- The Knowledge to Action (KTA) framework
- Framework for Research Dissemination and Utilization (RD&U)
- Consolidated Framework For Implementation Research (CFIR)
- Research and Policy in Development (RAPID) model
- Assessing country level efforts linking research to action (Linking RTA)
- Canadian Health Services Research Foundation (CHSRF) Self-Assessment tool
- Supporting Policy relevant Reviews and Trials (SUPPORT) tools

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# Determining Research Priorities

- *"Letting a hundred flowers blossom and a hundred schools of thought contend is the policy for promoting progress....."*  
Chairman Mao's Zedong, Peking, February 1957

V's

- Strategic

# Setting global research priorities for developmental disabilities, including intellectual disabilities and autism

M. Tomlinson,<sup>1</sup> M. T. Yasamy,<sup>2</sup> E. Emerson,<sup>3</sup> A. Officer,<sup>2</sup> D. Richler<sup>4</sup> & S. Saxena<sup>2</sup>

	Illustrative research questions
<p><b>Goal A</b> Advance identification, screening and early intervention</p>	<ul style="list-style-type: none"> <li>• How can health systems improve in early detection (during infancy and early childhood) of developmental disabilities in low and middle income countries?</li> <li>• What is the availability, cost and efficacy of early intervention and rehabilitation programs for children with developmental disabilities in low and low-middle income countries?</li> <li>• What is the effectiveness and efficiency of family-mediated early intervention on the future health and well-being of children with developmental disabilities in low resource settings?</li> <li>• How can we best operationally define and identify (screen for) people with developmental disabilities?</li> <li>• What are the most important priorities for investigation/assessment for children with developmental disabilities in low resource rural settings?</li> </ul>
<p><b>Goal B</b> Improve awareness, prevention and promotive interventions</p>	<ul style="list-style-type: none"> <li>• What are the most effective ways of promoting the rights to health and education of children with developmental disabilities in low and low-middle income countries?</li> <li>• What is the impact of global initiatives in disability (e.g. UNCRPD) on policies, laws and services for people with developmental disabilities?</li> <li>• How do public attitudes to developmental disabilities and the care of people with developmental disabilities vary across cultural and language groups and across types of developmental disabilities?</li> <li>• What are the common experiences and attitudes of primary healthcare workers towards people with developmental disabilities?</li> <li>• What are the nature and forms of stigmatisation in different cultures and contexts (low, middle, high income countries; rural/urban)?</li> </ul>
<p><b>Goal C</b> Identify causes, prevalence, biomarkers, and risk and protective factors</p>	<ul style="list-style-type: none"> <li>• What are the most common preventable causes of poor health among people with developmental disabilities?</li> <li>• What are the most important nutritional needs of children with developmental disabilities in low resource rural settings?</li> <li>• What are the most common preventable causes of developmental disabilities (e.g., neurotoxins, undernutrition, infections, poverty, poor education)? How do these vary across regions and countries (and within countries)?</li> <li>• What are the most common preventable causes of the social exclusion and reduced quality of life among people with developmental disabilities? How do these vary across regions and countries (and within countries)?</li> </ul>



## Goal D

Transform health system to improve access and build human resource capacity

- How best can non-specialists be trained and supervised to work with people with developmental disabilities?
- What are the important preventive health measures and barriers to health care for people with intellectual disability and how successfully are these implemented?
- What are the most efficient ways of training health care workers to reduce the discrimination faced by people with developmental disabilities in health care systems?
- How can assistive devices (computer software, hand-held devices, touch screen computers) support people with developmental disabilities to learn and communicate?
- What can be learned from a systematic study of public health systems and health care policy across countries with regard to what has worked and what hasn't with respect to prevention and intervention for developmental disabilities?

## Goal E

Improve support to parents and families

- What are the most efficient ways of supporting and empowering parents/families of people with developmental disabilities (in specific social and cultural contexts)?
- How can parents/families be most efficiently supported to provide a 'healthy start' in life for young children with or at high risk of developmental disabilities in low resource settings?
- What are the most efficient interventions to support parents/families of children with disabilities to manage their own stress?
- How does 'family context' interact with the behavioural challenges posed by children with developmental disabilities to produce either positive or negative impact on parents' mental health and well-being?
- How do the dynamic mechanisms in early and ongoing family processes that affect child and parent outcome vary across culture and ethnic identity?

# Assessing Proposed Research

- Answerability
- Effectiveness
- Deliverability
- Potential for Disease Burden Reduction
- Effect on Equity

See Rudan, I, et al. Croat Med J. 2008;49:720-33

# Future?

- Evaluating models/interventions/impact of service and policy changes
- Service related research
- Research partnerships
- Fostering research and researcher capacity
- Tools to improve research
  - Translation
  - Policy
  - Consumer and carer input
  - research guidelines in ID