

The NSW Agency for Clinical Innovation intellectual Disability Network Research and Development subcommittee.

Roundtable Research Discussion

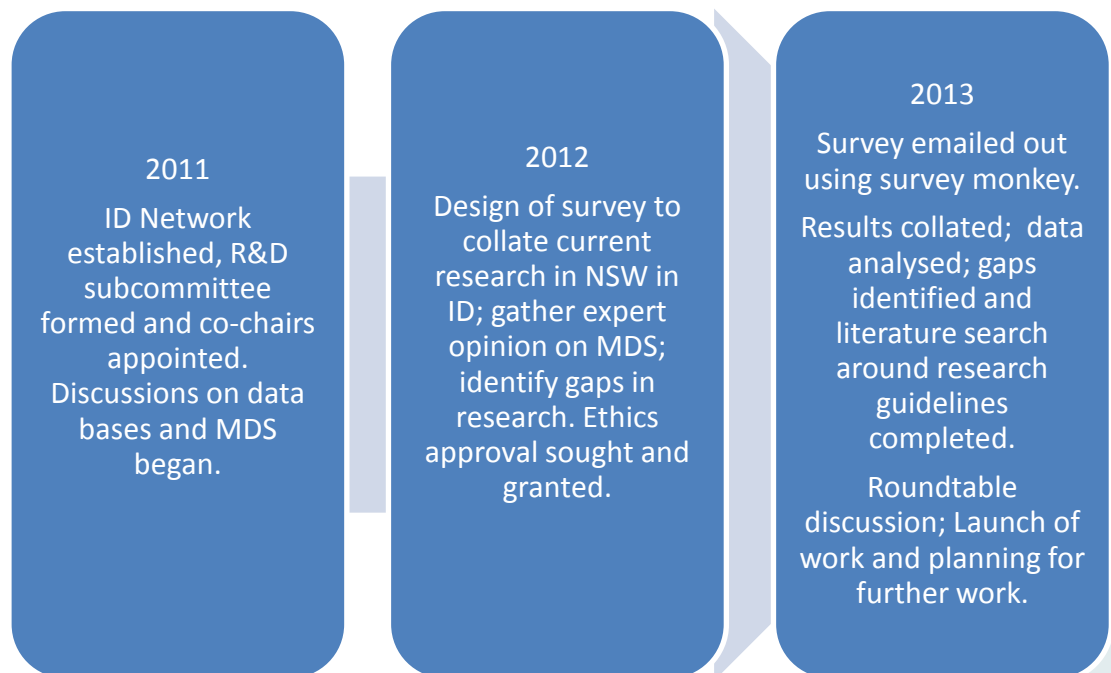
INTRODUCTION

The Roundtable Research discussion was organised by the NSW Agency for Clinical Innovation intellectual Disability Network Research and Development subcommittee. It was held at UNSW and convened by A/Prof. Julian Trollor and Dr Vivian Bayl, co-chairs of the subcommittee, on November 5, 2013, from 9-10:30 am. Invitees were drawn from subcommittee members and other ID Network members. The meeting was called to launch the catalogue of current research in NSW around Intellectual Disability and the gap analysis and to discuss the further development of guidelines and other potential work for the subcommittee.

ACI is committed to supporting high quality 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. (<http://www.aci.health.nsw.gov.au/about-aci/research>)

The key aim of the R&D subcommittee is to improve the health of people with intellectual disability in NSW by actively facilitating the development of research capacity and research networks.

SESSION ONE SUMMARY



Dr Vivian Bayl presented a summary of the development of the subcommittee and its work from its inception in September 2011 to date.

SESSION TWO

Sue Warth from Westwood Spice presented the content of three reports which have been collated as part of the activities of the R & D Subcommittee:

- Survey results and analysis
- Identified Research Gaps
- Research Guidelines for research about and involving PWID.

Each of these reports is available on the ACI website at www.aci.health.nsw.gov.au

SESSION THREE

A/Prof. Julian Trollor convened the roundtable discussion. It centred on three main areas:

1 Additional gaps identified

- The interface between academics and clinicians, and how to facilitate research involving both. JT spoke of a research forum / seminar series he is hoping to develop with a clinical research focus.
- The need for research in the area of taxonomy and how to facilitate information sharing.
- The translation of research into policy and of policy into practice
- The need to foster research interest and skills at undergrad level for medical and other health science degrees, in order to build capacity.

All agreed the lack of data was a large issue, beyond the work of the R&D subcommittee, and the difficulty of attracting funding for research in the area of ID.

2 Dissemination of this valuable work:

There was discussion around ideas for dissemination of the work of the subcommittee. Key issues for the subcommittee to resolve include the audiences for the three reports, and the mechanisms of dissemination. The information in the completed reports is not available elsewhere and is a valuable tool which could also be used in advocacy for change and funding and to drive the research agenda. It could be referred to in publications, sent to professional contacts interstate and overseas and used to inform funding applications. With the increase in NGOs and research bodies associated with them, they may be interested in this work to inform their future research interests.

All members of the ID Network were encouraged to promote the work.

It will be on the ACI website and ACI will maintain the currency of the research database.

3 Future areas of possible focus for the R&D subcommittee.

A strong theme of capacity building emerged in the discussion.

- Fostering academic and clinician partnerships for research
- Supporting the translation of research into policy and practice
- Encouraging a research component into health / med undergraduate study
- Seeking feedback from established consumer / carer groups about their perception of research priorities in the area of ID
- Developing a position statement on research in ID for ACI
- Annexing the ACI Research Guidelines with ID guidelines
- Investigating the feasibility of ethics committees having a disability impact statement

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Membership of the Network and the R&D subcommittee is open and has different layers of engagement.