Autism CRC Presentation
- Longitudinal Study of Adults
- 3DN Opportunities for Collaboration

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3DN’s Scope

Strategic Plan
2013 to 2015
3DN February 2014
Exemplars of 3DN’s Capacity Building Work

• State-wide survey of MH staff attitudes, confidence and learning needs in ID
• Training curriculum for mental health workers
• Competencies in IDMH for the NSW Mental Health Workforce
• Training strategy for psychiatry trainees
• Submissions to government on service and workforce
• Service model development in ID mental health
• National audits of ID health content in both Medical and Nursing curricula in universities across Australia; next step- a National ID Health toolkit
Exemplars of 3DN’s Research

- Ageing and dementia in the general population
  - Biomarkers
  - Structural and functional neuroimaging
- Ageing and dementia in people with an ID
- Specific populations
  - Fragile X tremor ataxia syndrome
  - People with ID as victims or offenders: criminal justice system context
- Attitudes and training needs of mental health practitioners
- Evaluation of training
- Analysis of MH policy
- Barriers and enablers to access to mental health care in people with an ID
- Working with large data sets:
  - BEACH: Primary care
  - Data linkage: disability/health/mortality
Primary Care: BEACH Data

- Identify if GP services and patterns of practice differ for people with and without ASDs with respect to:
  - Reasons for presentation
  - Problems managed
  - Clinical treatments provided
  - Profile of GPs and their practices for those who do or do not offer an occasion of service to a person with ASDs
- To consider what may be driving any observed differences
- Use of existing resources
- Early output for the CRC
Potential future projects

• NSW Disability/Health Data linkage
  – Contains 18,000 individuals with ASDs

• Potential projects
  – NSW Mortality rates and cause of death in people with an ASD
  – Health and mental health profiles of people with ASD
  – Emergency presentations in people with ASD
  – Hospitalisation of people with ASDs
  – Analysis of unnecessary hospitalisations
  – Cost of health care
  – Interaction between disability and health services

• Availability of funding from Autism CRC
Available online
3dn.unsw.edu.au
Down syndrome

- 1:1000 live births in Western Australia
- Leading cause of intellectual disability
- High levels of co-morbidity and varying levels of severity
- Increased life expectancy
- Majority of young adults live with their families well into adulthood
- Higher risk of behavioural, emotional and psychiatric problems
  - Poor behaviour associated with poorer maternal mental health
- Transition from school to post-school described as a time of ‘upheaval, stress and important decisions’
- Adult services are disjointed and unprepared for adults with intellectual disability
Purpose and Methodology

• Overall purpose:
  – Examine transition from school to post-school for young adults with Down syndrome
  – Investigate factors which are positively and adversely associated with different outcomes in adulthood

• Guided by the International Classification of Functioning, Disability and Health (ICF)
  – Developed by the World Health Organization in 2001
  – World Report on disability highlighted how people with intellectual disability were particularly excluded in areas such as employment and face negative treatment and abuse

• Down syndrome ‘Needs Opinions Wishes’ study
  – Ascertainment through Department of Education and Disability Services Commission
  – Population-based database of young people with Down syndrome residing in Western Australia
  – Consultation with consumer reference group and industry partners
Methodology

2004
- n=363/500
- 73% response fraction
- Aged 0 to 25 years

2009
- n= 203/229
- 89% response fraction
- Aged 16 to 30 years
- Transition focus

2011
- n= 197/223
- 88% response fraction
- Aged 16 to 32 years
- Social participation focus

Many domains assessed at every time point
## Questionnaire

<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>Construct measured</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body functions and structure</td>
<td>Emotional and behavioural problems</td>
<td>Developmental Behaviour Checklist – Adult version</td>
</tr>
<tr>
<td></td>
<td>Presence of health conditions</td>
<td>Counts</td>
</tr>
<tr>
<td>Activity</td>
<td>Functioning in ADLs</td>
<td>Index of Social Competence</td>
</tr>
<tr>
<td>Participation</td>
<td>Social participation</td>
<td>Assessment of Life Habits</td>
</tr>
<tr>
<td></td>
<td>Day occupations</td>
<td>Four categories</td>
</tr>
<tr>
<td>Environment</td>
<td>Parents mental health</td>
<td>Depression Anxiety Stress Scales</td>
</tr>
<tr>
<td></td>
<td>Family quality of life</td>
<td>Beach centre Family Quality of Life</td>
</tr>
<tr>
<td></td>
<td>Influence of environment</td>
<td>Measure of the Quality of the Environment</td>
</tr>
</tbody>
</table>
Post-school Day Occupations

- Supported employment
- Integrated in community
- TAFE
- VET Programs
- ‘Australian Disability Enterprises’
- Segregated setting
- ‘Alternatives To Employment’ (ATE)
## Overview of Thesis

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction</td>
</tr>
<tr>
<td>2</td>
<td>Literature review framed within the ICF</td>
</tr>
</tbody>
</table>
| 3        | Perception of children with disabilities on the meaning of wellbeing  
          | Qualitative study involving focus groups |
| 4        | Functioning in activities of daily living and participation  
          | Cross-sectional study |
| 5        | Family quality of life and participation  
          | Cross-sectional study |
| 6        | Behaviour changes and participation  
          | Longitudinal study exploring change in behaviour overtime |
| 7        | Social participation and the influence of the environment  
          | Cross-sectional study |
| 8        | Discussion and conclusion |
Findings from Chapter 6 and 7

• Association between change in behaviour and type of day occupations young adults were attending post-school
  – Young people attending open employment behaviour problems declined
  – Modelling positive behaviour from typically developing peers, satisfaction of participation in a meaningful occupation
  – Behaviour problems of those attending day recreation programs increased

• Societal participation of young adults with Down syndrome and influence of the physical and social environment
  – More difficulty participating in social roles than daily activities
  – Barriers to participation; negative attitudes from strangers, lack of support from friends, availability of jobs and public transport
  – Young adults’ participation in social roles was considered from a parental perspective to be influenced by the physical environment (including public infrastructure and community organization services) more than by the social environment
Acknowledgements

• Families and the young people with Down syndrome who completed questionnaires
• Supervisors: Professor Helen Leonard, Dr Sonya Girdler
• Telethon Kids Institute
• Down syndrome Association of WA
• Edith Cowan University
• Consumer Reference Group
• Industry Partners
  – Department of Education
  – Edge Employment
  – Disability Services Commission
Longitudinal study

- Unique profile of Australian adults with ASD
- Outcomes on productivity, physical and mental health, well-being, and societal participation
- Objectives:
  - Compare the data on these variables with a matched control group, in order to discriminate the unique ASD profile from what are general requirements.
  - Collect data that will support the development of tools and strategies to improve health and wellbeing for school leavers with ASD, i.e., young adults.
Plan

- Define domains to be measured in the longitudinal study
  - Liaise with Amanda Richdale and Mirko Uljarevic at LaTrobe University
  - Define measures to be included in both the younger and older adult versions of questionnaires
  - Review literature for most appropriate assessments for inclusion
  - Comparability to other longitudinal cohorts e.g. National Survey of Mental Health and Wellbeing

- Potential multiple versions of questionnaire (self-report, proxy report, suitability for adults with intellectual disability)
  - Gaining self-report data where possible
  - Collect information on main carers

- Engage with stakeholders and end-users during design process
- Collaborate with interstate Autism CRC teams to develop Program 3 projects
<table>
<thead>
<tr>
<th>Potential Domains</th>
<th>Adult with ASD/Adult with ASD and ID</th>
<th>Proxy report by carer</th>
<th>Information about main carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functioning in activities of daily living</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Engagement in employment, training or volunteering</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Relationships with friends, family and partners</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Social participation (recreational and community life)</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Physical activity and general health</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Health impairments</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Service use (including mental health services)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Quality of life</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Mental health (depression, anxiety, stress etc.)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Emotional and behavioural problems</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Sensory processing</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
Additional Domains for Consideration

- People with ASD self-perceptions of their functioning, cognition and participation
- Issues surrounding ageing
- Theory of mind assessment
- Online cognitive battery for higher functioning adults with ASD
- Illicit substance use, alcohol use and smoking
- Loneliness
- Strengths based measures
Acknowledgements/Declarations

Funding: Core
• Ageing Disability and Home Care | Family and Community Services NSW
• UNSW Medicine

Funding: Research and Projects
• NSW Ministry of Health & Related Organisations
  – MHDAO, MH Kids, HETI, ACI ID Network
• Australian Government Department of Health and Ageing
• Australian Research Council (ARC)
• National Health and Medical Research Council (NHMRC)
• NSW Institute of Psychiatry
• Autism CRC