Improving Health for people with disability: Mainstreaming specialised care

Dr Jacqueline Small
Developmental Paediatrician
Disability Specialist Unit, SCHN
• Good health is a prerequisite for participation in a wide range of activities including education and employment. (WHO, 2011)
Health is more than absence of disease

- Health—a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 1946)

- Having a disability does not mean a person is not healthy or that he or she cannot be healthy.
Ecological Systems Theory

- Bronfenbrenner
The environment affects our health
Interaction between health conditions and contextual factors

(WHO 2011)

- Disability refers to difficulties encountered in
  - Impairments
  - Activity limitations
  - Participation restriction
- ICF adopts neutral language and does not distinguish between the type and cause of disability
- “Health conditions” - diseases, injuries, and disorders,
- “impairments”-specific decrements in body functions and structures
- Disability arises from the interaction of health conditions with contextual factors
How healthy are people with ID
Health disparities emerge in childhood

- 60% children in SSP had multiple health conditions, many not detected
- 2-10 times hospitalisation in first year for DS, ID, ASD
- Mental health conditions 40-60% adolescents with ID
- In children with Down Syndrome
  - high rates of ear (more than half) and of eye (more than three quarters) problems.
Poorer lifestyle factors

• More likely to do low/very low level exercise
  – 43% adults with severe/profound don’t exercise (cw 31%)

• More likely to smoke and start earlier in life
  – 31% with severe/profound daily smokers (cw 18%)
  – (AIHW, 2010)

• Higher rates smoking 30.5% cw 21.7% (WHO)
Adults ID more likely to be obese

- CDC
Poorer health outcomes for adults with ID (AIHW, 2010)

- 35% PWID report poor or fair mental health, 5% severe.
- 15% adolescents and young adults ID with poor mental health, 8%.
- 25% PWD sought professional help for a mental health issue in the past year, 11%.
- Nearly 25% PWD severe or profound high psychological distress, 5%.
More and earlier chronic illness

- more likely to have a chronic illness
- more likely to have early onset of many chronic conditions.
  - In Victoria, more have diabetes 12% (cw 6%) (Dept Health 2011).
  - In Victoria, more have heart disease 8% (cw 1%) (Dept Health 2011).
  - If severe/profound disabilities- more have hypertension 9% (cw 5%) (AIHW 2010).
Increased rates of early avoidable deaths

- Median age death 54 years (80 years males, 84 years female gen pop)
- Age-standardised mortality ratios were 4.3 in the ID cohort and 1.7 in the non-ID cohort
- 32.8% of potentially avoidable deaths cw 16.7%
- Srasuebkul, Trollor and Florio, 2016
Many factors lead to health disparities

- genetic and biological bases of IDs
- behavioural or lifestyle factors
- access to appropriate healthcare interventions
  - communication barriers between patients and health professionals,
  - complexity of diagnosis,
  - lack of general and specialised skills in the health workforce, and
  - health promotion campaigns and research not focusing on people with intellectual disability.

- (AADDM 2015)
30% of risk of poorer health due to SE disadvantage

• A socially and statistically significant proportion of the increased risk of poorer health among children and adolescents with IDs may be attributed to their increased risk of socio-economic disadvantage.

• (Emerson and Hatton, 2007)
International and national initiatives to improve health
value contributions made to their communities,
• promotion of human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and
• in significant advances in the human, social and economic development of society and the eradication of poverty,
CRPD Article 25

- Right to highest attainable standard of health without discrimination.
- Take all appropriate measures to ensure access to health services.
- Provide quality and standard of free or affordable health care and programmes.
- Provide specific health services.
- Require health professionals to provide care of the same quality.
- Prevent discriminatory denial of health care or health services on the basis of disability.
Key national frameworks/policies

- NSW State Health Plan (6.1) NSW Kids and Families 2014-2024 plan to improve disability outcomes (4).
National Disability Insurance Scheme

• Increased inclusion in mainstream health services

• NDIs funds some related needs - aids and equipment, prosthetics/artificial limbs, home modifications, allied health
National Disability Strategy

2010–2020
National Disability Strategy
An initiative of the Council of Australian Governments
NSW Health Service framework: tiered model of care

• Tier 1 strategic health policy
• Tier 2 Primary and community health services
• Tier 3 Acute health care services
• Tier 4 Specialised intellectual disability health services.
• Tier 5 Clinical leadership, research and education
NSW Health specialised health hubs

- Multidisciplinary care is delivered by a team of clinicians with particular interest and expertise in the healthcare of people with ID.
- Consumer engagement and support is central and consistent with appropriate inclusion of people with ID.
- Pathways and channels to escalation for either advice or referral are clearly identified and practiced.
- Networked integration into a comprehensive approach to appropriate care is in place.
- Feedback to and support of mainstream health services occurs.
- Research towards and application of best available clinical evidence are pursued.
Specialised health services in NSW

- Diagnosis and Assessment Services - an example of Tier 4 services
  - Primarily located in metropolitan NSW.
  - Teams which function predominantly for the diagnosis and assessment of DD/ID in children and in other cases by teams in which this forms a smaller part of their service provision.
Emphasis on improving mainstream services

• understand the needs of people with ID and their carers.
• know how to communicate effectively with people who have an ID and adapt their ways of working to respond to their needs.
• recognise the contribution of carers and support their health care needs.
• are proactive in promoting the health and wellbeing of people with ID and their carers.
• promote and facilitate interagency co-ordination and collaboration.
- Giantuli et al. 2015 for ACI.
Mainstreaming specialised care
Specialised nurses can improve mainstream health care

• Knowledge of the health needs of people with ID
• Improve communication with people with ID.
• Enhance reasonable adjustments
• Involve and support carers.
• Promote the health and wellbeing of people with ID and their carers.
• Promote and facilitate interagency coordination and collaboration
Adjusting interventions to better support people with ID
People can get distressed

- “Tony gets really distressed if he doesn’t know the person, and when they touch him without first explaining what they are going to do and how. Normally people go to the doctor and we know that the doctor will examine us. Tony doesn’t know this. So if this happens with no warning he’ll be upset.”
Improving communication

Promoting healthy lifestyles, O’Leary 2014

• ‘HealthMatters Program’- health related outcomes for people with intellectual disabilities (ID), and on staffs’ knowledge and attitudes in supporting this population to adopt a healthy lifestyle.

• This study also explored facilitators and barriers to engagement in health promotion activities.

• Nutritional knowledge improved significantly for staff and people with ID.

• Consistent commitment from staff, managers and individuals with ID was critical to ensuring successful application of knowledge acquired from the programme in order to positively change health knowledge and behaviours.
Plate model improves healthy eating, Flygare Wallen 2013
Limited knowledge of diabetes,
MacRae et al 2015

• 49,046 participants with ID and diabetes and 31 care professionals and family members across Europe, N America, NZ, Australia, China and HK.
• Prevalence rates of DM-ranged from 0.4% to 25%.
• People with ID reported
  – a basic understanding of diabetes and wanted to know more.
  – Carers reported that they lack diabetes knowledge and do not
Adapting mainstream DM programmes, Taggart 2015

- Adaptation of DESMOND Programme for people with ID and type 2 diabetes-DESMOND-ID.
- Pilot - 36 adults with mild to moderate ID will be recruited from three countries in the United Kingdom.
- Family and/or paid carers may also participate in the study.
- Random assignment to one of two conditions
- Range of data will be collected - biomedical, psychosocial and self-management strategies and from carers.
- Focus groups with all the participants will assess the acceptability of the intervention and the trial.
Health checks, McConkey et al 2014

- Annual health checks for adult persons with ID is intended to counter the health inequalities experienced by this population.
- This study documents the uptake of checks across general practitioner (GP) practices in Northern Ireland over a 3-year period.
- Nevertheless the uptake by patients varied across the five trusts in Northern Ireland and were linked to the deployment of health facilitators.
- Younger people living with families, or independently, in more socially deprived areas were less likely to have had a health check.
interface between health and disability services, NDS 2016

- Service coordination between health and disability poor
- Coordinated care critical for living a good life
  - Medication use
  - Poor information sharing
  - Some health services physically inaccessible
- NDIS champions in health
Health needs aren't neglected
advocacy

• ACI- Intellectual Disability Network

• AADDMD

• NSW CID
Mainstreaming specialised health care

- PWD live healthier lives
- Recognition that much additional morbidity is preventable
- Models of Care - Sustained and effective collaboration
- Improvement in mainstream clinicians skills to support PWD
- Reasonable adjustments
Specialists making the health system work better

- Involving PWID, mainstream, specialist health prof, disability sector
- Inequities in health for people with ID.
- Adjustments made in healthcare
- Evidence based models of care, health promotion, treatment
- What does the data tell us? How can data change the system?