



Knowledge Exchange Seminar Series (KESS)

...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland



People with Intellectual Disabilities:

Promoting Health, Addressing Inequality

Dr Laurence Taggart & Dr Wendy Cousins,

Centre for Intellectual and Developmental Disabilities,
Institute for Nursing & Health Research,
University of Ulster

Content



- **What are the problems people with ID face?**
- **What are the health barriers/determinants?**
- **How can we overcome these inequalities and promote health?**
- **Concluding message**

Health Inequalities: Mortality

Lower life
expectancy

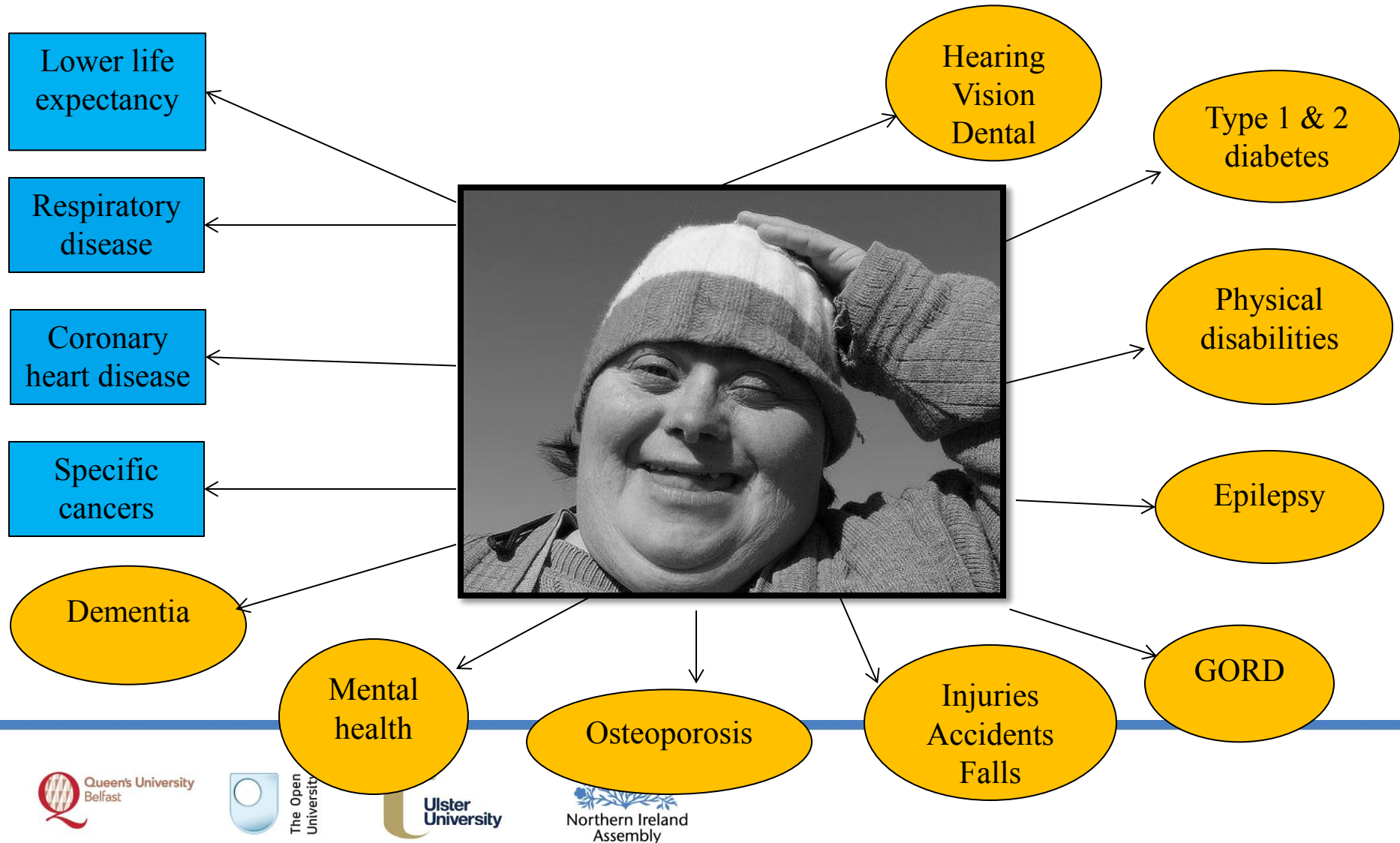
Respiratory
disease

Coronary
heart disease

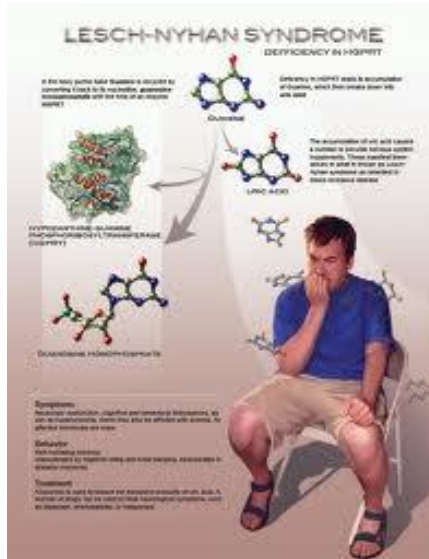
Specific
cancers



Health Inequalities: Secondary Health Conditions



Biological/genetic factors



Genetics
Age
Gender
Behavioural Phenotypes
Medication



Lifestyle factors



Diet/Nutrition
Exercise/Activity
Sedentary Behaviour
Obesity
Smoking
Alcohol
Mental Health
Sexual Health



Socio-economic, cultural and environment

For success,
attitude
is equally
as important
as *ability*

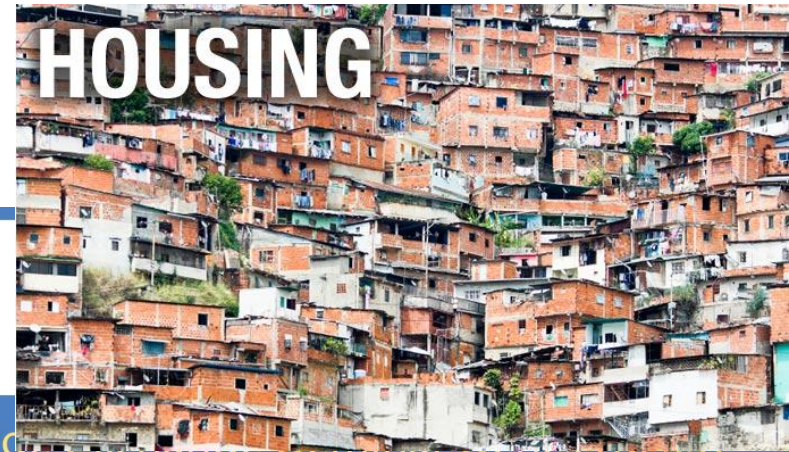
Attitudes
Discriminatory practices
Poverty / Income
Accommodation
Limited social support
Social exclusion



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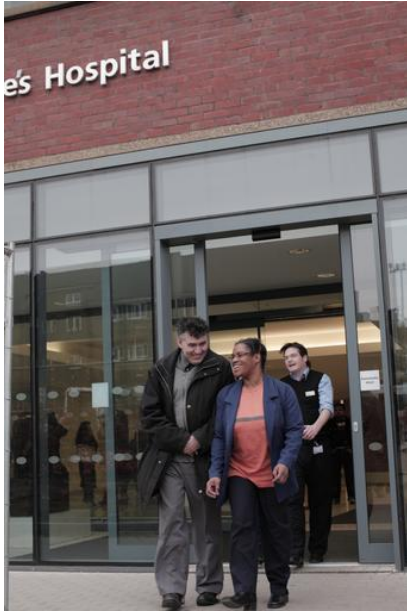


ster
iversity



- **Ageing:** People with ID are living longer with older family carers with limited income
- **Complex physical health:** People with ID are living longer with more complex physical and mental health conditions with additional costs for their family carers
- **People with ID not known to ID services:** The majority of people with ID ('Hidden Invisible') live in low socio-economic environments (Emerson & Hatton, 2013)
- **Low and middle income countries:** Majority of people with ID from these countries live in low socio-economic environments (Emerson & Hatton, 2013)

Health access and health promotion



Communication issues
Reliance on carers
Lack of co-ordination
Physical access
Lack of training of staff
Reasonable adjustments
User friendly literacy
Health screening
Health promotion



Failure of healthcare services



- Numerous international reports have been published:
 - The US Surgeons General Report (2002): *'falling of a cliff'*
 - Disability Rights Commission (2006): *'inequality'*
 - MENCAP Report (2004) (2007): *'indifference'*
 - Michael Report, DoH, (2008): *'discrimination'*
 - Six Lives, DoH (2009): *'sub-standard care'*
 - Confidential Enquiry, DoH (2013): *'unacceptable situation'*
- These reports repeat the same message that healthcare services consistently fail to work together and make reasonable adjustments to meet the health needs of people with ID effectively (Turner & Robinson, 2011, Tuffrey-Wijne et al., 2014)



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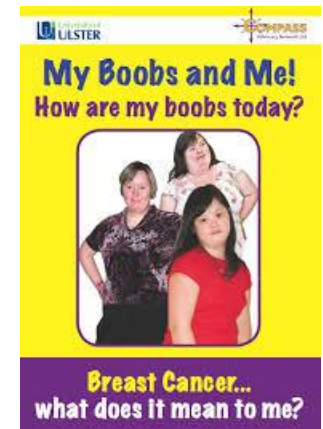
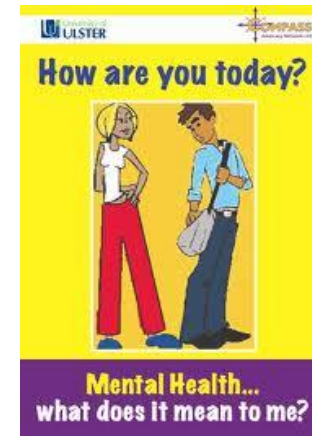
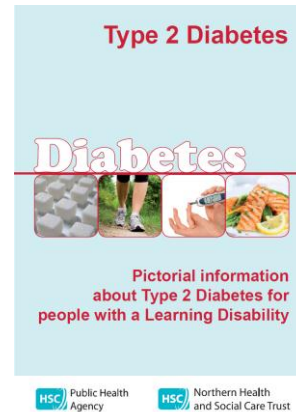
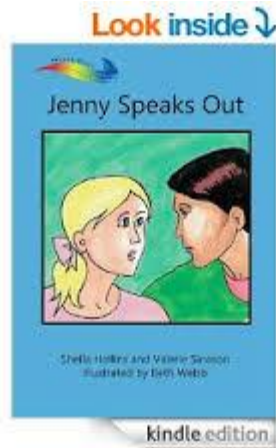
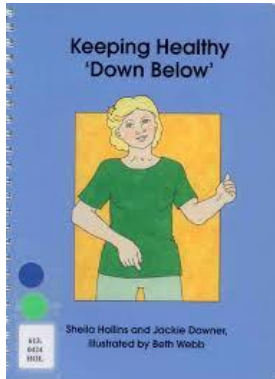
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Addressing the determinants of health and health inequalities

Challenge 1: Educating and empowering staff and people with ID

- **The foundation of health promotion and better health is about educating and empowering people with ID to make more informed healthier choices (Owatta Charter, 1986)**
- Translate research evidence into user friendly information
- Ensure that all people with ID have access to these resources
- Many people with ID are dependent upon family/paid carers, therefore the need to educate carers and healthcare professionals



Welcome to Easyhealth!



Health Leaflets



Food and Exercise



Health Videos



Useful Things for
your Health Care



Useful
Organisations



About this
website





My Stuff



My Health Tasks



Video Phonebook



Q & A



HealthQuest Survey



Make it Tonight



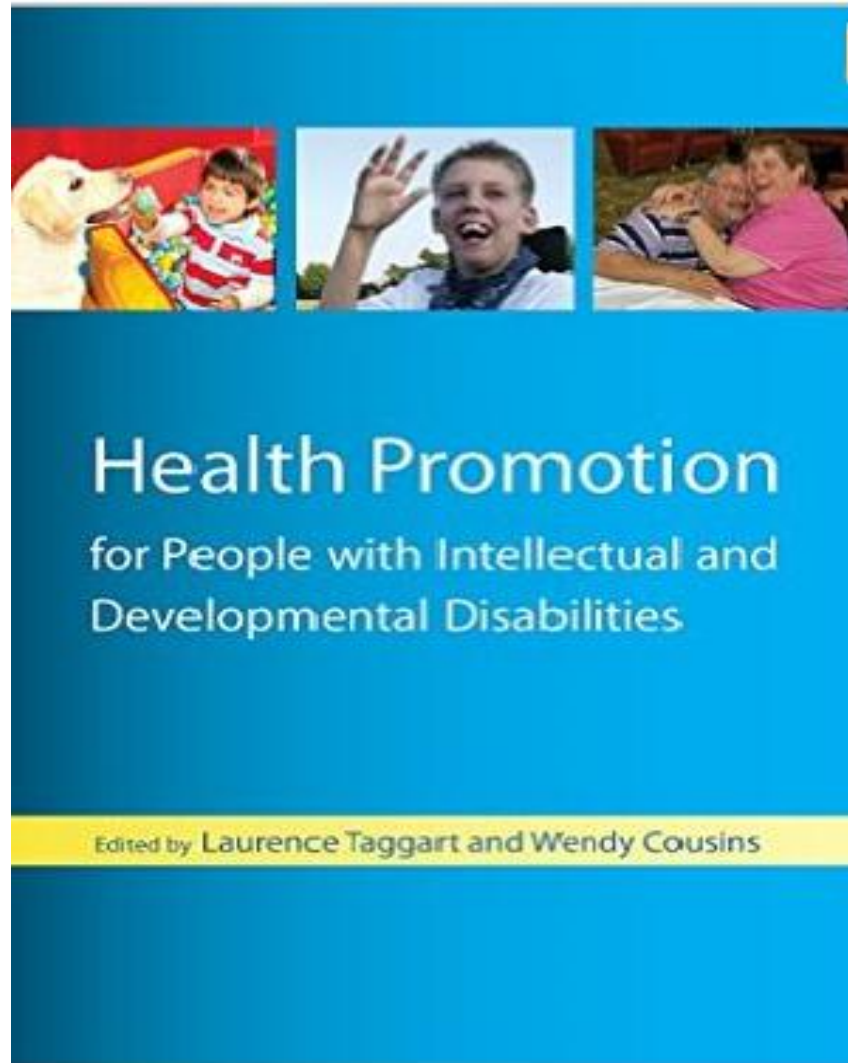
Health Education



The report of the
UK Modernising Learning Disabilities Nursing Review



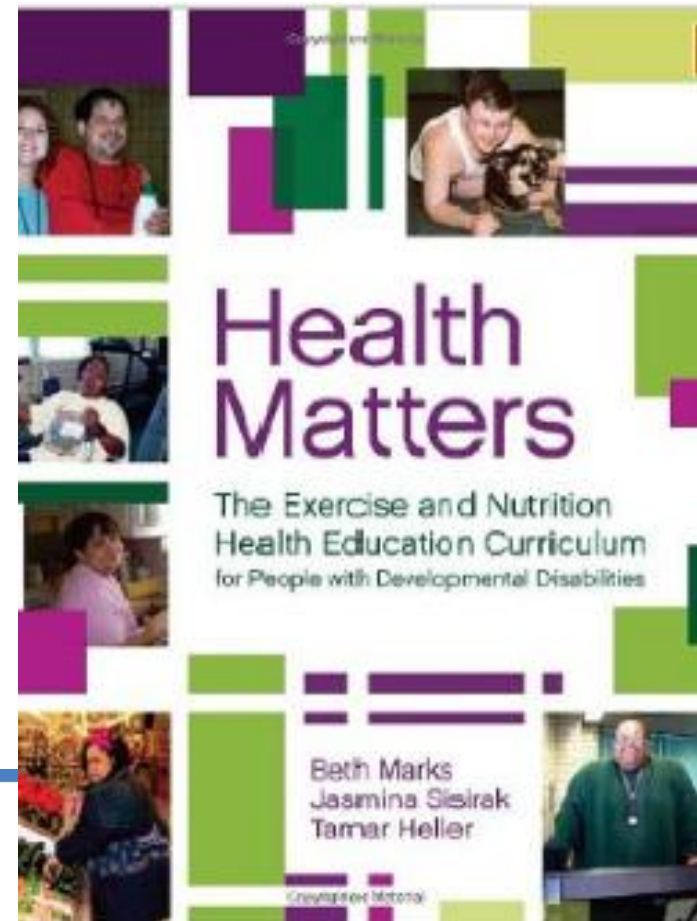
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Challenge 1: Reliance on family and paid carers

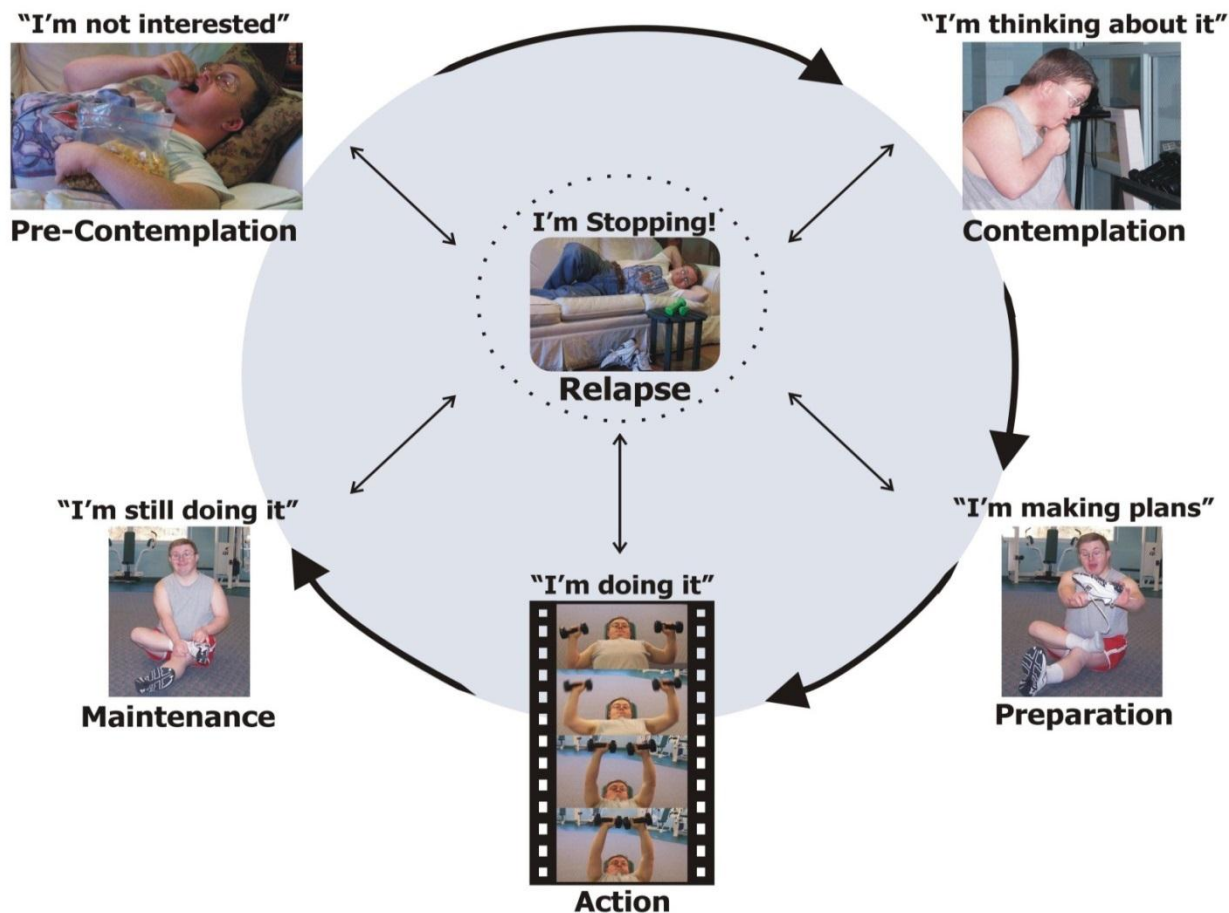
Health, Diet and Exercise: Health Matters (Marks et al., 2010, O'Leary (PhD std))

- Evidenced-Based Curriculum for adults with ID
- Aim to understand staff and service users' attitudes toward health, exercise & nutrition
- DEL PhD Studentship (2011-2014)
(O'Leary et al., forthcoming)



Becoming Physically Active and Choosing Healthy Foods

Stages of Behavior Change



Challenge 2: Unrecognised physical and mental health needs

Health Checks:

- People with ID do not access health services/interventions proportionate to their health needs: under utilisation (Cooper et al., 1997, Lin et al., 2005, Turk et al., 2010, Emerson & Hatton, 2013)
- A systematic review of international evidence on health checks for adults with ID has concluded (Robertson et al., 2010):

“... health checks for people with ID typically leads to:

- (1) the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life threatening conditions such as cancer, heart disease and dementia); and*
- (2) targeted actions to address health needs.”*

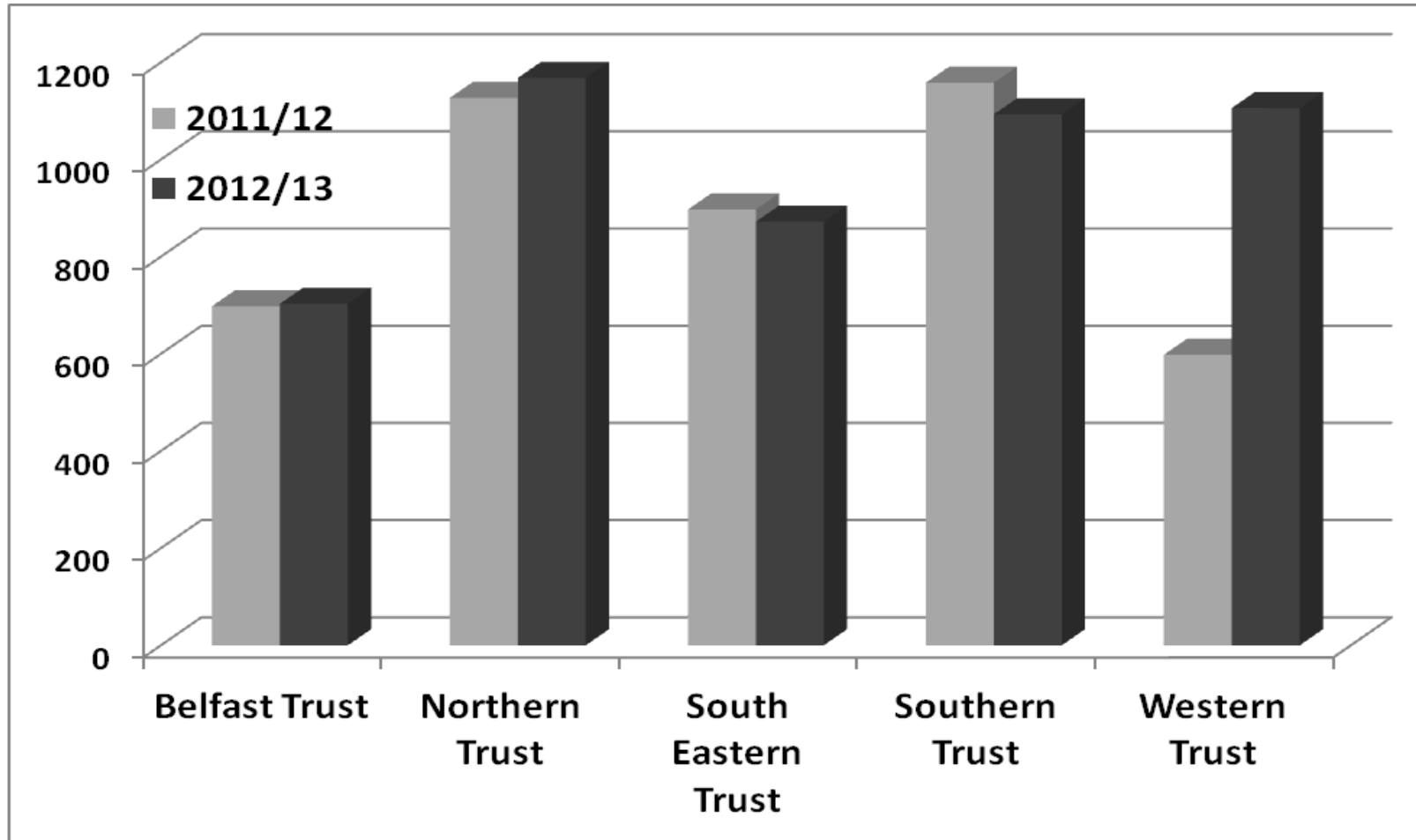
Challenge 2: Unrecognised physical and mental health needs

Health Facilitators:

- One innovative initiative is the development of Health Facilitators
- ID nurses who appointed to support GPs/practice nurses to undertake an annual health check of a person with ID
-
- Health facilitators provide a link between ID services and primary health care (McConkey, 2013, McConkey et al., in press)
- Development of Health Action Plans (Emerson & Turner, 2011, Robertson et al., 2011, Chauhan et al., 2012, McConkey, 2013, Lennox & Robertson, 2014)



The number of checks undertaken by GPs in 2011/12 and 2012/13 (McConkey, 2013)



Challenge 2: Unrecognised physical and mental health needs

Hospital Liaison Nurses:

- These are nurses who promote access to hospital services for people with ID by directly supporting them
- Their role is to:
 - ✓ Co-ordinate care
 - ✓ Education within clinical areas
 - ✓ Support and advice for hospital staff
 - ✓ Promotion of effective communication
 - ✓ Support of carers
 - ✓ Provide accessible information
 - ✓ Promote positive experiences and outcomes (Foster, 2005, Brown et al., 2014, a, b)

Challenge 4: Accessing public health community services

- There have been few public health promotion and interventions that have supported people with ID to access such groups in the community (US Surgeon General, 2002, Emerson & Hatton, 2013, Taggart & Cousins, 2014)
- Most of the evidence-based for health promotion and interventions for people with ID have been targeted for those people known to ID services (Foster et al., 2005, Heller et al., 2011)
- Emerson & Hatton (2013) stated that for those people with ID not known to services they are the group who receive little/no health promotion and interventions from either:
 - Community public health services and
 - ID services ('invisible' population)

Challenge 4: Accessing public health community services

- Integrating health promotion strategies within existing community-based structures can provide:
 - Continuous access to health literacy information
 - A range of activities
 - Community presence and connectedness
 - Low cost interventions and
 - Sustaining health promoting behaviours

Challenge 4: Accessing public health community services

‘DESMOND-ID’ prog for self-management of Type 2 diabetes (Taggart et al., 2012-15)

- DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed)
- Partnership approach: N Ireland, Scotland, Wales and England
- Based upon a theoretically driven clinical intervention on managing Type 2 diabetes
- 18-month adaptation process of DESMOND to DESMOND-ID
- Jan 2015 Pilot RCT





Challenge 4: Accessing public health community services

Supporting adults with ID to access fitness centres (Teresa Green, 1st yr PhD student, UoU)

- To develop and test an education programme for gym instructors to support people with ID to access local community fitness centres: use peer buddies
- Develop a multi-media education pack for gym instructors
- Gym instructors to identify and recruit potential gym/peer buddies
- These peer buddies may help with transport, support the person with ID with the exercises, develop social connectedness and community cohesion



Challenge 5: Greater partnership working between ID and health services

- Optimal healthcare for people with ID depends on partnerships and productive collaboration between all partners
- Having a strong working relationship with community partners is paramount to achieving successful health that will ensure active, ongoing participation from everyone and ensure long-term positive health benefits
- Scheduling preliminary meetings with all partners provides an opportunity to address concerns and respond to questions related to programme implementation for our community partners

Minister for Health, Dept of Health, N Ireland

‘Equal Lives’
(2005)

‘Transforming
Your Care’
(2011)

‘LD Service
Framework’
(2012)

Regional LD Health Care and
Improvement Steering Group

Regional Health
Facilitators Forum

Regional Health &
Social Wellbeing
Improvement Forum

Regional ‘Contact
with General
Hospitals’ forum



Queen's
University
Belfast



The Open
University



Ulster
University

Northern Ireland
Assembly

Concluding message



Thanks for listening

(l.taggart@ulster.ac.uk)





Northern Ireland
Assembly



Queen's University
Belfast



The Open
University



Ulster
University

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