

Impact case study (REF3b)

Institution: University of Ulster
Unit of Assessment: 3A Allied Health Professions, Dentistry, Nursing and Pharmacy – Nursing and Health Science
Title of case study: Addressing the Health Inequalities of People with Intellectual Disabilities (ID)
<p>1. Summary of the impact (indicative maximum 100 words) Research undertaken at the Centre for Intellectual and Developmental Disabilities(CIDD), has significantly impacted upon:</p> <ol style="list-style-type: none"> 1. The identification of health inequalities through improved health surveillance. 2. The development of a network of Health Facilitators linked to GP Practices to promote health screening/annual checks. 3. The development of accessible information to assist people with ID in making positive lifestyle choices and access healthcare services. 4. The development of health promotion interventions targeting secondary health conditions for people with ID. 5. The translation of this research into pre/post multi-disciplinary education. 6. The preparation of regional, national and international policy guidelines.
<p>2. Underpinning research (indicative maximum 500 words) The CIDD is led by Prof McConkey and a team of tenured staff including Prof Barr, Dr Slevin, Dr Taggart and Mrs Sowney. A focus of their research is addressing health inequalities (1). Over the last five years the CIDD has established an international profile with research grants totalling over £3million supplemented by over 20 PhD/MSc projects. Innovative research projects addressing the health disparities of this population have been completed and over 100 papers in international peer-reviewed journals have been published. Examples of these are presented below: (The numbers in parentheses relate to the references to the research):</p> <ul style="list-style-type: none"> • Two studies analysed the health screens conducted on over 800 persons with ID and identified the most common conditions, the referral patterns and follow-up actions taken (1). • Over 20 women with ID were individually interviewed about their understanding of breast cancer and experiences of receiving a mammogram (2). Key support and breast screening staff were also interviewed. This led to three publications. • Another study involving nearly 200 respondents with ID and diabetes explored their health and identified whether the diabetes quality of care indicators were met (3). This highlighted the poor management of diabetes for many people with ID. • Two studies identified the attitudes of over 500 mainstream health personnel to patients with ID. In addition the enablers/barriers to accessing primary healthcare, A&E and acute hospitals were identified through 1-1 interviews and focus groups involving over 50 service users, family carers and healthcare staff (4 and 5). • The knowledge and perceptions of risk and protective factors were explored with over 30 H&SC staff working with women with ID who have psychiatric disorders (6). <p>A strategic objective of the CIDD is the promotion of practice-based research and education, alongside knowledge exchange partnerships between Higher Education, Health & Social Care (H&SC) services and the voluntary sector with a particular focus on mainstream health services. Hence our programme of research has included healthcare practitioners, acute hospital staff and specialist services (breast screening services, palliative care). Two staff have held joint appointments with H&SC Trusts, and seven doctoral theses and one Master's thesis by research have been completed by H&SC personnel.</p> <p>Patient and public involvement has been central to the work of the CIDD. Working alongside key stakeholders from statutory and voluntary agencies (and with representation from service users and their families), the research aims and methods of projects were developed. This has assisted greatly with the dissemination of the research findings.</p> <p>CIDD undertook literature reviews commissioned by the Bamford Review of Mental Health and Learning Disability Services in NI (2006) and the Equality Commission (NI) (2008). The latter led to a formal investigation into how people with ID accessed health information and health</p>

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services that confirmed the inequalities and discrimination encountered by this population and their families (Source 1). The Bamford Review's recommendations for health service improvements (see source 1; chapter 7) were informed by our research which also underpinned the regional guidance issued by DHSSPS (2010) for all health and social care staff in Northern Ireland to support equity of access to, and use of general healthcare for people with intellectual disabilities (GAIN guidance) (Source 2).

3. References to the research (indicative maximum of six references)

1. Barr O, Gilgunn J, Kane T and Moore G. (1999) Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland. *Journal of Advanced Nursing*, 29 (6) pp.1482-1491. (Impact Factor: 1.5) (citation H index from Scopus is 45 and Google Scholar H index is 90)
2. Truesdale-Kennedy, M. N., Taggart, L. & McIlpatrick, S. J. (2011): Breast cancer knowledge among women with intellectual disabilities and their experiences of breast mammography. *Journal of Advanced Nursing*, 67 (6), 1294 – 1304. (impact Factor 1.5) (citation H index from Scopus is 5 and Google Scholar H index is 9)
3. Taggart, L., Truesdale-Kennedy, M. & Coates, V. (2012): Management and quality indicators of diabetes mellitus in people with intellectual disabilities. *Journal of Intellectual Disability Research*. (online: 29 OCT 2012, DOI: 10.1111/j.1365-2788.2012.01633.x) (Impact factor: 1.8) (Google Scholar H index is 1)
4. McConkey, R. & Truesdale, M. (2000) Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities. *Journal of Advanced Nursing*. 32, 158-163. (Impact Factor: 1.5) (citation H index from Scopus is 33 and Google Scholar H index is 44)
5. Sowney M and Barr O (2006) *Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units*. *Journal of Advanced Nursing*, 55 (1) pp.36-45. (Impact Factor: 1.477) (citation H index from Scopus is 15 and Google Scholar H index is 30)
6. Taggart, L., McMillan, R. & Lawson, A. (2010): Staffs' knowledge and perceptions of working with women with intellectual disabilities and psychiatric disorders. *Journal of Intellectual Disabilities Research*, 54 (1), 90–100. (Impact factor: 1.8) (citation 3 index from Scopus is 4 and Google Scholar H index is 6)

Grant income:

2008-2013 £133,552 Chair of Learning Disability: Joint Appointment with the Eastern Health & Social Services Board.

2008: £20,000 Breast Cancer Campaign, London: 'The experiences of women with intellectual disabilities accessing breast screening services'. (PI: Dr L Taggart)

2010: £96,067 Research & Development Office, Belfast. Promoting the health of young people with intellectual disabilities through a blended e-learning resource designed for teachers, classroom support assistants and parents. (PI: Dr L Taggart)

2012: £291,678: Diabetes UK: Diabetes education for adults with intellectual disabilities with Type 2 diabetes and their carers. (PI: Dr L Taggart)

4. Details of the impact (indicative maximum 750 words)

The programme of research undertaken within CIDD has been instrumental in addressing the health inequalities and the health promotion needs of people with ID. The impact is evident in the following six areas:

1. The identification of health inequalities through health surveillance:

Members of CIDD through robust research have clearly identified the health needs of this population (1–6). As a result, a 'health passport' was developed which provides a structured nursing assessment and assists in the communication of information between the person with ID and mainstream healthcare professionals (Source 3). In addition training courses for over 150 acute hospital staff in Northern Ireland were devised by University personnel in collaboration with a theatre company of people with ID. The training supported the implementation of the GAIN

Guidelines (Source 2).

The learning gained from this work led to an exploration of other chronic health conditions and a focus on diabetes emerged. A new project has brought together an inter-disciplinary team of international experts from across the four UK countries in order to adapt and test a diabetes education programme for people with ID. This is funded by a grant from Diabetes UK £291,678 in 2012.

2. The development of a network of Health Facilitators in GP Practices to promote health screening/annual checks:

The research undertaken by members of the CIDD was cited in Equal Lives (DHSSPSNI, 2005) (Source 1) that led to the pioneering appointment of nine Health Facilitators for people with ID across the five Health and Social Care Trusts in Northern Ireland. The health facilitators encourage attendance at annual health screens undertaken by GPs: with uptakes in certain areas (76%) exceeding those reported for other regions of the UK. They also support the implementation of health action plans within ID services and they have adapted and instigated health promotion activities around healthy hearts and exercise (Source 4).

3. The development of accessible information to assist people with ID to make positive lifestyle choices:

A colourful, user friendly information booklet on breast cancer/screening was developed that allows women to make more informed decisions about monitoring their own health and accessing breast screening services. It gives women with ID, their carers and professional staff a greater understanding of what breast cancer is, the signs/symptoms, what to do and the process involved in receiving a mammogram. This innovative publication was developed in collaboration with women with ID within an advocacy network and has been circulated widely within the UK and internationally (www.easyhealth.org.uk) (Source 3). A similar booklet on promoting good mental health has been published.

4. The translation of research into pre/post multi-disciplinary education:

Findings from research undertaken by CIDD researchers have guided the development of best practice standards for 'Care of People with Learning Disabilities in General Hospitals' (DHSSPSNI, 2010). Three major hospitals in Northern Ireland have implemented these standards focusing on the care of people with ID through service improvement plans. These plans focus on increased use of accessible information to explain admission, consent and care and treatment processes: as well as facilitating a comprehensive assessment of their needs and improving communication among hospital staff in meeting these needs. More recently, a new innovative e-learning module has been designed for teachers, classroom support assistants, H&SC professionals and parents to promote the physical and mental health of children and adolescents with developmental and ID. Also a training DVD a resource manual has been produced to increase the partnership between palliative care and ID services focusing on end of life care for people with ID (McLaughlin, PhD thesis, 2012)..

5. The influence of regional, national and international policy guidelines:

The research undertaken by CIDD researchers has resulted in specific recommendations in key Northern Ireland H&SC policy documents aimed at improving access to healthcare for people with ID (DHSSPSNI, 2005, Ch.7: www.dhsspsgov.uk/equallivesreportchpt7.pdf) and across the UK (Michael Report, 2008). These research findings were also cited in the World Report on Disability produced by the WHO in 2011(p.8) (Source 1).

5. Sources to corroborate the impact (indicative maximum of 10 references)

Source 1:

- DHSSPS (2005) Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland, Belfast DHSSPS. Chapter 7: Health and Well being.

www.dhsspsni.gov.uk/equallivesreportchpt7.pdf.

- Equality Commission Northern Ireland (2008) A formal investigation under the disability discrimination legislation to evaluate the accessibility of health information in Northern Ireland for people with a learning disability. Belfast: Equality Commission. Available at:

[http://www.equalityni.org/archive/pdf/FormalInvestDisability\(Full\).pdf](http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf)

- World Health Organisation and the World Bank (2011) *World Report on Disability*. Geneva, WHO Press. www.who.int/disabilities/world_report/2011/en/index.html

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- Guidelines and Audit Improvement Network (DHSSPS 2010)
- Guidelines on caring for people with a learning disability in General Hospital. Belfast, DHSSPS. www.gain-ni.org/images/Uploads/Guidelines/Gain%20learning.pdf.
- Letter of Support from K Fodey, Nursing Officer, DHSSPS.

Source 3:

- Health Passport (About me)
- Guidance on completing Health Passport: E-mail from Mr Maurice Devine about Health Passport
- Letter from Compass Advocacy network to support the importance of health promotion project.
- Centre for Intellectual and Developmental Disabilities (CIDDD): <http://www.science.ulster.ac.uk/inhr/cidd/index.php>
- A series of e-mails from front-line staff providing positive feedback on the breast screening booklets.

Source 4:

- Letter from Molly Kane and Aidan Murray about the Health Facilitators.