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## Knowledge Exchange Seminar Series (KESS)

### People with intellectual Disabilities: Promoting Health, Addressing Inequality

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#### Introduction

There are approximately 16,000 children and adults with intellectual disabilities (also known as 'learning disabilities') living in Northern Ireland and known to statutory services (Statistics on Community Care for Adults in Northern Ireland, 2012/13). This is a higher proportion of our population than other regions in the UK (McConkey et al., 2003). There are also a substantial number of people with borderline/mild intellectual disabilities who do not use statutory services and are therefore not identified within these statistics; they are sometimes called the 'invisible population' (Emerson & Hatton, 2013).

The United Nations Convention on the Rights of Persons with Disabilities (2007) has recognised '*that persons with disabilities should have the same right to the highest attainable standard of healthcare without discrimination*'. Additionally, the recent UN policy stated that service providers should offer health services for persons with disabilities that included '*early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities*.' In common with many developed countries, Northern Ireland is grappling with ensuring that people with intellectual disabilities receive the same and effective healthcare as their non-disabled peers. Yet despite advances in healthcare offered to the non-disabled population, there is insurmountable evidence that this population still face a shortened lifespan, discrimination and inequity in relation to health and healthcare (Heslopp et al., 2013). This raises questions about how healthcare can be provided with a particular focus on reducing mortality and morbidity, and improving quality of life for this under-represented population. Questions of who will provide this care and where this should be provided are of equal significance.

This seminar presents the health inequalities faced by people with an intellectual disability and explores potential solutions to deliver more local cost-effective and less discriminatory health

promotion and healthcare services for this often over-looked section of the population. Dealing with this issue is a central premise of both the 'Equal Lives' (DHSSPSNI, 2005) and 'Transforming Your Care' (DHSSPSNI, 2011) policies in Northern Ireland.

### **Changing demographics of people with intellectual disabilities**

There have been a number of national and international studies that have examined the ageing profile of people with intellectual disabilities and the universal consensus is that this population in common with others are living longer and it is projected that this increased longevity will continue (McConkey et al., 2003, McConkey, 2006). The DoH (2001) within the UK stated that life expectancy for people with intellectual disabilities is predicted to increase by 11% between 2001 and 2021.

### **Health of people with intellectual disabilities**

People with intellectual disabilities are exposed to a range of health conditions and social inequalities across their lifespan. These may impact on the individual and their family at any time from childhood, through transitions to adolescence, into adulthood and also into older age. International (The US Surgeons General Report, 2002) and national reports (Disability Rights Commission, 2006; MENCAP Report, 2004, 2007; Michael Report, DoH, 2008; Six Lives Report, DoH 2009), as well as regional studies (Barr et al., 1999, 2007; Devine et al., 2010; Marshall et al., 2003; McConkey et al., 2006, 2011, 2013; McGlade et al., 2009; Sowney & Barr, 2006; Taggart et al., 2007, 2010, 2012, 2013; Slevin et al., 2008, 2010, 2011, 2014) indicate that this population have poorer health compared to their non-disabled peers. The recent Confidential Inquiry Report into the Premature Deaths of People with Learning Disabilities (Heslopp et al., 2013) in the UK found that people with intellectual disabilities died on average 20 years earlier than adults in the non-disabled population and that many of these early deaths were avoidable. Cardiovascular disease, respiratory diseases, and stomach and gallbladder cancers were the three leading causes of death for this population (Taggart & Cousins, 2014).

People with intellectual disabilities are more likely to experience a range of secondary or chronic health conditions compared to their non-disabled peers including: sensory problems (including vision, hearing and dental), constipation, thyroid problems, gastro-oesophageal reflux disease, obesity, osteoporosis, epilepsy, Type 1 and 2 diabetes, mental health problems, addictions and dementia (for a review see Emerson & Hatton, 2013; Taggart & Cousins, 2014). Many of these conditions can be prevented and/or managed more appropriately; thus improving quality of life, increasing longevity, and reducing care costs.

### **Determinants of health**

According to Emerson & Hatton (2013) there are four key determinants of health inequalities affecting people with intellectual disabilities.

#### *Increased risk of health problems associated with specific genetic/biological causes of intellectual disabilities*

There is a strong link between people with Down syndrome and congenital heart disease and also Alzheimer's disease. People with intellectual disabilities may have syndrome-related conditions that result in difficulty eating or swallowing, dental problems, reduced mobility, bone demineralization, gastro-esophageal reflux, arthritis, decreased muscle tone and progressive cervical spine degeneration. Obesity is more prevalent in people with Down syndrome and Pradi-Willi syndrome. Mental health problems and challenging behaviours are more likely to be displayed in people with specific conditions such as Lesch-Nyhan syndrome, Autistic Spectrum Conditions, Rett syndrome,

Fragile-X syndrome and William's syndrome. People with intellectual disabilities who are frequently prescribed psychotropic and anti-seizure medications on a long-term basis have a higher risk of developing osteoporosis (brittle bone disease), which is compounded by lack of physical activity and diets limited in calcium and vitamin D.

### *Personal health risks and behaviours*

Few people with intellectual disabilities eat a balanced diet and family/paid carers have a poor knowledge about the appropriate recommendations on dietary intake (Hanna et al., 2011). Less than 20% of adults and 8% of children with intellectual disability engage in the WHO recommendations for physical activity (moderate to vigorous activity). High levels of sedentary behaviour are reported for adults with intellectual disability compared to their non-disabled peers. Women with intellectual disability, people with Down syndrome, those with a mild disability and those living in less restrictive facilities are more likely to be obese (Emerson & Baines, 2011).

Slevin et al. (2014) found that young people with intellectual disability were significantly obese, had higher waist circumferences, consumed more fatty and sugary foods, engaged in low levels of physical activity and spent fewer hours on moderate to vigorous activity compared to their non-disabled peers across Northern Ireland. More adolescents with intellectual disability were now smoking compared to their peers (Taggart & Temple, 2014). People with intellectual disabilities drink less than their non-disabled peers, although there is a small but sizeable group who abuse alcohol and illicit drugs with significant consequences (Taggart & Chaplin, 2014). People with intellectual disabilities have limited knowledge about forming appropriate relationships; intimacy and sexual health (i.e. contraception) and also family/paid carers have limited knowledge/confidence in supporting this population about good sexual health (Lafferty et al., 2013).

### *Deficiencies relating to access to health education, health promotion and access to care*

People with intellectual disabilities are more likely to have communication difficulties that limit how they communicate when ill or unwell, this then leads them to have a greater reliance upon family/paid carers who may have limited knowledge of the signs/symptoms of ill health (Hanna et al., 2011). People with intellectual disabilities face health inequalities from an early age (i.e. lack of resources, pragmatic barriers (i.e. physical access), accessible information, timely appointments, transport, delays in access to screening, and early diagnosis and treatment): recent evidence today still shows a lack of reasonable adjustments being made within primary healthcare, acute general hospitals and within mental health services (Tuffrey-Wijne et al., 2014). There is a lack of training for staff, and negative attitudes and discriminatory practices can be held by some primary and secondary healthcare personnel (O'Leary et al., forthcoming).

There is a lack of health promotion literacy/educational material (i.e. diet, activity, cancer, smoking, mental health) designed specifically for this population. There is low up-take of health screening opportunities (i.e. hearing, dental, vision, breast/cervical, testicular/prostate screening). There is limited use of health promotion programmes offered to the non-disabled population (i.e. weight reduction programmes, exercise/activity programmes, self-management programmes for chronic illnesses such as Type 2 diabetes). Access to health education and screening programmes are poorer for people with intellectual disabilities who have a severe/profound disability, who are aged over 60 years, who are not known to services and also those from ethnic communities (Emerson & Hatton, 2013).

The provision of an annual health check for adult persons with an intellectual disability is intended to counter the health inequalities experienced by this population. However, international evidence

illustrates annual health checks are given less often to people with intellectual disability than to the non-disabled population; yet it has been shown consistently that these lead to detection of unmet health needs and lead to targeted actions to address health needs (Glover et al., 2012, McConkey, 2013). McConkey, Taggart & Kane (in press) found that 64% of people with intellectual disabilities known to GP practices in Northern Ireland had received a health check, which is significantly higher than comparable percentages of around 46% reported for England. Nevertheless the uptake by patients varied across the five Trusts. Individuals were less likely to have had a health check if they were younger, living with families or independently, living in more socially deprived areas or not known to intellectual disability services. There is also limited access to appropriate mental health assessment and treatment facilities for people with intellectual disabilities.

### *Greater risk of exposure to social determinants of health*

People with intellectual disability are more likely to live in low socio-economic environments and experience poverty compared to non-disabled populations, and because of their cognitive impairment they will find it more difficult to break out of this poverty trap (World Bank, 2011). Many people across the world hold negative and discriminatory attitudes about people with intellectual disability. Such discriminatory attitudes and practices can restrict access to good housing, education, employment and timely and effective healthcare services which can lead to health problems developing and poor management of such health conditions. These attitudes and practices can also lead to people with intellectual disability experiencing harassment, bullying and hate crimes, which can lead to poorer physical and mental health. Overall, social determinants can exclude people with intellectual disabilities that contradict the core values explicit within 'Equal Lives' (DHSSPSNI, 2005).

### **Solutions to such health inequalities**

Despite many exemplars of evidence-base practices in health promotion in the non-disabled population such robust evidence is lacking for people with intellectual disabilities. The aim of this seminar is to identify the main barriers to health promotion and healthcare, and the innovative ways of overcoming them. Responding appropriately to the health inequalities faced by people with intellectual disabilities demands action on five strands. These five strands are inter-related but underpinned by the goals of changing attitudes, improving knowledge and understanding and developing new skills of all involved with this population.

### *Accessing primary care*

The first strand should focus upon supporting the person with intellectual disabilities to access their local GP/practice nurse to receive an annual health check. Regular health checks, including physical examinations that include record of blood pressure, weight, review of medication, breast/cervical or testicular examination, and assessment of vision and hearing, should be part of a person's health management programme. After this screening a health-action-plan can be developed to promote the person's wellbeing. GP practices will need to have a system in place in order to identify people with intellectual disabilities and a designated link person (i.e. health facilitator) will be required to support these healthcare professionals to communicate with this population and their carers (McConkey, 2013, McConkey et al., in press). Furthermore, when people with intellectual disabilities attend A&E or an out-patients appointment or are admitted into an acute hospital, they should have the opportunity to avail of the services of a liaison nurse who can support their journey through the hospital: supporting the person and their family, as well as the medical/nursing staff.

### *Working together to promote better health*



A second strand should focus upon greater co-operation between the person, their family carers, intellectual disability support staff and primary/secondary healthcare personnel to work together to promote the health of this population: that is better multi-agency working. It is each person's responsibility to identify the risk and protective factors of this population's health in order to empower the person with intellectual disabilities to make healthier lifestyle choices throughout the lifespan. Health promotion involves developing an environment that best supports good health outcomes for this population, and as such is not the sole responsibility of any one professional group. Hence this will require the education of the person, family carers, intellectual disability support staff and primary/secondary healthcare personnel. This will involve greater multi-agency working between education/school health; integrated health and social services; police & probation services; joint statutory, private and third sector working; and public health, etc.

### *Access to publicly funded population-based public health programmes*

A third strand is that people with intellectual disabilities should be supported to access publicly funded population-based public health programmes: but for this to take place 'reasonable adjustments' are required (Discrimination Act, 2005, 2010). Trials of new health promotion initiatives to improve health should be required to include marginalized populations. However to date, most of these programmes have neither recognized nor addressed the specific challenges posed by this population's cognitive deficits, low levels of literacy skills, communication difficulties, learning styles and mobility. Thus a promising approach is for existing programmes to be adapted and evaluated by intellectual disability personnel. This has the added benefit of providing comparative benchmarks for the health gains that can be expected within an intellectual disability population.

### *Tailored health programmes*

A fourth strand should focus upon people with intellectual disabilities who may be unable to access mainstream public health programmes, therefore more tailored and specially delivered health programmes are required that will address the barriers to healthcare that this population face. Although some exemplars of these types of programmes exist, there is a greater need for a more robust methodology and evidence-base to identify if such interventions work and their cost-effectiveness.

### *Self-management of chronic conditions*

Lastly, as publicly funded health programmes place a strong emphasis on individuals self-monitoring and self-managing their own chronic health conditions, people with intellectual disabilities should be included in these initiatives. This then requires trained personnel in primary healthcare and intellectual disability services, and evidence-based programmes using a range of effective health promotion strategies (i.e. theoretical underpinning, clear evidence-base, user friendly material, one-to-one and/or group education sessions, flexibility, repetition, use of kinesthetic learning, role-play, etc.). Furthermore, future health promotion programmes cannot ignore the added value that digital technology can have in facilitating the self-monitoring and self-management of a range of chronic health conditions by using commercially available portable, accessible devices.

## **Northern Ireland policy responses to the inequalities of this population**

Over 150 nations including the United Kingdom are signatories to the UN Convention on the Rights of People with Disabilities (2012). Regionally, 'Equal Lives: A Review of Policy for People with Learning Disabilities in Northern Ireland' (DHSSPSNI, 2005) and the 'Northern Ireland Learning Disability Service Framework' (2012) recommended a fundamental shift in how this population are supported to maintain a good quality of life within their natural environments, and with equality of

opportunity to generic healthcare services and where needed specialist services. However, there is a large gap between policy intention and its implementation. 'Transforming Your Care: A Review of Health & Social Care in Northern Ireland' (DHSSPSNI, 2011) proposed Trusts should make a joint commitment to improve the health and wellbeing of people with intellectual disabilities to reduce the health inequalities and ensure quality, safety and continuous improvement across all the services commissioned and provided.

The Bamford Mental Health and Learning Disability Action Plan 2012-15 also proposes actions to improve the health status of people with intellectual disabilities in key areas such as nutrition, obesity, exercise and mental health: with improved opportunities for people to gain the mental wellbeing benefits of participation in sport and physical recreation. A report to OFMDFM on shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the United Nations Convention on the Rights of Persons with identified substantive shortfalls with respect to Article 25 on Health however; specific reference was not made to the particular needs of individuals with intellectual disabilities in the document (Byrne et al., 2014). In times of austerity it is important people with intellectual disabilities are not seen as a soft target for cut-backs in services.

### **Conclusion**

Social determinants of health are extremely important for this population and lessons learnt from approaches used with other marginalised groups should be considered. Research and evaluation is critical to ensure that interventions achieve the expected outcomes in the most cost-effective manner. The challenge in establishing equitable health promotion programmes for people with intellectual disability is an issue in many countries. The need to measure health outcomes and to build new or extend existing partnerships with key stakeholders to improve access to health promotion activities and healthcare services is now widely recognized. Developing and promoting good evidence base for health promotion in this population would help support services achieve better health outcomes and avoid early death. Not only do priorities need to be established but it is also important to target interventions appropriately across people's lifespans. Better health is a key foundation for better lives in people with intellectual disability ('Equal Lives,' DHSSPSNI, 2005; 'Transforming Your Care', DHSSPSNI, 2011).

