

Institution: Cardiff University		
Unit of Assessment: Psychology, Psychiatry and Neuroscience (4)		
Title of case study: Improving the health of adults and young people with learning disabilities through the Cardiff Health Check		
Period when the underpinning research was undertaken: 2005 – 2008		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Michael Kerr	Clinical Professor	1992 - 2017
David Felce	Director	1994 - 2015
Frank Dunstan	Professor	1993 - 2016
Helen Houston	Vice Dean	1990 - 2014
Period when the claimed impact occurred: 01/08/2013 – 31/07/2020		
Is this case study continued from a case study submitted in 2014? Yes		
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>People with an intellectual disability experience more health problems than the general population but find it difficult to report illness. In the prior REF period, Cardiff researchers developed the Cardiff Health Check enabling GPs to proactively screen for physical health problems in adults with intellectual disabilities. Since REF 2014, the Cardiff Health Check's reach has been significantly extended. It now covers children aged 14-18 years old in England, was revised to enable an additional mental health review, as recommended in a NICE guideline, and is used by all GPs in England, Wales and Northern Ireland who use the Digital Template as part of the NHS Directed Enhanced Service. Since August 2013, there has been a significant increase in use of the Cardiff Health Check, with almost 800,000 carried out in England alone, generating 475,000 individual Health Action Plans designed to improve patient health.</p>		
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>Prior to Cardiff's research, there were no standardised health checks specifically for individuals with intellectual disabilities. This meant that treatable illnesses frequently went undetected, a gap in care that resulted in reduced quality of life and significant early mortality (as evidenced by the 'Confidential Inquiry into premature deaths of people with learning disabilities' [5.1a]). For example, men with intellectual disabilities die, on average, 13 years sooner than men in the general population; the difference for women with intellectual disabilities is 20 years earlier.</p> <p>2.1 The Cardiff Health Check</p> <p>To address the urgent need for proactive health checking in adults with intellectual disabilities, the Cardiff team developed and evaluated the Cardiff Health Check (also known as the Welsh Health Check). The assessment tool allows GPs to conduct medication reviews and to proactively screen patients for various health indicators, via measurement / screening of weight, blood pressure, urine, smoking, alcohol consumption and cholesterol. The Cardiff Health Check also considers immunizations, includes cervical and mammography screens, and measurement of respiratory, cardiovascular, abdominal, central nervous system function. It additionally covers issues common in intellectually disabled people, including epilepsy, behavioural disturbance, poor mobility and communication difficulties.</p> <p>To evaluate the effectiveness of the Cardiff Health Check, the Cardiff team recruited GPs and trained them to conduct health checks in patients with intellectual disabilities [3.1]. Subsequent interviews identified where medical conditions had been identified through the health check and, when this occurred, treatment plans were put in place. The research found that 93 of 190 (49%) participants had unidentified health needs which required intervention. Further, nearly 40% of individuals had two or more unmet health needs (e.g., breathing difficulties, high blood pressure, breast cancer). The study also confirmed that, once GPs had</p>		

become aware of these health needs, they were more likely to offer support to manage health conditions (e.g. ordering further tests and referring patients to other specialities) [3.1]. In summary, use of the Cardiff Health Check ensured that 93% of previously unidentified health needs were subsequently acted on by GPs.

Two further research studies built on this important work as follows:

- Comparison of medical records pre- and post-health check demonstrated positive impacts on health promotion actions, such as referral to specialists, further screening (e.g., mammography) or tests (e.g., urine) [3.2]. Health promotion actions increased from 1.2 to 2.2 per year, per person. The mean number of patients having no follow-up actions reduced from 74.5% to 61.7%.
- Analysis of 108 individuals with intellectual disabilities, who had previously received a Cardiff Health Check [3.3], found that a second follow-on health check (undertaken at 28 or 44 months) successfully identified new health needs, which in turn resulted in more positive health actions from clinicians. This finding evidenced the vital importance of the Cardiff Health Check being delivered annually to individuals with intellectual disabilities, facilitating identification of ongoing, but also new, health needs.

The research demonstrated the significant benefit of GPs undertaking regular health checks in individuals with intellectual disabilities, with these checks identifying previously unknown health needs which could be proactively supported, including via the use of individual Health Action Plans.

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

[3.1] Baxter H, Lowe K, **Houston H**, Jones G, **Felce D** & **Kerr M** (2006) Previously unidentified morbidity in patients with intellectual disability. *British J. General Practice*, 56, 93-98. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1828252/>

[3.2] **Felce D**, Baxter H, Lowe K, **Dunstan F**, **Houston H**, Jones G, Grey J, Felce J & **Kerr M** (2008a) The impact of checking the health of adults with intellectual disabilities on primary care consultation rates, health promotion and contact with specialists. *J App Res Intellectual Disabilities*, 21, 597-602. <https://doi.org/10.1111/j.1468-3148.2008.00432.x>

[3.3] **Felce D**, Baxter H, Lowe K, **Dunstan F**, **Houston H**, Jones G, Felce J & **Kerr M** (2008b) The impact of repeated health checks for adults with intellectual disabilities. *J App Res Intellectual Disabilities*, 21, 585-596. <https://doi.org/10.1111/j.1468-3148.2008.00441.x>

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

Our REF 2014 impact case study outlined how Cardiff University's research on a Cardiff Health Check led the Welsh Government and the Department of Health to begin funding annual Cardiff Health Checks for all adults with learning disabilities across Wales and England. Analysis of the benefits of the Cardiff Health Check (Buszewicz et al (2014) *Lancet Psychiatry*, Dec;1(7):522-3) showed clear positive impact. Comparison of English GP practices that adopted the Cardiff Health Check, versus those that did not, found that use of the health check increased health actions, including blood tests, general and specific health assessments and medication reviews, as well as identification of thyroid disease, gastrointestinal disorders and obesity. The Cardiff Health Check also facilitated Health Action Plans and secondary health referrals.

Building on this successful impact, since August 2013, the Cardiff Health Check:

1. was extended to cover young people with intellectual disabilities aged 14-18 years old in England, where previously the health check was only used in adults (18 years and older);
2. was expanded to include a mental health review, addressing recommendations from the 2016 NICE guideline (*Mental health problems in people with learning disabilities: prevention, assessment and management*, NG54);

3. has increased substantially in use, facilitated by its inclusion in the online Digital Template, implemented in 2017 as part of the NHS Directed Enhanced Service, and used by GPs across England, Northern Ireland and Wales.

4.1 Extending the Cardiff Health Check to young people aged 14-18 years old in England

The 2013 'Confidential Inquiry into premature deaths of people with intellectual disabilities' recommended use of the Cardiff Health Check in people with learning disabilities [5.1a, p.112]. The Inquiry also noted that a lack of standardised approaches impacted on transition from child to adult health services, leading to health disadvantages for people with learning disabilities [5.1a, p.75]. In response, the Department of Health reviewed its provision of health checks [5.1b], resulting in changes to the 2014-15 General Medical Service Contract [5.1c]. These changes directed GP practices in England to: "identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer them an annual health check..." [5.1c, p.31].

Since this change was introduced, the number of young people with intellectual disabilities aged 14-18 years old receiving a Cardiff Health Check in England has doubled (e.g., 7,164 in 2019-20, compared to 3,147 in 2015-16) [5.2]. Increased use of the Cardiff Health Check ensures that unknown medical conditions can be identified, supporting early medical interventions designed to avoid unnecessary pain and discomfort, and reduce the likelihood of long-term hospitalisation. For individuals with complex health needs, Cardiff Health Checks also help avoid presentation at A&E departments with acute medical conditions (e.g., Carey et al. noted "a reduction in preventable emergency hospitalisations after the introduction of health checks" [5.3, p.58]).

4.2. Inclusion of the Cardiff Health Check in NICE Guidelines

In 2015, NICE's *Challenging Behaviour and Learning Disabilities* guidance (NG11) noted that "Some care environments increase the likelihood of behaviour that challenges. This includes ... where physical health needs and pain go unrecognised or are not managed" [5.4, p.5]. In response, these guidelines specifically named the Cardiff Health Check as a means to identify these unknown physical health requirements. The guidance further stated that "GPs should offer an annual physical health check to children, young people and adults with a learning disability in all settings, using a standardised template (such as the Cardiff Health Check template)" [5.4, p.12].

The 2016 NICE guideline *Mental health problems in people with learning disabilities: prevention, assessment and management* (NG54) also included the recommendation that GPs offer an annual health check, using a standardised template, to all adults with intellectual disabilities (number 1.6, entitled "Annual Health checks" [5.5, p.6]). The guideline further recommended extending the scope of annual screening to include a mental health review, thereby delivering more effective mental health treatment for patients with intellectual disabilities.

Prior to the NICE NG54 guideline, GPs were only able to use the Cardiff Health Check to screen for physical conditions. Building on [3.1-3.3], and in collaboration with the Royal College of General Practitioners, Kerr developed an extended version of the Cardiff Health Check [5.6], which now includes ECG monitoring of patients taking antipsychotic medication; indicators for Down's syndrome and dementia; and information relevant to assessment of behaviour and mental illness. This revised version was recommended by the Royal College of General Practitioners in 2018, in their step-by-step guide to health checks for primary healthcare teams who care for people with an intellectual disability [5.7, p.3].

4.3. Patient benefit

As part of the NHS Directed Enhanced Service, in 2017 the Digital Template was introduced. The Digital Template is an online version of the Cardiff Health Check, used by GPs in England, Northern Ireland and Wales who opt to provide annual health checks under this service [5.8]. An advantage of the Digital Template is that it is integrated with patient's medical records and "incorporates all aspects of the recently refreshed Cardiff Health Check" [5.8, p.2], enabling

assessment of both physical and mental health needs in individuals with intellectual disabilities.

In 2019-20 all 191 Clinical Commissioning Groups in England used the Digital Template as a basis for delivering health checks [5.2]. The impact of the Cardiff Health Check since August 2013 is evidenced by the following NHS data (from England) [5.2]:

- an increase in learning disabled patients receiving a health check from 124,785 (44% of those registered as having a learning disability) in 2013-14 to 156,287 in 2019-20;
- on average, almost double the number of health checks were carried out in England during the REF period (133,035 per annum), in comparison to the number carried out in both England and Wales up to July 2013 (78,000 per annum);
- since August 2013, at least 798,215 learning disabilities health checks were undertaken, leading to the generation of at least 475,318 individual Health Action Plans.

Use of the Cardiff Health Check makes a vital difference to patients' health, and saves lives.

- A study by Kennedy et al. (2019) of mortality data among individuals with learning disabilities in Wales revealed 2.08 deaths per 1,000 individuals per year in those receiving a Cardiff Health Check (versus 3.55 deaths per 1,000 individuals per year in those who do not receive a health check) [5.9].
- Diagnosis of constipation in individuals with learning disabilities increased from 2% in 2014-15 to 13% in 2016-17 [5.10a, p.2]. This is a significant change given that complications from chronic constipation in people with intellectual disabilities can be life threatening (as highlighted in two serious case reviews in 2015, undertaken by Suffolk County Council, following the deaths of patients with learning disabilities from chronic constipation) [5.10b].
- In 2016-17 almost 80% of eligible patients with a learning disability aged 60-69 years received screening for colorectal cancer, an increase from 69% in 2014-15 [5.10a, p.2].

4.4 Summary

The expanded Cardiff Health Check is now the standard of care for GP monitoring of patients with intellectual disabilities in Wales, Northern Ireland and England, with individuals now screened for both their physical and mental health. Almost double the number of Cardiff Health Checks have been undertaken since REF2014, with increased numbers of individual Health Action Plans. The vital impact of the Cardiff Health Check is further evidenced by lower mortality rates in individuals with learning disabilities who have health checks compared to those who do not.

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

[5.1] Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD): a. Final report (133 pages) b. Government response to CIPOLD (32 pages) c. General Medical Services Contract 2014/15 – Guidance and Audit Requirements (84 pages)

[5.2] Summary of NHS Digital data on Health Checks and Action Plans from NHS Digital 'Learning Disabilities Health Check Scheme' data series

[5.3] Carey IM, Hosking FJ, Harris T, et al. (2017) Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment. *Epidemiol. Community Health*, 71, 52-58. DOI:10.1136/jech-2016-207557

[5.4] *Challenging Behaviour and Learning Disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges* - NICE guideline [NG11] (2015)

[5.5] *Mental health problems in people with learning disabilities: prevention, assessment and management* - NICE guideline [NG54] (2016)

[5.6] Extended Cardiff Health Check Template, revised 2016

[5.7] Royal College of General Practitioners (2018). *Step-by-step to Health Check for people with a learning disability*. London: Royal College of General Practitioners

[5.8] NHS England (2017). *National Electronic Health Check (Learning Disabilities) Clinical Template: A summary and overview of the Learning Disability Annual Health Check electronic clinical template (2017)*

[5.9] Kennedy N, Brophy S, Kennedy J, Kerr M (2019), Mortality in adults with learning disabilities with and without a health check: a cohort study. *Lancet*, 394, S27. DOI: 10.1016/S0140-6736(19)32824-7

[5.10] a. NHS Digital (2017). *Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017* b. Suffolk Safeguarding Adults Board, Suffolk County Council (October 2015). *A Serious Case Review – James*, and *A Serious Case Review – Amy*