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**The Impact of Health Checks for People with Intellectual disabilities:  
An Updated Systematic Review of Evidence**

**Abstract**

Health checks for people with intellectual disabilities have been recommended as one component of international health policy responses to the poorer health of people with intellectual disabilities. This review updates a previously published review summarising evidence on the impact of health checks on the health and well-being of people with intellectual disabilities. Electronic literature searches and email contacts were used to identify literature relevant to the impact of health checks for people with intellectual disabilities published from 1989 to 2013. Forty-eight publications were identified, of which eight articles and two reports were newly identified and not included in the previous review. These involved checking the health of people with intellectual disabilities from a range of countries including a full range of people with intellectual disabilities. Health checks consistently led to detection of unmet health needs and targeted actions to address health needs. Health checks also had the potential to increase knowledge of the health needs of people with intellectual disabilities amongst health professionals and support staff, and to identify gaps in health services. Health checks are effective in identifying previously unrecognised health needs, including life threatening conditions. Future research should consider strategies for optimising the cost effectiveness or efficiency of health checks.

Keywords: health checks; intellectual disabilities.

## Highlights

- Updated systematic review on health checks for people with intellectual disabilities
- Health checks lead to detection of both common and serious unmet health needs
- Health checks lead to targeted actions to address health needs
- Health checks may increase knowledge of health professionals and support staff

## 1. Introduction

### 1.1. Health inequalities and people with intellectual disabilities

People with intellectual disabilities<sup>1</sup> have poorer health than their non-disabled peers, differences in health status that are, to a significant extent, avoidable (Emerson and Hatton, 2014, Ouellette-Kuntz, 2005, NHS Health Scotland, 2004, Krahn *et al.*, 2006, US Department Health & Human Services., 2002, Van Schrojenstein Lantman-de Valk, 2005, O'Hara *et al.*, 2010). These health inequalities start early in life and result from the interaction between multiple processes. Firstly, people with intellectual disabilities are at increased risk of exposure to well established 'social determinants' of health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination (Beresford and Rhodes, 2008, Emerson, 2010, Emerson *et al.*, 2012, Emerson and Hatton, 2010). There is also increased risk associated with specific genetic and biological causes of intellectual disabilities (e.g., congenital heart disease in people with Down's syndrome and Williams syndrome; hypothalamic disorders in people with Prader-Willi syndrome; mental health problems among people with autism spectrum disorders and a number of specific syndromes) (Dykens *et al.*, 2000, Emerson and Einfeld, 2011, Harris, 2005, Batshaw *et al.*, 2007). In addition, communication difficulties and reduced health 'literacy' can reduce the capacity of people with intellectual disabilities to convey health needs to others (e.g., relatives, friends, paid support workers) (McKenzie and Powell, 2004). People with intellectual disabilities may also be less likely to receive or act upon health promotion information. Finally, there may be deficiencies in access to and the quality of

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<sup>1</sup> The term 'learning disabilities' is sometimes used in this paper in relation to the UK context and is synonymous with intellectual disabilities

healthcare provision for people with intellectual disabilities (Alborz *et al.*, 2005, Michael, 2008, Giraud-Saunders, 2009, Disability Rights Commission, 2006, Mencap, 2007). For example, a recent investigation of the causes and circumstances of 244 deaths of people with intellectual disabilities in England found that 28% were 'amenable' in that in light of current knowledge all or most deaths from that cause could have been avoided through the provision of good quality healthcare (Heslop *et al.*, 2013a).

### *1.2. Health Checks as a Response to Health Inequalities*

Health checks vary in how they are delivered and the following definition has been suggested (Lennox and Robertson, 2014): "... the systematic gathering of a comprehensive health history that includes the person's current and past health information, and their psycho-social context. This history is reviewed by a primary care health professional, considered and clarified where necessary, and leads to a directed, systematic physical and mental health examination which results in identification of any unmet health needs that are documented and optimally acted upon. The process optimally includes specific information about commonly missed and syndrome-specific health conditions to inform the person with intellectual disability, their caregivers and the health professional" (p195).

The implementation of health checks has been recommended internationally as one component of health policy responses to the poorer health of people with intellectual disabilities. Within both the United Kingdom (UK) and Australia, there have been policy initiatives to promote health checks for people with intellectual disabilities. In 2007, the Australian government introduced a new Medicare rebate for people with an intellectual disability who have an annual health check, at an estimated cost of \$11 million over four

years (Pyne, 2007). The Comprehensive Health Assessment Program (CHAP) has been licensed and used widely across Australia to deliver these health assessments in what is described as unusually rapid translation of evidence into practice (Lennox *et al.*, 2010).

In the UK, the Disability Rights Commission in 2006 recommended the introduction of annual health checks for people with intellectual disabilities in England and Wales as a 'reasonable adjustment' in primary health care services (Disability Rights Commission, 2006). 'Reasonable adjustments' refers to the legal duty of public sector services to make their services as accessible and effective as they would be for people without disabilities (Hatton *et al.*, 2011). Annual health checks for every adult on a local authority register were introduced as a Directed Enhanced Service (DES) in primary care services in Wales in 2006, after which there was a year on year improvement in uptake, with the proportions of people with intellectual disabilities who received a health check in 2006/07, 2007/08 and 2008/09 being 31%, 34%, and 41% (Perry *et al.*, 2010). In England, a DES to deliver annual health checks for people with intellectual disabilities began in 2008/9 and has been extended to 2014/15. In 2012/13, 92,329 people with intellectual disabilities in England received a health check, 52% of those eligible to receive one (Glover and Niggebrugge, 2013). In Scotland, one of the recommendations of the Government is that the Learning Disability Strategy Implementation Group will work with the newly created Scottish Learning Disability Observatory to establish and implement a targeted health screening programme (health checks) for people with intellectual disabilities across NHS Scotland (Scottish Government, 2013).

In Canada, periodic health examinations were recommended in guidelines for the primary care of adults with developmental disabilities (Lunsky *et al.*, 2014). However, based

on data from over 66,000 adults with developmental disabilities, the periodic health examination occurred for only 22% of adults with developmental disabilities over a two-year period, slightly less than the 26% for adults without developmental disabilities (Lunsky *et al.*, 2013). In New Zealand, it was recommended that primary health care providers should have health assessment tools for people with intellectual disabilities as part of recommendations to urgently address systemic neglect of the health of adults with intellectual disabilities (National Advisory Committee on Health and Disability, 2003). At present, a number of health assessment tools are being used in New Zealand, including the CHAP which is being used by one support provider to check the health of people accessing its residential services (Ministry of Health, 2013). Initial review of the implementation of the CHAP by the provider indicates that conditions are being identified and being treated, that are life enhancing and potentially lifesaving (Garriock, 2013, Personal Communication).

### 1.3. Rationale for Health Checks

The underlying rationale for the use of health checks is that: (1) primary care services tend to be reactive, responding to problems raised by patients (Martin *et al.*, 1997b); (2) people with intellectual disabilities may be unaware of the medical implications of symptoms they experience, have difficulty communicating their symptoms, or may be less likely to report them to medical staff (Beange *et al.*, 1995, Martin *et al.*, 2004b, McKenzie and Powell, 2004, Purcell *et al.*, 1999, Kerr *et al.*, 2003); (3) carers may not always attribute the manifestations of clinical symptoms to physical or mental illness (Wilson and Haire, 1990); (4) as a result, health checks provide a way to detect, treat and prevent new health

conditions in this population (Cassidy *et al.*, 2002, Wilson and Haire, 1990, Barr *et al.*, 1999, Backer and Jervis, 2007, Jones *et al.*, 2009, Disability Rights Commission, 2006, Michael, 2008). It has also been argued that health checks can help provide baseline information against which changes in health status can be monitored, a particular issue given the frequency of changes in paid carers supporting people with intellectual disabilities and the difficulties that people with intellectual disabilities may have in detecting and reporting longer term changes in health status (Martin, 2003, Jones *et al.*, 2009).

It has also been argued that health checks may be cost effective as the detection of new or underlying medical conditions may reduce the consumption of resources in other areas of healthcare (Ryan and Sunada, 1997), such as services for challenging behaviour and mental health problems (Gunsett *et al.*, 1989, Ryan and Sunada, 1997) and reduce the need for future and potentially more expensive treatment.

Whilst a review of evidence on the effectiveness of health checks for people with intellectual disabilities has been published previously (Robertson *et al.*, 2010, Robertson *et al.*, 2011), much of the research included in the review was published prior to the implementation of the policy responses outlined above. In view of this, and the continuing international interest in health checks, an update of this review is timely. This paper updates the results of the previous systematic review of published research concerning the impact of health checks on the health and well-being of people with intellectual disabilities.

## **2. Methodology**

### *2.1. Search Strategy*

Searches of electronic literature databases (Medline, Cinahl, Web of Science and PsycINFO) were initially conducted in June 2010 to identify relevant peer reviewed articles

published from 1989 onwards in the English language. Searches were conducted again in August 2013 to identify literature published since June 2010. In each database, terms for intellectual disabilities were combined with search terms relating to health checks (e.g. health screening; health monitoring). In addition, a request for information on research relevant to the review was sent to the membership of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) Health Special Interest Research Group in June 2010. A similar request was sent in August 2013, and at this time the request was also emailed to additional intellectual disability networks and the Intellectual Disability UK Research mailing list. This enabled the identification of research literature not identified in the electronic searches, for example relevant articles which were “in press”.

## *2.2. Criteria for selection*

All articles identified by searches were assessed for their relevance to the review objectives firstly by reading abstracts. If abstracts were unavailable, or did not provide enough detail to assess the relevance of the article, the full text of the article was obtained and relevance assessed from this. Studies were included if they: were published in English between 1989 and 2013; presented information on the effectiveness of health checks for people with intellectual disabilities based on quantitative or qualitative research; were peer reviewed. Studies were excluded if they: were not published in English; did not focus on the effectiveness of health checks for people with intellectual disabilities, for example studies mapping coverage of health checks for people with intellectual disabilities; were not peer reviewed.

All relevant studies were included in the review regardless of methodological quality, although studies were categorised by research design in order to illustrate the overall number of studies identified in relation to established hierarchies of evidence (GRADE Working Group, 2004).

### *2.3. Data Extraction & Synthesis*

Data were extracted from the full text of articles identified as meeting the inclusion criteria. Textual descriptions were produced for each study. This included: bibliographic details; the country within which the study took place; details of the health check employed; details of who conducted the health check; sample size and characteristics; study design and data sources; outcome measures; main results; and issues raised in the discussion. This information was also tabulated.

Two researchers independently reviewed the textual descriptions of the studies in order to identify themes emerging from the literature for inclusion in the review results. Following pooling of identified themes, final themes for inclusion in the review were agreed and studies providing evidence in relation to these themes identified from the textual descriptions. It was generally not possible to compare results between studies directly due to variation in the implementation of health checks and variation in how outcomes were recorded. As such, no meta-analysis was conducted. This process was repeated with all studies newly identified in August 2013.

## **3. Results**

### *3.1. Number of studies identified*

A total of 45 peer reviewed academic journal publications and three reports were identified for inclusion in this review. In 2010, 38 publications were included in the review,

one of which was a report (Perry *et al.*, 2010). Some of the results of this report have subsequently been pooled with data from another study (Heslop *et al.*, 2013b) in a peer reviewed journal article (Perry *et al.*, 2014). Two additional reports were included in this update: a report on an evaluation of the DES in England (Chauhan *et al.*, 2012); and a report on an evaluation of the DES in Northern Ireland (McConkey, 2013). These reports were judged to have undergone a process of peer review. In total, this updated review includes eight additional peer reviewed academic journal articles, and two additional reports. Key features of all studies and themes emerging from them are summarised here.

### 3.2. Geographical Spread

Of newly identified articles, two were from Australia and all others from the UK. Overall, the majority of the publications identified were based on studies conducted in the UK, including 19 from England (Hunt *et al.*, 2001, Cassidy *et al.*, 2002, Martin *et al.*, 2004a, Bollard, 1999, Wilson and Haire, 1990, Martin *et al.*, 1997a, Martin *et al.*, 1997b, Wells *et al.*, 1997, Martin, 2003, Martin *et al.*, 2004b, Hunt *et al.*, 2006, Backer and Jervis, 2007, Chauhan *et al.*, 2010, Walmsley, 2011, Chapman, 2012, Codling, 2007, Codling, 2012, Michell, 2012, Chauhan *et al.*, 2012), 5 from Wales (Perry *et al.*, 2010, Jones and Kerr, 1997, Baxter *et al.*, 2006, Felce *et al.*, 2008a, Felce *et al.*, 2008b) 4 from Scotland (McKenzie and Powell, 2004, Cooper *et al.*, 2006, Jones *et al.*, 2009, Romeo *et al.*, 2009), and 3 from Northern Ireland (Barr *et al.*, 1999, McConkey *et al.*, 2002, McConkey, 2013). Additional publications were identified based on studies conducted in the following countries: 8 from Australia (Lennox *et al.*, 2006, Beange *et al.*, 1995, Lennox *et al.*, 2007, Lennox *et al.*, 2010, Lennox *et al.*, 2001, Lennox *et al.*, 2008, Gordon *et al.*, 2012, Lennox *et al.*, 2013); 5 from the United States

(Gunsett *et al.*, 1989, Carlsen and Galluzzi, 1994, Aronow and Hahn, 2005, Hahn and Aronow, 2005, Ryan and Sunada, 1997); one from New Zealand (Webb and Rogers, 1999); and one from Ireland (Marsh and Drummond, 2008). One paper was based on a pooled analysis of the results of two RCT studies from Australia and one non-randomised matched control group study from Scotland (Lennox *et al.*, 2011). One was based on pooled focus group data gathered from people with intellectual disabilities in Wales and England (Perry *et al.*, 2014).

### 3.3. Study Design

No randomised controlled trials (RCTs) or other additional studies with robust designs were newly identified. Of the 48 publications, only 3 were based on RCTs (Jones and Kerr, 1997, Lennox *et al.*, 2007, Lennox *et al.*, 2010). Two publications were newly identified which present further information from one of these RCTs: one on costs associated with the health check (Gordon *et al.*, 2012); and one on General Practitioner (GP) perceptions of using the health check (Lennox *et al.*, 2013). One study had a non-randomised matched control group (Cooper *et al.*, 2006). As noted above, one was based on a pooled analysis and this included three of the aforementioned studies (Lennox *et al.*, 2011). One additional study used randomized groups varying in relation to the interval between repeated health checks (Felce *et al.*, 2008a). Following a pilot study (Lennox *et al.*, 2008), a further RCT has been carried out with 728 children with intellectual disabilities in Australia but the results of this RCT are not currently available (Lennox *et al.*, 2012).

The majority of studies were based on clinical interventions where a sample of people with intellectual disabilities received a single episode of a health check and

information was presented on the outcome(s) of the health check. Four studies have investigated the impact of repeating health checks in previously checked groups, none of which were newly identified (Cassidy *et al.*, 2002, Martin, 2003, Hahn and Aronow, 2005, Felce *et al.*, 2008a). One newly identified study analysed data recorded in GP clinical systems using a cohort observational design with follow-up over two years, as well as semi-structured interviews with people with intellectual disabilities and their family or paid carers, and qualitative interviews with health professionals (Chauhan *et al.*, 2012). A further newly identified study in Northern Ireland analysed information gathered from GP returns regarding health checks to the Health and Social Care Board, as well as a sample of patient satisfaction questionnaires from GP practices and feedback from primary care staff obtained at a consultation workshop (McConkey, 2013). A number of other studies, three of which were newly identified, used questionnaires, interviews, or workshop discussions to look at the views of service users, carers, GPs or practice nurses with regard to health checks (Cassidy *et al.*, 2002, Martin *et al.*, 1997b, Barr *et al.*, 1999, Bollard, 1999, McConkey *et al.*, 2002, Lennox *et al.*, 2013, Walmsley, 2011, Chapman, 2012) and one was based on a cross-sectional survey of community learning disability nursing services in Scotland (McKenzie and Powell, 2004). Of other newly identified articles: one study used focus groups to look at the views of service users regarding health checks and this was pooled with additional focus group data looking at service user experiences of primary healthcare (Perry *et al.*, 2014); clinical audit was used to evaluate health checks in relation to the recording of information for specific questions (Codling, 2007, Codling, 2012); and inclusive research involving people with intellectual disabilities visiting GP surgeries has been reported (Michell, 2012).

### 3.4. Sample Size and Characteristics

The sample sizes for those receiving health checks varied from a single case study (Marsh and Drummond, 2008) to 1,311 people with intellectual disability supported by an agency in New Zealand (Webb and Rogers, 1999). A pooled analysis (Lennox *et al.*, 2011) included a total of 795 participants of whom 407 received health checks and 388 received usual care. In newly identified reports, data recorded in GP clinical systems was analysed and compared to those not receiving a health check for nearly 2,000 patients with intellectual disability from 160 practices (Chauhan *et al.*, 2012); and GP returns for five Health and Social Care Trusts in Northern Ireland were analysed for the years 2011/12 and 2012/13 (McConkey, 2013). In total, over 5,000 people with intellectual disabilities received health checks in the course of the studies included in this review, the clinical records of nearly 2,000 more analysed, and GP returns regarding health checks for five Health and Social Care Trusts in Northern Ireland analysed. The samples covered a full range of ages, from children (in studies where samples include both adults and children) up to the age of 86 years. The samples also covered the full range of severity of intellectual disabilities and living situations, including family homes, tenancies, supported accommodation, and large residential facilities.

### 3.5. Outcomes of Health Checks

Newly identified studies supported the finding of the previous review that health checks lead to the detection of previously undetected health needs. Overall, where the proportion of those who had previously undetected health conditions identified was given (Cassidy *et al.*, 2002, Martin *et al.*, 1997a, Jones *et al.*, 2009, Ryan and Sunada, 1997, Baxter

*et al.*, 2006, Wilson and Haire, 1990) proportions ranged from 51% (Baxter *et al.*, 2006) to 94% (Cassidy *et al.*, 2002).

Other studies reported the number of previously undetected or unmanaged health needs identified per participant with figures indicating that multiple health conditions were detected (Beange *et al.*, 1995, Lennox *et al.*, 2008, Carlsen and Galluzzi, 1994, Hahn and Aronow, 2005, Cooper *et al.*, 2006) ranging from 2.2 additional diagnoses (Carlsen and Galluzzi, 1994) to 5.2 health problems requiring intervention (Hahn and Aronow, 2005). In one newly identified study using semi-structured interviews with GPs implementing the DES, two practices had collated records on outcomes (Walmsley, 2011) and one practice identified 90 health conditions from 65 annual health checks.

Three studies have also compared the number of health needs detected in those receiving health checks with control groups (Lennox *et al.*, 2007, Lennox *et al.*, 2010, Cooper *et al.*, 2006). A pooled analysis of these three studies, involving a total of 795 participants, gives odds ratios for the detection of new diseases in those receiving health checks compared to control groups (Lennox *et al.*, 2011). New diseases identified included thyroid disease (odds ratio (OR)= 1.1; 95% confidence interval (CI) 0.5-2.7; 3% of those in the health check groups), psychiatric disorder (OR 1.8; 95% CI 0.8-4.0; 4%), heart disease (OR 1.9; 95% CI 0.6-6.5; 2%), reflux disease (OR 1.9; 95% CI 0.7-4.8; 3%), hypertension (OR 2.4; 95% CI 0.6-9.5; 2%), constipation (OR 1.6; 95% CI 0.7-3.9; 3%), and 'other diseases' (OR 3.1; 95% CI 1.6-6.1; 10%). A newly identified evaluation of the impact of the DES in England found that health checks were associated with increased identification of disease conditions incentivised through the Quality Outcomes Framework (QOF) (odds ratio for 'new QOF disease' coding between

those who had and had not had a health check was 7.97; 95% CI 2.42-26.27), and with increased screening and health promotion activity (Chauhan *et al.*, 2012).

In addition, a number of studies indicate that health checks did identify previously undiagnosed conditions as evidenced by the need for further assessments and referrals following health checks (Wells *et al.*, 1997, Backer and Jervis, 2007, Barr *et al.*, 1999). A newly identified analysis of GP returns in Northern Ireland (McConkey, 2013) summarised the number of referrals from a list of eight predetermined types of referral made following the health check. In 2012/13 the most common referral was for a thyroid function test (1,384 referrals, 28% of those who had a health check), followed by consultant (490 referrals, 10%), vision (357 referrals, 7%), and (based on assumption 50% of those having a health check were women) cervical screening (124 referrals, 6%). Other referrals were: dental (263, 5%); hearing (196, 4%); mammography (102, 4%) and counsellor (74, 1.5%). Only one study found that the intervention employed made no significant difference to the identification of health needs (Jones and Kerr, 1997). In this case, the intervention was the insertion of a prompt card into medical notes which was designed to promote opportunistic health screening by GPs rather than health screening per se.

Some of the most frequently identified conditions were what might be considered as 'less serious' health conditions. For example, in one study 50% of participants were found to have wax totally obscuring one or both eardrums (Wilson and Haire, 1990), and a high prevalence of ear wax has also been noted in other studies (Martin *et al.*, 1997a, Hahn and Aronow, 2005, Baxter *et al.*, 2006). The impact of what may seem a minor condition is illustrated by the fact that in one study nearly half of those with ear wax subsequently failed a hearing test (Wilson and Haire, 1990). Indeed, sensory loss was commonly identified

during health checks, for example a cluster randomized trial of the CHAP involving 543 adults with intellectual disabilities found 22 new cases of sensory loss in the intervention group compared to one in the control group (Lennox *et al.*, 2007). One case study of a health check identified hearing deficit as a possible cause of withdrawal and lack of interest in surroundings (Marsh and Drummond, 2008). Other commonly identified conditions include: skin conditions (Lennox *et al.*, 2006, Lennox *et al.*, 2001, Barr *et al.*, 1999, McConkey *et al.*, 2002); dental problems (Barr *et al.*, 1999, Lennox *et al.*, 2008); constipation (Lennox *et al.*, 2011, Hahn and Aronow, 2005, Walmsley, 2011); anaemia (Hunt *et al.*, 2001, Carlsen and Galluzzi, 1994); and foot problems (Barr *et al.*, 1999, McConkey *et al.*, 2002, Walmsley, 2011).

Studies have also identified previously undiagnosed conditions that include serious and life threatening conditions including: heart disease (Wilson and Haire, 1990, Walmsley, 2011); hypertension (Wilson and Haire, 1990, Baxter *et al.*, 2006, Hahn and Aronow, 2005, McConkey *et al.*, 2002, McConkey, 2013); testicular cancer (Wilson and Haire, 1990); dementia (Cassidy *et al.*, 2002, Baxter *et al.*, 2006, Jones *et al.*, 2009, Carlsen and Galluzzi, 1994); breast cancer (Baxter *et al.*, 2006); diabetes (Baxter *et al.*, 2006, Hahn and Aronow, 2005, Lennox *et al.*, 2007, Walmsley, 2011); hypothyroidism (Baxter *et al.*, 2006, Carlsen and Galluzzi, 1994, Ryan and Sunada, 1997, Barr *et al.*, 1999, McConkey, 2013); mental health problems (Cassidy *et al.*, 2002, Jones *et al.*, 2009); cataracts (Ryan and Sunada, 1997, Lennox *et al.*, 2001, McConkey *et al.*, 2002); epilepsy (Lennox *et al.*, 2007, Ryan and Sunada, 1997); arthritis (Hahn and Aronow, 2005); compound fracture in leg and toxic levels of anticonvulsants (Gunsett *et al.*, 1989); skin cancer (Carlsen and Galluzzi, 1994); and chronic

pain, multiple sclerosis, colon cancer, pancreatic cancer, rectovaginal cancer and lung cancer (Ryan and Sunada, 1997).

### 3.6. Health Actions Resulting from Health Checks

A newly identified evaluation of the DES in England found that health checks led to increased screening and health promotion activity (Chauhan *et al.*, 2012). This supports the finding of the previous review that studies consistently provide evidence of health checks leading to targeted actions to address identified health needs (Lennox *et al.*, 2006, Hunt *et al.*, 2001, Bollard, 1999, Lennox *et al.*, 2011, Baxter *et al.*, 2006, McConkey *et al.*, 2002, Martin *et al.*, 2004a, Martin *et al.*, 2004b, Hunt *et al.*, 2006, Webb and Rogers, 1999, Lennox *et al.*, 2007, Lennox *et al.*, 2008, Lennox *et al.*, 2010, Hahn and Aronow, 2005). In the UK, an audit of actions resulting from health checks for 190 participants, of whom 93 had new health needs identified, indicated that management had been initiated for 90% of identified needs by the time of the audit and treatment concluded for 61% of needs (Baxter *et al.*, 2006). However, whilst a study in Wales found a significant increase in health promotion actions post health check, there was no significant change in rates of contact with primary or specialist care (Felce *et al.*, 2008b).

The targeted actions identified partly reflect the conditions outlined in the foregoing section on the identification of previously undiagnosed health needs, with actions including for example: ear wax removal (Hunt *et al.*, 2001, Bollard, 1999, Martin *et al.*, 2004b); podiatry (Hunt *et al.*, 2006); dental review (Lennox *et al.*, 2008); treatment for anaemia (Hunt *et al.*, 2001); and referral for skin conditions (McConkey *et al.*, 2002). Where health checks have been undertaken outside of general practice settings, these have led to referrals to a GP (Hunt *et al.*, 2001, McConkey *et al.*, 2002, Hunt *et al.*, 2006) with as many

as 32 out of 35 participants being referred to a GP (Hunt *et al.*, 2001). Other common actions included: immunisations (Lennox *et al.*, 2006, Hunt *et al.*, 2001, Lennox *et al.*, 2007, Lennox *et al.*, 2008, Lennox *et al.*, 2010); screening for breast, testicular or cervical cancer (Lennox *et al.*, 2007, Martin *et al.*, 2004a, Hunt *et al.*, 2006, Martin *et al.*, 2004b); blood tests (Hunt *et al.*, 2001, McConkey *et al.*, 2002, Martin *et al.*, 2004b, Hunt *et al.*, 2006, Lennox *et al.*, 2008); and general health promotion such as healthy eating advice (Hunt *et al.*, 2006). In addition to these what might be considered routine actions, a number of life saving actions have been noted including: provision of a pacemaker, surgery for previously undetected melanoma, and mastectomy for previously undetected breast cancer (Webb and Rogers, 1999); and surgery and radiotherapy for seminoma (Wilson and Haire, 1990).

A pooled analysis of data involving a total of 795 people with intellectual disabilities presents information on clinical activities following health checks (Lennox *et al.*, 2011). The intervention group received far more sensory testing and provision of health promotion or disease prevention activities, with large and statistically significant increases in vision testing (OR=4.2; 95% CI 2.3-7.4), hearing testing (OR 10.8; 95% CI 3.4-34.3), hearing loss identified (OR 12.6; 95% CI 2.2-71.0), Hepatitis B immunisation (OR 8.5; 95% CI 3.5-20.8) and tetanus/diphtheria immunization (OR 3.8; 95% CI 2.0-7.5).

### *3.7. Health Gains Resulting from Health Checks*

It remains the case that very few studies have evaluated the extent to which providing health checks for people with intellectual disabilities leads to health benefits either in the short or long term. Reported health benefits resulting from health checks include: weight loss for those overweight or obese (Hunt *et al.*, 2001, Bollard, 1999, Martin *et al.*, 1997a, Wells *et al.*, 1997); reduction of seizure severity following change of

medication, stabilization of mood following medication review by consultant psychiatrist, improvement in comfort and hearing following ear wax removal, less tired following iron injections, reduction in urinary tract infections and improved mobility (Bollard, 1999); effective treatment of constipation, ear wax, infections, anaemia, hypothyroidism and diabetes and diabetes (Hunt *et al.*, 2001); remission of psychiatric symptoms following treatment of primary medical condition (Ryan and Sunada, 1997); improvement in challenging behaviour following treatment of medical conditions (Gunsett *et al.*, 1989); and statistically significant improvements at follow-up of an in-home preventative healthcare programme for health strengths, health risks, life satisfaction score, number of falls, and self-reported pain (Aronow and Hahn, 2005). A non-randomised matched control group study of health assessment by a primary healthcare nurse with total sample of 100 found that after one year there were significantly more met health needs for the intervention group than for the control group (mean 3.56 versus 2.26,  $p < .001$ ) (Cooper *et al.*, 2006). However, a newly identified evaluation of the impact of the DES in England found no significant difference between health check and no check groups for intermediate outcomes (e.g. blood pressure controlled) in relation to QOF comorbidity (Chauhan *et al.*, 2012).

### *3.8. Outcomes of Repeated Health Checks*

No newly identified studies were found in relation to the outcomes of repeated health checks. The small number of studies that have looked at the outcomes of repeated health checks suggest that health conditions continue to be identified in repeat health checks (Cassidy *et al.*, 2002, Martin, 2003, Felce *et al.*, 2008a), including serious conditions such as breast lumps, diabetes and high blood pressure (Felce *et al.*, 2008a). One study found that repeated home visits were an important feature of the intervention employed

with additional problems being identified during repeat visits (Hahn and Aronow, 2005). It has been argued that annual health checks may be justifiable in view of the numbers of health needs identified in repeat checks and the lack of relationship between the interval between health checks (mean group intervals 28, 44 and 14 months) and the number of new health needs identified (Felce *et al.*, 2008a).

### 3.9. Perceptions of Health Checks

Overall, newly identified studies confirm the finding that health checks seem to be acceptable to the majority of people with intellectual disabilities and family carers who support them (Cassidy *et al.*, 2002, Perry *et al.*, 2014, Roy *et al.*, 1997, Barr *et al.*, 1999, Perry *et al.*, 2010, Lennox *et al.*, 2008, Chauhan *et al.*, 2012). In an audit of 408 patient satisfaction questionnaires related to the DES in Northern Ireland, 100% were happy with the health check (McConkey, 2013).

Newly identified studies provide further information on the experience of people with intellectual disabilities. Based on focus groups, Perry *et al.* (2014) found that typically those who lived with support had health checks explained to them by a support person and that often it was the most able who lived relatively independently who were least 'prepared' for the health check. Some felt nervous when attending and longer waiting times increased this anxiety. Some people had to effectively wait twice if having to see both a nurse and a GP which was unpopular. Having to wait a long time for hospital appointments following referral, and not being given a reason for referral, also caused anxiety. With respect to test results following health checks, participants were clear that they preferred to receive results, irrespective of whether follow-up action was required. Participants reported that not hearing results sometimes provoked anxiety: "They need to tell you the results of

tests even if there is nothing wrong” (p 8). Similarly, based on focus groups and questionnaires, one study suggests that people with intellectual disabilities need to be better informed about what to expect from health checks (Walmsley, 2011). It was noted that an invitation to see the doctor can be frightening and it needs to be made clear that being invited for a health check does not mean that anything is wrong. Similarly, an evaluation of the DES in England noted that going to the Doctor may be associated with being ill making health checks a source of confusion and anxiety (Chauhan *et al.*, 2012). Invitation letters were not always in ‘Easy Read’ (Michell, 2012) and do not always make sense to people with intellectual disabilities leading to appointments being missed (Chauhan *et al.*, 2012).

A small number of newly identified studies have explored the perceptions of GPs or other health professionals regarding health checks. Based on semi-structured interviews with GPs in six practices which were implementing the DES in England (Walmsley, 2011), whilst some GPs were positive about the potential of health checks to improve health care, some were sceptical saying they already offered good care. Some GPs were dismissive of the idea that additional steps are needed to ensure equitable access with two stating that: ‘We treat all patients the same’. Benefits reported by GPs included: familiarising people with intellectual disabilities and carers with GP practices and encouraging appropriate use of primary care; a chance to tell people that if they have a minor problem such as constipation it is OK to contact the GP; opportunity to give health promotion advice; opportunity to offer support to carers e.g. with regards to challenging behaviour; and the DES generally making GPs aware of people with intellectual disabilities and their needs. In Australia, 46 GPs took part in qualitative telephone interviews at the commencement and conclusion of a RCT of

the CHAP (Lennox *et al.*, 2007) with thematic analysis being used to identify relevant and important themes (Lennox *et al.*, 2013). Overall, the CHAP was viewed as acceptable and useable in primary healthcare, with reported benefits prominently including the detection of previously unidentified health problems. In a study of the DES in England, health professionals treated health checks as an add-on that was not integrated into usual care meaning that removal of the DES may lead to discontinuation of health checks (Chauhan *et al.*, 2012). Finally, nearly 50 primary care staff attended a consultation workshop regarding experiences of health checks and feedback was overall positive, with it being noted that previously undetected problems had been identified such as hypertension and hypothyroid (McConkey, 2013).

### *3.11. Impact of Health Checks for Social Care Staff*

A small number of newly identified studies have noted the impact of health checks in relation to support staff, an additional theme to those identified in the previous review. In an Australian study of the perceptions of GPs in the intervention arm of a RCT of the CHAP, GPs identified gains for support workers in enhancing their knowledge, and knowledge at the wider organisational level (Lennox *et al.*, 2013). Forty per cent of GPs highlighted greater support worker knowledge, confidence and experience of support as a gain of the CHAP. Several highlighted the value in generating a comprehensive written history that could be held by support workers and their organisations as being beneficial for people with intellectual disabilities. Following the trial, GPs reported a number of unanticipated issues with the capacity of support workers to contribute to the CHAP process. The authors suggest that steps to enable support workers to take a more active role in healthcare interventions may be indicated, for example, ongoing professional development for staff

and policy structures within the residential organisation that support adherence to the health assessment process.

Similarly, inclusive research involving self-advocates in England reported one GP as considering health checks not to be useful due to paid carers, for example, not knowing anything about the person that they have brought for a health check and it is suggested that paid carers may need training on how to give support during health checks (Michell, 2012). In a related study involving semi-structured interviews with GPs implementing the DES, one highlighted the importance of educating carers to support healthier lifestyles and manage long term conditions, without which they believed health checks would not be effective (Walmsley, 2011).

### *3.12. Impact of Health Checks for Health Professionals*

Some health professionals may be unaware of the health needs of people with intellectual disabilities and health checks have been reported to increase awareness of these health needs (McKenzie and Powell, 2004, Lennox et al., 2013, Bollard, 1999, Lennox et al., 2001). Newly identified studies reinforce this suggestion. For example, one third of GPs taking part in a RCP of the CHAP in Australia thought that the health of people with intellectual disabilities was the same as, or better than, that of the general population (Lennox et al., 2013). The CHAP was viewed as a means of improving their knowledge and understanding of the health and needs of people with intellectual disabilities. In England, some GPs were found to be dismissive of the idea that additional steps are needed to ensure equitable access to healthcare for people with intellectual disabilities with two stating that 'We treat all patients the same', and it has been suggested that the DES generally makes GPs aware of people with intellectual disabilities and their needs

(Walmsley, 2011). Involvement in health checks may lead to more favourable attitudes to undertaking health checks (McConkey *et al.*, 2002).

### *3.13. Identifying Gaps in Health Services*

An additional theme arising from newly identified studies was that the process of implementing health checks can potentially have an impact in relation to identifying gaps in health services. In England, a clinical audit of health checks implemented initially as a locally enhanced service (LES) found that the only part of health check questionnaires completed for 100% of those audited was 'weight' (Codling, 2007, Codling, 2012). The section that asked when they had last had an eye test had not been completed in the majority of health checks for audits in both 2006 and 2008. This led to a study to find out why they were not accessing optical services and to increase access to and uptake of eye tests. The authors note that the accumulation of need arising from annual health checks helped to shape the future eye care for people with intellectual disabilities.

### *3.10. Barriers to Implementing Effective Health Checks*

Newly identified work has begun to identify GP reported barriers to implementing health checks. A significant barrier to the DES in England is reported to be difficulty with aligning different 'lists' of people who might be eligible (Chauhan *et al.*, 2012, Walmsley, 2011). Difficulty in agreeing eligibility was perceived as a barrier to doing annual health checks in all but one practice in the study by Walmsley (2011) and was reported to slow down implementation. Shortcomings of the recommended Cardiff Health Check (Hoghton, 2010) have also been reported, including incompatibility with practice software systems, misalignment with health action plans, insufficient attention to health promotion and

mental health, lack of space for follow-up actions to be documented (Walmsley, 2011); and being considered too long and clinically unnecessary (Chauhan *et al.*, 2012). In the study by Walmsley (2011), some practices felt that annual health checks were not cost effective, especially if home visits were offered to conduct them. GPs were not on the whole well informed about intellectual disabilities and a known contact person in the Community Learning Disability team emerged as a clear need. Ready access to accessible health information and easy read appointment letters on a locally known website were requested. GPs needed to know what constitutes good practice, and how to implement checks. Finally, some people with intellectual disabilities do not attend primary care and GPs may not know how to reach them other than by writing if they are not on the phone. In addition, GPs have also noted that paid carers sometimes do not know anything about the person they are taking for a health check (Michell, 2012).

In one area of England, GPs attended one of two workshops run by learning disability link nurses, one for those implementing the DES and one for those not implementing the DES (Chapman, 2012). It was noted that main barriers to the delivery of health checks were the non-attendance of patients, and lack of information on patients making assessment and diagnosis difficult. Notably, the lack of evidence of the long-term benefits of health checks was one reason for practices not offering them. In Australia, the time taken to complete the assessment and the logistics of organising and coordinating the assessment process featured prominently as barriers to implementation for GPs (Lennox *et al.*, 2013). GPs also reported a number of issues with the capacity of support workers to contribute to the process, including lack of a consistent support worker, sometimes resulting in gaps in medical history. Patient factors such as lack of compliance and communication barriers

between the GP and patient were anticipated by GPs as potential barriers prior to using the CHAP, but these themes did not reappear as major barriers following use of the CHAP.

Additional barriers were noted in the previous review. One study which specifically asked about barriers to implementing health checks was a cross-sectional postal survey of community learning disability nursing services in Scotland (McKenzie and Powell, 2004). Barriers to implementing or improving the health screening service noted by respondents were: practical issues such as access to premises and equipment; staffing levels, skills and experience; communication or cooperation problems with Primary Healthcare Trusts, nursing management and other team members; time; and management in terms of providing support, leadership and direction.

A potential barrier to the implementation of health checks is the reluctance of GPs to undertake health checks (McConkey *et al.*, 2002, Kerr, 1996, Perry *et al.*, 2010). Measures such as enhanced training for specific practices have resulted in an increase in health checks (Perry *et al.*, 2010). A further potential barrier is low uptake of health screening with, for example, 29% of those scheduled to have health checks not having them (Felce *et al.*, 2008a) and only 33% of offered health checks being translated into actual health checks (Perry *et al.*, 2010). A telephone call by a community nurse to confirm attendance and answer queries has been found to increase uptake (Jones *et al.*, 2009). During health checks, some people with intellectual disabilities may be reluctant to participate in invasive tests (Wells *et al.*, 1997, Martin *et al.*, 1997b).

Once health checks have been conducted, there may be barriers that prevent the identification of health needs being translated into action to address these needs. In a study

in Northern Ireland, health screens were conducted by a specialist health screening service and outcomes forwarded to the person's own GP with a referral letter if necessary (McConkey *et al.*, 2002). However, as many as half of GPs took no further action on the referrals, with 49% not recalling having received a referral letter for the patient. The authors suggest that the most central reason for involving GPs more closely with health screening is that they are in a position to ensure that problems detected are attended to.

### 3.14. *The Cost of Health Checks*

One newly identified study adds to evidence regarding the cost of health checks (Gordon *et al.*, 2012) being only the second study to have included a comprehensive assessment of the cost of health checks. In the first study, service use patterns and costs for 50 adult participants with intellectual disabilities who received the C21st Health Check were compared to 50 individually matched control participants who received standard care only (Romeo *et al.*, 2009). The health check was carried out by a primary health care nurse who discussed the results with a specially employed GP before sending a summary report to the participant's own GP. The nurse directly actioned referrals to professionals within the local intellectual disabilities service, and other referrals were recommended to the GP to action. The total cost of the health check intervention was £4,080 (covering equipment and professional time), averaging £82 per person. It was concluded that the health care check was relatively cheap and was not associated with higher health costs for service usage.

In the second study, an analysis of the costs associated with health checks based on an RCT involving adults with intellectual disabilities (not in receipt of 24 hour support) in Australia (Lennox *et al.*, 2010) was reported (Gordon *et al.*, 2012). For 242 participants,

Medicare Australia data on consultations, procedures and prescription drugs (including vaccinations) were collected for 12 months preceding and 12 months post-intervention. Over 12 months, patients receiving health assessments incurred total costs (in Australian dollars) of \$4523 (95% CI: \$3521 to \$5525) similar to those in usual care \$4466 (95% CI: \$3283 to \$5649). Costs were not significantly higher compared with the 12 month pre-intervention period. The findings show there were no significant differences in government costs for medical and pharmaceutical services between those who did and did not receive a health assessment. This is despite the assessment leading to significantly increased health promotion and case finding activities. The authors note that health assessment may reduce future health costs through early diagnosis or treatment of conditions, although it was not possible to test this hypothesis with the data.

## **4. Discussion**

### *4.1. Discussion of the evidence for health checks*

Overall, the main findings of this updated review are similar to those of the previous review, with newly identified studies largely supporting previous conclusions. Most of the studies in the previous review were conducted prior to incentivisation of health checks via the DES scheme, and the newly identified studies extend the findings of previous studies on non-routine practice to studies of more routine practice in relation to the DES. Evidence consistently suggests that health checks are effective in identifying a wide range of previously unidentified conditions. Conditions detected included serious and life threatening conditions such as cancer, heart disease and dementia. More commonly, health checks have identified a substantial proportion of participants with what might be regarded as more minor health conditions, such as impacted ear wax and sensory impairments. The

evidence also suggests that health checks consistently lead to targeted actions to address health needs. A second study has now added to evidence regarding the costs of health checks (Gordon *et al.*, 2012) supporting the prior conclusion that they are not associated with higher health service usage costs. However, the suggestion that health checks may reduce future health costs remains untested.

There is still very little evidence on the extent to which the provision of health checks leads to short, medium or long term changes in health status. Indeed, an evaluation of the DES in England found no significant difference between health check and no health check groups for intermediate outcomes, such as blood pressure controlled, in relation to QOF comorbidity (Chauhan *et al.*, 2012). There is a clear need for larger and longer term studies to establish whether health checks reduce morbidity and premature mortality (Lennox *et al.*, 2007). While lack of evidence on this issue is of concern, it needs to be kept in mind that the aim of health checks is to assist in the identification of *treatable* morbidity. Failures of health systems to appropriately *respond* to identified treatable morbidity cannot ethically or legally be used to justify failing to make 'reasonable adjustments' to the detection of potentially treatable ill health.

As well as supporting previous conclusions, the updated review also led to the identification of new themes and information. One new theme was the potential for the implementation of health checks to have a wider impact beyond the individual attending for a health check. This includes the potential for identifying gaps in health services (Codling, 2012), increasing awareness of the needs of people with intellectual disabilities amongst health professionals, and enhancing support worker and organisational knowledge (Lennox *et al.*, 2013). The importance of support staff in the health check process also emerged as a

new issue, with lack of support staff knowledge on the person attending for a health check being highlighted as one barrier to implementing health checks. It has been noted that health checks may impact on social care staff for the following reasons (Manthorpe and Martineau, 2010): (1) social care staff may be asked to initiate such contacts; (2) social care staff may be asked to consider the ability of a person they are supporting to consent to such initiatives and examinations, or may be involved in best-interests decisions if the person is not able to make the decision (under the Mental Capacity Act 2005); (3) social care staff may be asked to understand and maintain the records and results of such checks; (4) social care staff may be asked to act as escorts, chaperones and supporters with communication; and (5) social care providers may be scrutinized by the regulator of health and social care services, the Care Quality Commission, or local commissioners of health and social care services to see if annual health checks are being carried out in respect of the people using their services. The authors argue the need to consider the effects of health checks in a whole system approach to improving the health of people with intellectual disabilities.

The newly identified studies also provide information on the perceptions of GPs regarding health checks in the context of the DES. Overall, GPs are positive about health checks and report numerous benefits, although some were reported to be sceptical about the need for health checks. Barriers to health checks in the context of the DES have also been reported by GPs including practical issues such as difficulty aligning different lists to identify who is eligible, and concerns with the useability of the Cardiff Health Check.

Overall, new studies confirm the finding that health checks are acceptable to the majority of people with intellectual disabilities and family carers who support them. However, the studies also reinforce the need to improve communication with people with

intellectual disabilities, with going to the doctor being associated with being ill, making an invitation for a health check a source of confusion and anxiety (Chauhan *et al.*, 2012, Walmsley, 2011). Not being told about test results also caused anxiety (Perry *et al.*, 2014).

#### 4.2. Strengths & Limitations

The studies reviewed involved checking the health of over 5,000 people with intellectual disabilities from a range of countries, and analysing clinical records or GP returns regarding thousands more. These include the full range of people with intellectual disabilities in terms of age, gender, severity of intellectual disabilities and living situation. There remain, however some significant limitations in this evidence base. These include: (1) a relatively small number of RCTs or alternative robust designs; (2) relatively sparse information on such issues as the costs of health checks, the optimal timing of health checks, and the rate of implementation of targeted actions resulting from health checks. Importantly, there is little evidence on the impact of health checks on future health and well-being and the extent to which any such effects may be moderated by such factors as age, severity of intellectual disabilities, gender, ethnicity and level of socio-economic deprivation (Lennox *et al.*, 1997). Finally, this review has not considered how differences between countries in the structure of healthcare systems and the history of regulation may have impacted on the outcome of the studies reviewed.

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