

# Previously unidentified morbidity in patients with intellectual disability

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## ABSTRACT

### Background

Adults with a learning disability frequently have unmet health needs. The cause for this is complex and may be related to difficulties in accessing usual primary care services. Health checks have been widely recommended as a solution to this need.

### Aim

To determine the likelihood that a structured health check by the primary care team supported by appropriate education would identify and treat previously unrecognised morbidity in adults with an intellectual disability.

### Design of study

Individuals were identified within primary care teams and a structured health check performed by the primary care team. This process was supported by an educational resource. Face-to-face audit with the team was performed 3 months following the check.

### Setting

Forty general practices within three health authorities in south and mid-Wales participated. They had a combined registered patient population of 354 000.

### Method

Health checks were conducted for 190 (60%) of 318 identified individuals; 128 people moved, died, withdrew from the study, or refused to participate.

### Results

Complete data were available on 181 health checks; 51% had new needs recognised, of whom 63% had one health need, 25% two health needs, and 12% more than two. Sixteen patients (9%) had serious new morbidity discovered. Management had been initiated for 93% of the identified health needs by the time of audit. This study is the first to identify new disease findings in a primary care population and the likelihood that such disease will be treated.

### Conclusions

The findings reflect a concern that current care delivery leaves adults with an intellectual disability at risk of both severe and milder illness going unrecognised. Health checks present one mechanism for identifying and treating such illness in primary care.

### Keywords

health care; health screening; mental retardation; morbidity.

## INTRODUCTION

People with an intellectual disability (termed 'mental retardation' within the US) make up 0.6–2.5% of the population in the UK.<sup>1</sup> There is increasing evidence from different health systems that such people experience a disparity in health compared with the general population.<sup>2,3</sup> This disparity is seen in reduced life expectancy,<sup>4</sup> high morbidity,<sup>5</sup> reduced participation in health promotion activities,<sup>6</sup> and an increase in healthcare utilisation.<sup>7</sup> The reasons underlying this disparity are complex and seem likely to relate to:

- characteristics of individuals, such as genetic disposition;
- difficulties in communicating health needs; and
- deficits in service provision.<sup>8</sup>

Poorer access to health promotion services and findings of untreated common diseases in surveys of the health of this population<sup>9</sup> have raised the concern that there are potential barriers affecting the ability of people with an intellectual disability to access and receive primary care services. Various solutions have been postulated to address this, including:

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- increasing remuneration to primary care services;
- educational initiatives;<sup>8</sup>
- greater case management of health care through health facilitation;<sup>10</sup> and
- health checks performed in primary care.<sup>8</sup>

It is this latter intervention that has gained most support and is the subject of this research.

Health checking involves a structured physical examination and the questioning of a person with intellectual disability delivered at regular intervals — currently postulated to be yearly — in a primary care setting. Evaluations of this potentially expensive and time-consuming process have, to date, been limited. Although health checks have identified health needs in Australia,<sup>5</sup> New Zealand,<sup>11</sup> and the UK,<sup>12</sup> studies have not differentiated newly identified morbidity from chronic disease; identified individual characteristics such as communication difficulties, which may impact on disease recognition; or established whether problems identified with health checking were actively managed. The present study was conducted to assess the impact of using the Cardiff Health Check<sup>13</sup> within primary care in the UK. It was designed to address:

- the disability characteristics of the primary care population of people with an intellectual disability;
- the nature of newly discovered disease; and
- the likelihood that such disease, if recognised, is actively managed.

## METHOD

### Sample

Forty general practices within three health

authorities in south and mid-Wales participated. They had a combined registered patient population of 354 000 — 20% of the 1.8 million in the territory. Each practice identified their patients with an intellectual disability with help from the research team and recruited them into the study using a pro forma letter ( $n = 374$ ). After written consent had been obtained, or assent from carers if the patient lacked the capacity to consent, the initial sample for whom baseline data were collected was reduced to 318. Health checks were conducted for 190 (60%); 128 people moved, died, withdrew from the study, or refused or did not receive a health check.

The characteristics of the initial and final samples are given in Table 1. The latter was similar to the former in terms of age, sex, abilities/disabilities, challenging behaviour, and threshold indicators of mental illness; the final sample, however, had a higher proportion of patients from staffed accommodation and a slightly greater representation of people with the triad of social impairments characteristic of autism: qualitative abnormalities in reciprocal social interaction; qualitative abnormalities in communication; and a restricted, stereotyped and repetitive repertoire of interests and activities.

### Procedures

Ethical approval was first obtained, followed by either informed consent by participants or assent on their behalf. In addition to age, sex, and place of residence, information was gained on each participant's skills, challenging behaviour, social abilities, and psychiatric status by interviewing a carer who knew the person well, using the Adaptive Behaviour Scale,<sup>14</sup> the Disability Assessment Schedule,<sup>15</sup> the Aberrant Behaviour Checklist,<sup>16</sup> and the Psychopathology Instrument for Mentally Retarded Adults.<sup>17</sup> These data will be reported in greater detail in future publications.

The primary care team then invited participants to attend a health check and physical examination conducted by the doctor or nurse following the Cardiff Health Check format. This included a structured interview to cover health promotion, systems enquiry and specific issues relevant to people with an intellectual disability as covered below.<sup>13</sup> In preparation for this, each practice had been given an educational resource package as part of the study, which included chapters covering patient identification, health checking, causation, nutrition, epilepsy, challenging behaviour, autism, sensory impairment, and using antipsychotic medication.

On average, 18 weeks later, a post-health-check

## How this fits in

This study provides a major advance in how health care can be provided to adults with a learning disability in primary care through structured health checks. The study builds on previous published studies by having a large primary care base of 40 practices, identifying new morbidity at health check rather than chronic conditions, and evaluating outcome in terms of the primary healthcare team addressing the issues. The study highlights the high level of new morbidity found at health check and that primary care teams readily address these morbidities in the majority of cases.

interview was conducted by the research team with the primary care team member who had administered the health check. It explored:

- whether all sections of the health check had been performed;
- whether, on the basis of medical notes and clinician's knowledge, identified health needs were newly identified problems or not;
- whether action had been taken; and
- the outcome of that action since the time of the health check.

Indicators of possible health needs found during health promotion screening were classed as health needs for the purposes of this study where they warranted some action on the part of the primary healthcare team. Post-health-check interviews were conducted for 181 patients of the 190 in the final sample.

## RESULTS

Ninety-three of the 181 individuals (51%) had health needs newly identified as a result of the health check. Of these 63% had one health need identified, 25% two health needs, and 12% more than two health needs. There were 147 health needs identified in total (Table 2).

The identified problems may be deemed serious for 16 patients (9% of those audited, 17% of those with newly identified health needs). As detailed in Table 2, these include patients with breast cancer ( $n = 1$ ), suspected dementia ( $n = 1$ ), asthma ( $n = 1$ ), post-menstrual bleeding ( $n = 1$ ), diabetes ( $n = 2$ ), hypothyroidism ( $n = 2$ ), high blood pressure ( $n = 4$ ), or haematuria ( $n = 4$ ).

Management had been initiated for 90% of the identified health needs by the time of the audit (Table 2). Treatment had been concluded for 61% of the 133 health needs concerned and was ongoing for the remaining 39%. In some of the 14 instances (10%) where management had not occurred, patients or carers had refused treatment; in others treatment delays had occurred due to difficulties in pursuing treatment or other external factors.

## DISCUSSION

This is the first study to evaluate the impact of health checking in a large UK primary care population. The sample was identified from primary care practices that served approximately one-eighth of the population of Wales. It was not randomly selected. Practices nominated adults for the study after they had gained permission to do so.

**Table 1. Characteristics of subjects in the initial and final samples.**

	Initial sample ( $n = 318$ )	Final sample ( $n = 190$ )
Mean age in years (range)	41.46 (17–86)	42.76 (17–86)
Male (%)	43.7	43.2
Living in staffed accommodation (%)	45.6	53.7 <sup>a</sup>
Mean ABS <sup>b</sup> score (range)	171.21 (14–304)	166.90 (31–304)
Triad of social impairments <sup>c</sup> (%)	33.0	37.9 <sup>d</sup>
Challenging behaviour(%)	14.8	16.3
Indication of mental illness <sup>e</sup> (%)	45.9	43.4

<sup>a</sup>Significant between group difference at  $P < 0.001$ . <sup>b</sup>ABS = Adaptive Behaviour Scale,<sup>13</sup> a measure of presence/absence of independent skills. <sup>c</sup>The triad of social impairments are characteristic of autism spectrum disorder.<sup>27</sup> <sup>d</sup>Significant between group difference at  $P < 0.05$ . <sup>e</sup>Meeting threshold levels on the Psychopathology Instrument for Mentally Retarded Adults;<sup>17</sup>

### Summary of main findings

The study found unidentified health problems in over half of the sample and serious illness in an impressively high minority. Although the significance of detecting the latter is self-evident, it is important to note that the other conditions more commonly found — such as vision and hearing difficulties, and blocked ear wax — may be more significant for these people than the general population because of their impact on already limited social, communicative, and practical abilities.

### Comparison with existing literature

Untreated causes of possible pain, such as inflammation of the ear canal, have been implicated in the possible aetiology of self-injury among people with severe intellectual disabilities who, unable to communicate their distress and gain appropriate treatment, engage in repetitive behaviour to stimulate endogenous pain control.<sup>18</sup> The treatment of obesity has been shown to reduce the likelihood of cardiovascular problems,<sup>19,20</sup> early intervention for sensory impairment or mobility can prevent further deterioration,<sup>21–24</sup> and the importance of the review of psychotropic medication in this population has been particularly emphasised.<sup>25</sup>

This study has confirmed earlier findings<sup>24</sup> that, although patients with disability may fail to report symptoms, conditions can be diagnosed as long as

**Table 2. Previously unidentified health needs found and subsequent action.**

	Newly identified health need	Total cases	Management completed	
			/in progress	No management
Potential health needs arising from health promotion screening (disease confirmed)	Glucose found in urine	4	3	1
	(Confirmed as diabetes)	(2)	(2)	
	Thyroid function test	22	20	2
	(Confirmed as hypothyroid)	(2)		
Problems with behaviour, medication and other	Mammography indicated	1	1	0
	(Breast cancer confirmed)	(1)	(1)	
	Suspected dementia	1	1	0
	Behaviour problem	1	1	0
	Mobility problem	5	5	0
	Skin problem	12	12	0
	Dental problem	1	1	0
	Medication change necessary	2	2	0
	Medication blood levels to be monitored	2	1	1
	Overweight	5	3	2
Problems with sensory impairment	Vision difficulties	7	7	0
	Eye infection	1	1	0
	Hearing difficulties	2	2	0
	Blocked ear wax	46	41	5
	Ear canal inflamed (otitis externa)	1	1	0
Respiratory system	Asthma	1	1	0
	Difficulty breathing (dyspnoea)	1	0	1
	Unusual lung sounds	1	1	0
Cardiovascular system	Cardiovascular monitoring necessary	1	1	0
	Systolic murmur	2	2	0
	High blood pressure	4	4	0
	High cholesterol	3	3	0
Digestive system	Disordered digestion (dyspepsia)	1	1	0
	Weight loss	1	1	0
	Constipation	3	3	0
	Diarrhoea	1	1	0
	Flatulence	1	1	0
	Haemorrhoid	1	1	0
Genitourinary system	Painful urination (dysuria)	1	0	1
	Incontinence	2	1	1
	Urinary tract infection	4	4	0
	Blood found in urine (haematuria)	4	4	0
Gynaecological	Post-menstrual bleeding	1	1	0
	Painful menstruation (dysmenorrhoea)	1	1	0
Total number of medical problems identified		147	133	14

health professionals use routine diagnostic screenings with a knowledge of risk factors and atypical presentations, in addition to taking account of carer observations. Restricted communication, social impairments, and additional behavioural or emotional difficulties are common in

people with intellectual disabilities. Such a population is unlikely to fit easily into an on-demand health service.

**Strengths and limitations of the study**

Based on information from 16 practices on the total

number of individuals identified, as opposed to those referred to the research team, it was estimated that the 40 practices would have identified a total of some 745 adults. This is somewhat lower than the 995 that would be predicted from the total number of adults on learning disability registers in Wales for that year extrapolated to a similar base population.

There are also areas where the achieved sample was not representative of the population of people with intellectual disabilities as a whole. For example, one would have expected slightly more males than females and that fewer people were living in staffed accommodation. However, in other aspects, including age, ability and presence of challenging behaviour, the sample characteristics were in line with other surveys.

There are also some other cautions that should be considered in interpreting the findings of this study. In addition to the sample not being entirely representative is the fact that the primary care teams were aware that the outcomes of action taken after completion of the health checks would be monitored. This may have contributed to the high rate of action taken; the link between health checking and action leading to health gain in regular practice may not be so direct. It should also be noted that the results reflect the impact of health checking in a population that had not previously received such proactive screening. Subsequent checking of a previously checked population may well identify fewer new health needs. Whether health checking would need to recur annually or at a greater interval requires further research.

The recognition of disease in the presence of communication disorder takes time and knowledge. People with intellectual disabilities may well need longer, or even additional consultations, to address certain medical problems.<sup>26</sup> This intervention offered both the time through the health check to assess patients thoroughly and involve their carers when required, and provided the health professional with key knowledge through the educational package. Such proactive detection and treatment of morbidity in people who have been shown to have a high rate of unmet health needs holds out the promise of health gain, despite the undoubtedly complex nature of the population.

### **Implications for clinical practice and future research**

Any health system needs to be able to deliver the following components at a primary care level: sufficient time and communication skill, education on the special issues of health to the physician at

the point of primary care contact, structured physical examination and clinical histories, and monitoring of the outcome of care. Health checking with educational support offers one way of achieving such standards to serve well one of the most important groups in the population.

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### **Ethics committee**

Bro Taf, Dyfed Powys and Ewent Ethics Committees

### **Competing interests**

The funder, Henry Smith Charity, had no involvement in the study design; in the collection, analysis and interpretation of data; in the writing of the report; or in the decision to submit the paper for publication

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