The Impact of Checking the Health of Adults with Intellectual Disabilities on Primary Care Consultation Rates, Health Promotion and Contact with Specialists

David Felce*, Helen Baxter†, Kathy Lowe‡, Frank Dunstan§, Helen Houston§, Glyn Jones*, Jill Grey*, Janet Felce* and Michael Kerr*

*Welsh Centre for Learning Disabilities, Centre for Health Sciences Research, Cardiff University, Cardiff, UK; †Department of Primary Health Care, University of Bristol, Bristol, UK; ‡Unit for Development in Intellectual Disability, University of Glamorgan, Pontypridd, UK; §Department of Primary Care and Public Health, Centre for Health Sciences Research, Cardiff University, Cardiff, UK; *Bro Morgannwg NHS Trust, Cardiff, UK

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Background Studies have found that health checking in primary care led to the identification of previously unrecognized morbidity among adults with intellectual disabilities. The aim here was to evaluate whether health checking stimulated increased consultation with the general practitioner or another member of the primary care team, increased health promotion actions undertaken outside the health check or increased contact with specialists.

Method Data on the above three categories of activity were abstracted from the medical records of 77 adult participants with intellectual disabilities for eight 6-month periods before and seven 6 month periods after they had undergone a health check. Comparisons of access to care before and after the health check were made using non-parametric statistics.

Results On average, participants had 5.4 and 1.8 primary care and specialist consultations per year respectively. There were no significant differences in either rate before and after the health check. The frequency of health promotion actions increased significantly after the health check from a mean of 1.2 to 2.2/year.

Conclusions Comparison of the primary care and specialist consultations rates of people with intellectual disabilities with those for the general population might suggest that the former have greater access to these services. However, comparison to the general practitioner consultation rates of patients with other chronic conditions would seem to indicate that contact with primary care may not be commensurate with need. Attention to health promotion is inadequate. Further research is required to substantiate whether health checking increases health promotion and how increased health promotion activity would affect the health of this population.

Keywords: consultations, health checks, health promotion, intellectual disability, primary care

Introduction

People with intellectual disabilities may see general practitioners (GP) slightly more frequently than those of the general population (Stein & Ball 1999) but their greater health problems might suggest that their access to primary health care may still be inadequate (Howells 1986; Wilson & Haire 1990; Beange et al. 1995); (b) practical difficulties in arranging appointments and attending for consultation (Minihan et al. 1993; Beange 1996; Chambers et al. 1998); and (c) the consultation not being sufficiently adapted to the needs of this population (Eyre 1996; Lennox et al. 1997). In addition, people with intellectual disabilities
have a lower involvement in health promotion than the general population, particularly receiving less by way of routine immunizations and blood pressure checks, oral care, cervical and breast cancer screening and measures related to avoiding cardiovascular disease (Webb & Rogers 1999; Beange & Durvasula 2001; Lewis et al. 2002; Rimmer & Braddock 2002; Ouellette-Kuntz 2005).

A number of the above barriers to access, such as the need to present with an identified health problem and for an adapted consultation process, would be potentially lessened by a system of regular health checking informed by the needs of people with intellectual disabilities. Research into practitioner-led checking of health status has shown that conditions can be diagnosed among people with intellectual disabilities as accurately as for patients in the general population, given specific knowledge of the population and an approach which takes account of carer observations (Evenhuis 1997). Health checks have been found to be effective in identifying health needs among adults with intellectual disabilities in Australia (Beange et al. 1995), New Zealand (Webb & Rogers 1999) and the UK (Martin et al. 1997; Baxter et al. 2006; Cooper et al. 2006). This study analyses the impact of health checking conducted in primary care, supported by a written educational pack. The main focus of this study was to assess the extent to which previously unidentified morbidity would be identified at an initial check among an unscreened sample of adults with intellectual disabilities (Baxter et al. 2006) and by repeated follow-up checks at different intervals from the initial one (Felce et al. under review). A supplementary focus described here sought to evaluate whether health checking promoted greater access to care, specifically whether it increased consultation with the GP or another member of the primary care team, increased health promotion actions undertaken outside the health check or increased contact with specialists.

**Materials and Methods**

**Participants**

In the first study (Baxter et al. 2006), written consent or assent from carers was obtained for 318 adult participants with intellectual disabilities from 40 general practices in south and mid-Wales. Health checks were conducted and the results audited for 181 participants of this group. In the second study (Felce et al. under review), following sample attrition but some further addition to it, 108 adult participants from 27 general practices either underwent repeat health checks or no further intervention. Data on consultations with the GP or another member of the primary care team, health promotion actions undertaken and contact with specialists before and after the initial health check were collected for 181 participants of this group. Data collection proved time consuming and gaining information about the other 31 potential participants was not possible because of resource constraints. Table 1 compares the characteristics of this final sample with those of the 108 participants in the second study and with those of the 318 in the first study.

**Procedures and measurement**

Ethical approval was obtained for both phases of the research. At the start of the first study, information was

| Table 1 Characteristics of the final sample (n = 77) compared with those of the Felce et al. (under review) sample (n = 108) and the initial sample identified for the Baxter et al. (2006) study |
|-------------------------------------------------|--------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Mean age (range) | Male (%) | Staffed home (%) | Mean ABS1 score (range) | Triad of social impairments2 (%) | Severe challenging behaviour3 (%) | Indication of mental illness4 (%) |
| Initial Baxter et al. sample (n = 318) | 41 (17–86) | 44 | 46 | 171 (14–304) | 33 | 15 | 46 |
| Felce et al. sample (n = 108) | 43 (18–80) | 48 | 64 | 156 (12–293) | 45 | 21 | 43 |
| Final sample (n = 77) | 43 (18–80) | 53 | 60 | 163 (27–293) | 42 | 13 | 39 |

2The triad of social impairments is characteristic of autism spectrum disorder (Wing & Gould 1979).
3At least five behaviours rated ‘3’ or a total score of 31 or more on the Aberrant Behavior Checklist (Aman & Singh 1986).
4Meeting threshold levels on the Psychopathology Instrument for Mentally Retarded Adults (Matson 1988).
gained on each participant’s age, gender, place of residence, skills, challenging behaviour, social abilities and psychiatric status by interviewing a carer who knew the participant well. Participant skills were assessed by using Part One of the Adaptive Behavior Scale (2nd edn) (ABS) (Nihira et al. 1993). A total ABS raw score was calculated by combining the domain scores. Participant challenging behaviour was assessed by using the Aberrant Behavior Checklist (ABC) (Aman & Singh 1986). Whether participants had the triad of social impairments (Wing & Gould 1979) was assessed by using nine items of the Disability Assessment Schedule (DAS) (Holmes et al. 1982) concerning abnormalities of social and imaginative activities, stereotypes and echolalia. Participant psychiatric status was assessed by using the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson 1988). The presence of four of the seven assessed items in any of the eight subscales indicates a threshold level for that psychiatric problem. A participant was categorized as having a mental illness if at least one subscale reached this threshold level.

All participants underwent an initial health check as part of the Baxter et al. (2006) study. Information on consultations with the GP or another member of the primary care team, health promotion actions undertaken and contact with specialists was abstracted from the participants’ medical records for eight-6-month periods before and seven-6-month periods after the initial health check. Consultation data did not include telephone contact but did include direct contact with a practice nurse, healthcare assistant or other practice-based professional in addition to the GP. Health promotion actions were defined as those covered by the health check, including assessment of weight, height, blood pressure, cholesterol level and immunization status and conduct of urine analysis, cervical screening or mammography. However, only health promotion actions which occurred in addition to those undertaken as part of the health check were counted. Their frequency was ascertained by a researcher reviewing the medical notes and counting the number of health promotion actions that had occurred within each time period. The frequencies of consultations, health promotion actions and contact with specialists were calculated (mean per 6 months) and compared using Wilcoxon matched-pairs signed-ranks tests. Thirty-two of the sample (42%) underwent a repeat health check within 42 months after the initial check (i.e. during the post-initial check data collection period). The remainder did not. Differences between these two subgroups in frequency of GP consultations, health promotion actions undertaken and contact with specialists before and after the initial health check were compared using Mann–Whitney U-tests.

Results

The overall average frequency of consultation with a GP or another member of the primary care team was 2.7 in each 6-month period (i.e. 5.4/year). There was no significant difference between periods before or after the initial health check ($z = -0.364, P > 0.05$). There was no significant difference between those who had a repeat health check within the data collection period and those who did not, either before ($U = 648, P > 0.05$) or after the initial health check ($U = 532, P > 0.05$). The maximum number of contacts per person in a 6-month period ranged between nine and 27 prior to the initial health check and between 15 and 22 afterwards. Across the entire period, there was no one who did not see the GP or another member of the primary care team at least once; 6.8% had such contact on average less than once a year, 15.5% had such contact between once and twice per year, 37.0% had such contact between two and four times per year, 18.1% had such contact between four and 8 times per year, and 21.9% had such contact more than 8 times per year.

The frequency of health promotion actions increased significantly after the initial health check from a mean of 0.6 (i.e. 1.2/year) to a mean of 1.1 (i.e. 2.2/year) ($z = -3.986, P < 0.001$). Those who had a repeat health check within the data collection period had a higher number of health promotion actions undertaken than those who did not both before the initial health check ($U = 395, P < 0.01$) and afterwards ($U = 422, P < 0.05$). The frequency of health promotion actions increased significantly for both subgroups after the initial health check ($z = -2.686, P < 0.01$ and $z = -3.054, P < 0.01$ respectively). In all time periods before the initial health check, about three-quarters of the participants had no health promotion actions undertaken (mean 74.5%, range 70.1–81.8%). This reduced to below two-thirds in time periods after the initial health check (mean 61.7%, range 57.1–64.9%). The maximum number of health promotion actions undertaken per person in a 6-month period ranged between five and 24 prior to the initial health check and between eight and 23 afterwards. Across the entire period, 5.6% underwent no health promotion actions, 51.3% had less than one health promotion action per year, 22.3% had between one and two health promotion actions per year and 20.8% underwent more than two health promotion actions per year.
The overall average frequency of contact with specialists was 0.9 in each 6-month period (i.e., 1.8/year). There was no significant difference between periods before or after the initial health check ($z = -0.178, P > 0.05$). There was no significant difference between those who had a repeat health check within the data collection period and those who did not, either before ($U = 609, P > 0.05$) or after the initial health check ($U = 562, P > 0.05$). Across time periods, the proportion of participants who had no contact with specialists ranged from 37.8% to 64.0% (mean 54.4%). The proportion having one contact ranged from 14.7% to 39.2% (mean 25.0%). The maximum number of contacts per person in a six month period ranged between 4 and 9 (mean 7.5). Across the entire period, 4.3% never saw a specialist, 37.1% saw a specialist less frequently than once a year, 22.9% saw a specialist between once and twice a year and 36.7% saw a specialist more than twice a year.

**Discussion**

Access to services is central to the principle of equality of health care. Measuring access poses certain difficulties and these are reflected in the data here. Ideally, access should relate to the health status of individuals and their needs for specific services. Whether access is commensurate to need can only be determined if the level of need is known. The supposition to date is that need is generally under-identified among people with intellectual disabilities. The introduction of health checking reflects an attempt to ascertain need more accurately. It might be expected that the identification of previously unidentified morbidity, one of the demonstrated consequences of health checking (Beange et al. 1995; Martin et al. 1997; Webb & Rogers 1999; Baxter et al. 2006; Cooper et al. 2006), would occasion greater contact with treatment services and affect the access to care indicators measured here.

Consultation rates provide a broad measure of access to care. There was no evidence to indicate that health checking stimulated a greater frequency of consultation. The mean rate of contact with the GP or other primary care professional found here (5.4/year) is slightly higher than a the rate for the general population in south Wales (4.4) which the present authors calculated from data available from the former Bro Taf Health Authority. Such a comparison is generally consistent with the reports in the literature. In particular, a recent Dutch survey (Stratemans et al. 2007) reported that people with intellectual disabilities saw their GP on average 5.4 times per year compared with 3.2 for the general population.

The concern remains, however, that there is a deficit in the level of contact relative to the high health needs of this population. It is perhaps more relevant to compare consultation rates of patients with intellectual disabilities with those of patients with another chronic condition than with those of the general population. Department of Health (2006) guidelines on meeting the physical health needs of people with severe mental illness states that the GP consultation rate for people who use mental health services is 13–14 times per year in comparison with a general population average of three to four times per year. Morgan et al. (2000) showed that the annual mean number of consultations with either a GP or another member of the practice staff for patients with diabetes from 30 general practices in Wales was 18.5 compared with 5.7 for those without. Schellevis et al. (1994) reported mean annual GP consultation rates for patients in five disease groups in the Netherlands: hypertension (4.7), chronic ischaemic heart disease (5.5), diabetes (5.7), chronic respiratory disease (4.9) and osteoarthritis (4.2) compared to two reference groups without chronic disease (3.0 and 2.8 respectively). They also demonstrated that consultation rates among patients with co-morbidity were 9–52% higher than those among patients with a single chronic disease. The present authors do not mean to suggest that healthcare needs are directly comparable across the conditions considered above but rather that there is a general tendency for consultation rates among patients with chronic conditions to be greater than those among general population samples and for rates to rise with the complexity of morbidity. Compared with some other patient groups, such as those with diabetes, the development of guidelines for the management of patients with intellectual disabilities in primary care is in its infancy. One might expect consultation rates to rise with more systematic attention being paid to their health.

Inadequate access to health promotion seems likely to be an important factor in the inequality in health among people with intellectual disabilities. The data on the frequency of health promotion actions undertaken reinforce the message about inadequate health promotion delivery and also provide a picture of the variability in health promotion received. The majority of participants received fewer than one health promotion action per year throughout the 7.5-year period studied. Setting this against a rate of 5.4 consultations per year would suggest that primary care professionals do not take the opportunity provided by routine presentation at the surgery to check the health of this population.
There is some suggestion that the introduction of health checks stimulated increased health promotion activity but the evidence for this needs to be interpreted with caution. There was no control group; all participants had had an initial health check. There was, therefore, no control for the passage of time. It is conceivable that the increase in health promotion actions was because of a general improvement in primary care for this population unrelated to the health check. To explore this, the present authors analysed both the 4-year period before the initial health check and the $3\frac{1}{2}$-year period after it in two halves (the latter spanning the first 2 years and the subsequent $1\frac{1}{2}$ years). The present authors then calculated the rate of health promotion actions across these periods for two subgroups: those who had a repeat health check within 42 months of the initial health check ($n = 32$) and those who did not ($n = 45$). The rate of health promotion actions for the former was stable across the two 2-year periods prior to the initial health check (mean values for each 6 months $= 0.7$ and $0.8$ respectively). The rate then rose in the 2-year period after the initial health check (mean for each 6 months $= 1.4$) and rose again in the following $1\frac{1}{2}$ years (mean for each 6 months $= 1.8$). This would suggest that there were effects which might be attributable to both the initial and repeat health checks. The rate of health promotion actions for those who did not have a repeat health check rose across the two 2-year periods prior to the initial health check (means for each 6 months $= 0.3$ and $0.7$ respectively) and did not increase subsequently (means for each 6 months in the first 2 years afterwards $= 0.8$ and in the subsequent $1\frac{1}{2}$ years $= 0.7$). This provides no support for health checks affecting health promotion. It is possible that the difference in the pattern of the above results reflects a difference between the two subgroups, with participants who had repeat health checks being part of general practices which were more attentive to their care. This would be consistent with the finding that they received significantly more health promotion actions prior to the initial health check. One might, therefore, reach a qualified conclusion that health checking has the potential to increase the frequency of health promotion actions given well-motivated primary care.

Specialist health contact is relatively common for people with intellectual disabilities. Morgan et al. (2000) showed that patients with diabetes had elective referrals to medical specialists at the rate of 0.44/year compared with that for patients without diabetes of 0.15/year. A quarter of the former (24.6%) and 10.4% of the latter had at least one referral to a medical specialist. The rate of 1.8/year for adults with intellectual disabilities found here and the proportion of 59.6% having an average of at least one specialist contact per year are high in comparison. However, it is difficult to comment further. It is clear that variation exists in specialist contact within the population with intellectual disability but it is not known whether the variation found, would be more than reasonable, given the variation in morbidity among the population. Further research is needed to show whether patients with an intellectual disability are referred for specialist assessment at similar points in any ill health episode and for similar reasons as the general population, and whether comparative referral rates at a population level reflect the comparative occurrence of conditions.

Before concluding, it is important to acknowledge the significant sample attrition which occurred during the course of this longitudinal study. A third of the general practices declined to take part in the second stage of the study, a further fifth of the potentially eligible participants did not reply to follow-up letters or refused to continue to take part in the study and there was further loss for other reasons. In addition, data from 31 were not collected participants because of lack of time and resources. Although the latter appeared not to bias participant descriptors further, the final sample did not represent an epidemiological cross-section and some caution therefore needs to be exercised in generalizing the results. The present authors would offer the following conclusions. Although health checking increased the identification of ill health among participants (Baxter et al. 2006; Felce et al. under review), this was not associated with significant change in the rates of contact with either primary or specialist care. There is some suggestion that health checking may have stimulated primary care practitioners to undertake more health promotion actions, but limitations in the research design do not allow us to be conclusive. Further research is required to substantiate this potential effect. More studies are required to evaluate the impact of health promotion in this population and whether the level of contact with primary and specialist professionals is commensurate with need.

**Correspondence**

Any correspondence should be directed to Professor Michael Kerr, Welsh Centre for Learning Disabilities, Centre for Health Sciences Research, Cardiff University, 2nd Floor, Neuadd Meirionydd, Heath Park, Cardiff CF14 4YS, UK (e-mail: mp_kerr@yahoo.com).

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