Contact between people with learning disability and general practitioners: a cross-sectional case note survey

Ken Stein and David Ball

Abstract

Background This paper describes primary care consultation rates in a sample of people with learning disability. The study was carried out as part of a wider survey of primary care for this population group in response to concerns over quality of care and debate between general practitioners (GPs) and the local health authority over the need for additional remuneration for caring for people with learning disability. Estimates of consultation rates in the literature to date are conflicting and we sought to provide local data on the number and type of contacts with the primary care teams to inform this debate.

Method A primary care case note review was carried out of 112 people with learning disability aged over 18, identified from an administrative sample of 967 people known to health and social services. Contact rates (with practice nurses or GPs) were calculated and indirectly standardized for age using data from the fourth National Morbidity Survey in General Practice (MSGP4).

Results Standardized consultation ratio in men was 156 (95 per cent confidence interval (CI) 142–172), in women was 111 (95 per cent CI 102–121) and for both sexes was 127 (95 per cent CI 120–135). Average contact rate was 4.6 per person per year. Eighty per cent of contacts were with GPs. Eighteen per cent (95 per cent CI 11–25 per cent) of subjects consulted, on average, more than once every two months. Limited information on underlying cause of learning disability and severity was available. Consultation rates were independent of age and sex, and were not increased in people with Down’s syndrome or epilepsy compared with the rest of the sample population. Consultation rates were highest in people living in staffed group homes (p = 0.01). The presence of special arrangements between practices and residential facilities did not appear to increase service contact, but this finding is prone to measurement bias.

Conclusions Contrary to the findings of previous studies, people with learning disability consult primary care teams more frequently than the general population. However, this should not be taken as supporting calls for additional resources without addressing the effectiveness and appropriateness of health care offered.

Keywords: learning disability, primary care, consultation rates, case note survey

Introduction

The role of general practitioners (GPs) in caring for people with learning disability has been the subject of comment and concern, generally in the context of the development of community care reforms and specifically with the closure of long stay mental handicap hospitals. General practitioners are acknowledged to have a central role in the care of people with learning disability and are the health professionals most frequently in contact with people living in the community. However, the quality of primary care services for people with learning disability has been criticized, based on evidence for high levels of unrecognized morbidity and relatively low rates of consultation. Recent National Health Service (NHS) Executive guidance on commissioning services for people with learning disabilities emphasized the need for the NHS to provide primary care services in response to the increased health needs of this population.

In January–March 1996 we undertook a case note survey of a sample of adults (ages 18+) with learning disability in an average English Health District to estimate service use and to audit provision against recommendations made by the Royal College of General Practitioners and other agencies. This was in response to concerns in the Health Authority about the quality of primary care provision and concerns among GPs that closure of a local long stay hospital and development of community care would markedly increase patient demand. Here we describe the investigation of consultation rates.

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Methods

All 270 GPs in the district were asked by letter to indicate whether they wished to be excluded from the audit. Cases were selected from a sampling frame of adult residents of Southampton and SW Hampshire with learning disability identified by health and social service computer systems \((n = 969)\). Sample size was calculated to inform the audit of primary care provision.\(^{16}\) General practitioners of cases were identified from the Family Health Services Authority (FHSA) register and sample size was adjusted for non-identification based on a preliminary random sample of 40 cases.

In addition to age and sex, which were available from the sampling frame, further general information was sought:

1. Residential type was obtained from practice records or staff (own home, family home, staffed or unstaffed group home, single placement, health service hostel);
2. Severity of learning disability;
3. Cause of learning disability;
4. Severity of learning disability: assessed according to IQ criteria (see Table 1) or opinion of specialists in learning disability.

Details of whether practices had any special arrangements with residential providers in the community (e.g. regular visiting arrangements or contracts for additional services as clinical assistants) were collected during practice visits from practice managers and GPs.

Numbers of contacts with GPs or practice nurses in the preceding 24 months were estimated from paper and computer records. Age- and sex-specific contact rates with GPs and practice nurses in the sample were standardized for age by the indirect method, using rates from the fourth national study of morbidity in general practice (MSGP4).\(^{17}\) Results are expressed as standardized consultation ratios (with values for the population of England being 100).

Recorded provision of new patient health checks was compared with available routine data for Hampshire. Case notes were reviewed by both of us between January and March 1996. Inter-rater reliability was checked on a sample of 11 case notes in two practices at the beginning of the survey and considered to be acceptable for a data item if there was agreement in more than 80 per cent of cases.

All data were entered into Epi-Info v5.01b\(^{18}\) for analysis, using non-parametric methods where appropriate. Comparison of simple proportions and calculation of confidence intervals were carried out using Confidence Interval Analysis version 1.0.\(^{19}\)

Results

Eleven GPs (4 per cent) refused to participate in the survey. Adjusted sample size was 138 cases, for whom GPs were identified for 119. Seven further cases were not reviewed. The GPs of two withdrew from the survey after selection of cases, and in five cases the notes were unavailable because subjects had recently changed practice. One hundred and twelve case notes were therefore reviewed. Seventy-five GPs were involved, in 39 practices. The range of subjects per GP was one to seven, but only 10 (13 per cent) GPs had more than two subjects in the sample. The sample was representative of the sampling frame in terms of age, sex and source of ascertainment (health or social service records). Inter-rater reliability was acceptable for all variables.

Information on residential type was available from case notes or practice staff in over 85 per cent of cases (see Table 2). No information was available about cause of learning disability in the sampling frame. Table 3 shows the causes of learning disability recorded for the sample. In the majority of cases no clear cause was recorded. Other studies based on population registers suggest about a quarter to a third of cases of severe learning disability are due to genetic causes, of which Down’s syndrome forms 90 per cent.\(^{20}\)

The measurement of severity is not straightforward. Intelligence Quotient gives clear criteria, but measurement...
in adults is not a feature of regular assessments. Classification systems stress the importance of the opinion of a skilled clinician’s assessment in categorizing severity.\textsuperscript{21,22} Table 4 shows severity of learning disability in this sample. Again, the largest category was those for whom no assessment of severity was available from the clinical record.

The 112 people involved in the review contacted the primary care team a total of 1041 times in the preceding 24 months; 1009 were face-to-face contacts with GPs or practice nurses, the remainder being telephone calls or repeat prescription requests. Median number of contacts for the two year period was 7 (range 0–58, mode = 4; Fig. 1). Twenty people (18 per cent) had contact with the primary care team on average more than once every two months. Average GP consultation rate was 4.1 (3.3–4.8) per person per year. Eleven night visits were recorded in the case notes of eight people over the two year period. There were no recorded contacts with health visitors. Types of contact are shown in Table 5.

The standardized consultation ratio (GP and practice nurse contacts) was significantly higher for people with learning disability of both sexes compared with the population of England (Table 6), and more so in men than women. There was no relationship between age and number of contacts ($r^2 = 0.0116$).

Severity of learning disability in the person concerned was known for 67 per cent of the contacts recorded. The moderately disabled group had the highest contact rate (Fig. 2) but differences were not significant (Kruskal–Wallis test, $H = 2.4$, $p = 0.49$).

There was a significant difference in consultation rates according to residential type (Fig. 3); the rate was highest for those in staffed group homes (Kruskal–Wallis non-parametric analysis of variance: $H = 16.74$, $p = 0.01$).

People with Down’s syndrome did not consult more or less often than those with learning disability related to other causes.

### Table 4 Severity of learning disability

<table>
<thead>
<tr>
<th>Severity</th>
<th>$n$</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>18</td>
<td>16.1</td>
</tr>
<tr>
<td>Moderate</td>
<td>21</td>
<td>18.8</td>
</tr>
<tr>
<td>Severe</td>
<td>33</td>
<td>30.4</td>
</tr>
<tr>
<td>Unknown</td>
<td>40</td>
<td>34.8</td>
</tr>
</tbody>
</table>

### Table 5 Number and type of contacts with primary care team

<table>
<thead>
<tr>
<th>Type of contact</th>
<th>Total</th>
<th>Face to face</th>
<th>All GP contacts</th>
<th>GP surgery consultations</th>
<th>GP day home visits</th>
<th>GP night visits</th>
<th>Practice nurse contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of contacts</td>
<td>1041</td>
<td>1009</td>
<td>915</td>
<td>691</td>
<td>213</td>
<td>11</td>
<td>94</td>
</tr>
<tr>
<td>Average/person per year</td>
<td>4.6</td>
<td>4.5</td>
<td>4.1</td>
<td>3.1</td>
<td>1.0</td>
<td>0.0</td>
<td>0.4</td>
</tr>
<tr>
<td>Median</td>
<td>7</td>
<td>6</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Range</td>
<td>0–58</td>
<td>0–58</td>
<td>0–58</td>
<td>0–58</td>
<td>0–20</td>
<td>0–3</td>
<td>0–19</td>
</tr>
</tbody>
</table>
(p = 0.51). People with epilepsy saw their GP, on average, one more time per year (4.7 versus 3.7 contacts per person per year) but this finding may be due to chance alone (p = 0.07). Whether the practice of a person whose notes were reviewed had a special arrangement (e.g. regular visits) with a community facility had no influence on the number of contacts with the primary care team (p = 0.54).

Over two-thirds of the sample (76 cases) had been registered for over five years. Of the 36 who had registered with a practice since 1 April 1990, and were therefore eligible for a new patient check, 28 (77.8 per cent) had the examination recorded.

Information on the claims for registration fees, which are dependent on provision of a new patient examination, was obtained from the FHSA for the whole of Hampshire for the financial year 1994–1995. Claims for registration fee payment were made for approximately 65 per cent of people who moved to a new doctor, although the denominator for this figure includes people under 18, for whom no health check is required. More detailed information on new patient registrations was not available from the FHSA.

### Discussion

The validity of our study is limited by its retrospective nature and dependence on primary care case notes and computer records, which are far from a perfect record of activity. A study of recording of health promotion information validated against patients’ reports and audio-tapes showed that blood

| Table 6 Standardized consultation ratio for people with learning disability |
|-----------------------------|-----------------------------|
| Standardized ratio | 95% CI                        |
| Males   | 156 | 142–172 |
| Females | 111 | 102–121 |
| Persons | 127 | 120–135 |

![Figure 2](image-url) **Figure 2** Mean number (with 95 per cent CI in parentheses) of contacts and severity of learning disability (LD).

![Figure 3](image-url) **Figure 3** Number (with percentages in parentheses) of contacts with primary care teams by residential type. LBHU, locally based hostel units.
pressure measurement was recorded in 83 per cent of cases, but that advice on smoking and alcohol use were recorded in less than half. A more detailed study of the content of consultations using simulated patients showed that only 32 per cent of actions carried out in consultations were recorded in the notes.

However, although these results show that clinical records underestimate activity carried out in primary care, case notes may still be used for comparing activity in different groups of patients, assuming that the rate of under-recording is approximately constant between groups.

It is likely that the sampling frame did not include all people with learning disability in the District. The methods used identified a similar number of people as the previous estimate of administrative prevalence in the District (2 per 1000). Administrative data collected at a single point may include some service users without learning disability and exclude others with learning disability but not currently receiving services. Comparison with a detailed population register in Bristol showed that our sampling frame identified a smaller proportion of people living in their own home or with relatives, which is the group most likely to be excluded from such a one-off administrative sample. It is therefore possible that the consultation rates we report are biased towards overestimating the true rate. However, even if we assume only half the people with learning disability in the District were identified in the sampling frame and that all the remainder showed the same consultation rate as those living in the family home, an elevated consultation rate of 3.7 would still be observed.

The limited number of night visits recorded may also reflect poor recording of activity. In many practices, case notes may not be taken on a night visit, although good practice suggests that a record of the consultation should be entered into the notes at the first opportunity. The finding that no health visitor contacts were recorded may be due to presence of a parallel health visitor case note system in many practices.

The findings that contact rate with the primary care team was independent of age and severity of learning disability was surprising. We expected consultation rates to increase with age and severity. Possible sources of error include unrecognized confounding by challenging behaviour, and measurement bias in assessment of severity. There was no difference in contact rate according to sex, which in MSGP4 was mainly due to increased female consulting rates in the 15–44 year age group. No previous studies have considered primary care use according to severity or sex in people with learning disability.

Consultation rates in the group with Down’s syndrome were not significantly different from the rest of the sample, contrary to Howells’ findings. Epileptics did not show an increased consultation rate, which may reflect the limited involvement of GPs in the care of epilepsy in general.

The finding that patients registered with practices reporting a special arrangement with residential facilities did not have higher rates of contact with the primary care team was unexpected, and should be viewed with caution. The criteria for defining a special arrangement may not have been sufficiently explicit to allow accurate measurement, and further data collection on the actual nature of the arrangements would have been helpful. Medical case notes may not have been available, or used during consultations at community homes, giving potential for measurement bias.

Residents of group homes had more contact with the primary care team than people in other types of residence. This may represent increased health care needs in this group, increased demand by carers in residential homes, or more appropriate supply to group homes for similar levels of need. However, to what extent any of these explanations account for our finding is not certain.

Cause of learning disability was known for less than half the sample (46 per cent). Although this is similar to other studies, some investigators have shown established aetiology in up to 90 per cent in community samples. Recognition of an underlying condition may be important for identification of raised risk of associated morbidity (e.g. diabetes in Prader–Willi syndrome), but is not solely dependent on GPs.

The annual GP consultation rate of 4.1 per person per year is higher than the rates of 2.6 and 2.7 reported in 1986 and 1990 among attendees at adult training centres in the United Kingdom, but identical to that in a 1989 Swedish study of medical records. However, importantly, the rates reported in both UK studies were based on carer reports, and are subject to recall bias. Furthermore, attendees at adult trainee centres are likely to be less representative of the general population of people with learning disability than this sample.

Our findings also contradict Langan et al.’s more recent case–control study of consultation with GPs, which did not express results as average consultation rates per year, but concluded that the 78 subjects with learning disability ‘use their GP very little (if any) more than do the control patients’. The new patient health check was carried out in a similar proportion of eligible people with learning disability as the general population, suggesting that attendance for the health check is acceptable to people with learning disability. Whether such regular checks, which have been widely recommended, are an effective means of health promotion is uncertain.

We have shown that people with learning disability are likely to consult more frequently than the general population, and that rates are similar to those seen in young children or the elderly, for whom increased capitation payments are made to GPs. A potential source of bias in our results is that MSGP4 was carried out in 1991–1992, some five years before our survey, but we do not believe secular variation in consultation rates is likely to account for the increased consultation rates observed.

Increased use of primary care services might be taken as supporting the view of some GPs that increased capitation
payments should also be made for people with learning disability. However, problems of defining the relevant group accurately, associated administrative costs, and the precedent that this would set (what, for example, about people with severe mental illness, or children with complex physical disabilities?) suggest caution in adopting this approach.

Furthermore, demonstration of increased consultation rates does not imply that care is appropriate to meet needs. Previous work has suggested that management of medical problems in people with learning disability is often inadequate, and that training in communication and the nature of health needs of people with learning disability could be improved. We believe that more work is required to develop skills in primary care, particularly through undergraduate and postgraduate training. The finding that 10 per cent of contacts were with practice nurses suggests the need to involve the whole primary care team.

More innovative approaches, such as the use of specially trained nurses, health visitors or clinical medical officers to augment primary care services and facilitate liaison with specialist services should be rigorously evaluated. Hitherto there has been much concentration on the social needs of people with learning disability, and these are being successfully addressed through the promotion of an ‘ordinary life’ in the community. Although we endorse these moves on humanitarian grounds, we believe that the health needs of people with learning disability and the skills required to meet them should not be ignored.

Acknowledgements

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