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executive summary 37

The role of health check programmes in improving access to mainstream NHS healthcare services for people with learning disabilities.

Background

People with learning disabilities are more prone to ill health than the general population. For example, it is well-established that people with Downs syndrome have increased risks of heart problems, hypothyroidism and early onset dementia (Howells, 1986). Their communication and cognitive difficulties mean that both they, and those who care for them experience difficulties in identifying signs and symptoms of ill health, hence approaches to healthcare services may be delayed. Health check programmes have been proposed as a means to facilitate healthcare to this group and several models have been trialled including nurse and GP led services. Previous published reports found that a high proportion of the health needs of people with learning difficulties were going unmet (Howells 1986; Wilson and Haire 1990; Harries 1991). However, few have investigated whether patients subsequently gained access to services.

Aims

- To investigate the role of joint practice and learning disability nurse-led health checks in facilitating access to the full range of NHS services.
- To explore the experience of those implementing, running and using health checks in order to identify salient issues for service providers considering whether to offer this service.

Methods

The study used a mixed methodology including audit and interview strands.

- Thirty-four sets of patient notes were audited on the 34 issues covered by health check protocols by the learning disability service for patients who had attended two or more health check appointments.
- The anonymised data on initial appointments was studied for evidence of follow up access to a range of healthcare services.
- In addition, a sub-group of 18 patients' second health check data was analysed to see whether the evidence supported offering regular as opposed to episodic health checks.
- Semi-structured interviews were conducted with practice staff at nine general practices and learning disability health professionals, who had experience of the programme.
- Six service users and their carers were also interviewed about their experiences.

Results

Initial Health Checks

- 97% of attendees had one or more health needs and 84% of this need received some follow up healthcare attention.
- In 76% of cases it was confirmed that the person had access to healthcare services in relation to identified need.
- In another 14% of cases there was strong evidence that healthcare services were accessed.
- Those needs that could be dealt with within the health check appointment itself were most likely to be met with 90% of preventative healthcare and 78% of health advice and education needs being addressed.
- 50% of patients were referred to a range of other healthcare services and access was confirmed for 88% of identified needs.

Second Health Checks

- 78% of patients had one or more health concerns.
- Half of the group had fewer health needs noted at their second check, while 11% had the same number and 39% had a greater number of recorded health needs.
- 41% of the needs identified at initial health checks were no longer recorded as a concern.
- Persistent health concerns were evident, especially in relation to weight, blood pressure, diet and exercise.
- 84% of health needs noted in second health checks were recorded as having a follow up, as with initial health checks.
- In 73% of these cases healthcare services were confirmed as having been accessed in response to need. In a further 18% of cases, there was good evidence that services were accessed. These figures were very similar to the rates established for initial health checks (76% and 14% respectively).
- The need for preventative healthcare was most often identified. As with the first health checks, this was usually addressed within the health check appointment.
- Health education and advice where required was also given at the clinic.
- Referrals to other healthcare services were made for 39% of patients, compared to 50% who were referred on after initial health checks.
- 75% of identified needs requiring referral were addressed by the appropriate healthcare services.

Health Checks Overall

- 24% (8) of the patients whose notes were audited in this study were diagnosed with a significant health problem, including hypertension, epilepsy and mental illness.
- Four were diagnosed as a result of a need identified at their first health check, two after a second health check and two after having a third health check. This suggested that regular health checks were needed if health problems were to be diagnosed and treated.
- The need for regular health checks may lie in the cumulative nature of addressing health issues provided by this type of programme.
- Patients with learning disabilities may not have every health issue checked at every health check and it may take time for the patient to feel comfortable with the nurses involved and with the setting itself.

- They may need preparatory familiarisation before procedures such as blood pressure testing can be undertaken.
- Patients who are extremely anxious may only be comfortable with very general questions about their health status initially. As familiarity builds, further health issues may be broached.

- There may be insufficient time to cover all areas of the health check.

The Interview Study

- Practices wanted to ensure that their patients with learning disabilities were not disadvantaged in relation to their other patients.
- They also saw the involvement of the Joint Learning Disability Team (JLDT) as a way to facilitate provision of a 'well-person' check.
- Several practice staff had not previously thought of people with learning disabilities as 'a group' who needed special attention.
- The creation of a 'register' of patients with learning disabilities was seen by some as the first step to enhancing this awareness.

The Proportion of Patients in Practices

- The numbers of people with learning disabilities in practices varied between 10 and 40 depending on practice size (between 0.001% and 0.007% of list size approx).
- The largest practices (>10,000 patients) reported having lower proportions of patients with learning disabilities (0.001% to 0.003%).
- The smallest practice (list size 2,000 approx) reported the largest proportion of patients with learning disabilities (2%).

The reason for this discrepancy was unclear. It may be attributable to the presence of a group home for people with learning disabilities in the catchment area. Where this is the case, people with learning disabilities may represent a larger proportion of the list size for small practices than the average.

Health Checks

Nurses and carers saw health checks as appropriate for people with all levels of learning disability.

- For people with mild learning disability, who may have limited or no contact with services on a regular basis, health checks were seen as a useful link both to ensure that health appointments were being kept and to provide access to other services (specialist and mainstream).
- People with more severe learning disability have correspondingly greater health needs coupled with increased difficulties in recognising and communicating signs and symptoms of ill health. For these people, the health check was seen as a valuable opportunity to spend time investigating common health issues for people with learning disability in an ongoing way that built relationships and trust in their general practice.

Annual or Biennial Repeat Clinics?

- Biennial clinics were perceived as more manageable logistically because they minimised demands on both practice and learning disability nurses.
- They were also seen as acceptable for people who were generally well or attending disease specific clinics at the same time.
- However, practice and learning disability nurses were concerned at leaving repeat surveillance for this long because of the underlying 'risk factors' (difficulties identifying need and seeking help).
- Carers also supported the provision of annual as opposed to biennial health checks.

Resources

The resources demanded of practices and learning disability services varied. For practices, this involved a room and practice nurse time, which was estimated at between 12 and 15 hours over a number of months. This commitment was considered comparatively small and some managers felt the cost was easily absorbed by the practice. The resource commitment from the JLDT was significant because they were involved in clinics and meetings for the same number of hours as practice nurses, but also spent time distributing and following up appointments with telephone calls to clarify for patients what the check was for. This commitment was then multiplied by the number of practices running health checks. However, the JLDT service management regarded the resource expenditure as necessary because of obligations under the white paper Valuing People: A New Strategy for Learning Disability for the 21st Century (published on 20 March 2001)[1], in regard to facilitating access to healthcare and providing health action plans. It was provided by prioritising health checks over other services.

The Future

- Practices were positive about continuing the programme.
- Most wanted the programme to continue to be delivered as a joint practice and learning disability service because each nurse was considered to bring different strengths to the clinic.
- However, other models were proposed including moving to generic well-person appointments after an initial practice/learning disability health check.
- In the absence of a directive or incentive for practices to implement health check clinics, roll out to other practices within the PCT was predicted to be slow and problematic.

Conclusions and policy recommendations

NHS services should be more proactive

The NHS Plan (2000)[2] , and learning disabilities strategy document Valuing People (2001)[3] outlined the aspiration that people with learning disabilities should use mainstream NHS services (with appropriate support). Access to services was recognised as a key issue in relation to timely and effective intervention. To this end, considerable effort has been expended in ensuring that waiting times for appointments with health professionals and for treatment are kept to a minimum. However, the needs of people with learning disabilities mean they demand a more proactive NHS service, if they are to gain access to services in a timely and efficient manner.

Regular Health Checks are Beneficial

Health checks appeared to be an appropriate vehicle to facilitate access to healthcare. Health improvement is difficult to ascertain in the absence of rigorous longitudinal studies. However, access to healthcare is a useful surrogate if one accepts the premise that timely access to appropriate healthcare is essential to health improvement. The access to healthcare demonstrated in the audit suggests that this group of individuals were likely to experience health benefits in the long run. The study also suggested that offering health checks to all people with learning disabilities on a regular basis would bring significant health benefits. The marginally reduced, but repeated identification of health need and diagnosis of significant health conditions over a succession of health checks suggested a need for regular, rather than episodic (life event prompted) checks. The definition of 'regular' would need to be determined by available resources, but it should occur no less than once every two years.

Clinics should be nurse-led

Previous research has shown GPs are unwilling to become involved in health check programmes themselves (e.g. Kerr et al, 1996). This study found comparatively few of the individuals required referral to their GP. The bulk of their need was for preventative healthcare, and/or health education and advice appropriately provided by nursing staff. This study therefore suggests that clinics should be nurse-led.

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[1]http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilitis/LearningDisabilityPublications/fs/en?CONTENT_ID=4032080&chk=w%2Bvo48

[2]http://www.dh.gov.uk/PublicationsAndStatistics/Publications/AnnualReports/DHAnnualReportsArticle/fs/en?CONTENT_ID=4064827&chk=3ReuSO

[3]http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilitis/LearningDisabilityPublications/fs/en?CONTENT_ID=4032080&chk=w%2Bvo48

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