Disability Rights Commission

A Literature Review on the Effectiveness of Interventions to Improve the Physical Health of People with Learning Disabilities

Alison Alborz
Afroditi Kalambouka
Ross McNally
Gill Parkinson

University of Manchester
6th Floor Humanities Building
Devas St
Manchester M13 9PL

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Executive Summary

Literature Review on the Effectiveness of Interventions to Improve the Physical Health of People with Learning Disabilities

The aims of this review were to examine the literature on the effectiveness of interventions aimed at improving the physical health of people with learning disability across all age groups and levels of disability. To identify, evaluate and summarise evidence of specific, practical and effective interventions that aim to improve the physical health of people with learning disabilities.

Searching generated 6087 titles and abstracts, of which 774 remained after application of initial inclusion/exclusion criteria. Due to time limitations 250 of these publications were obtained, remaining references were in less accessible journals, which tended to be older (pre 2000) or less prestigious. 41 publications met the inclusion criteria once full text had been considered. Quality evaluation revealed that identified studies tended to be poor. Some reports on interventions with no data on evaluation were retained in the full report as examples of interventions that were being introduced where they were the only studies identified on particular issues or with a particular participant group. Overall 2 highly rigorous, 11 rigorous, 16 less rigorous and 12 poor studies were identified and included in the review. Details from 'poor' studies are not included in this summary but are included in the full report.

Findings are presented under three headings. 'Interventions with people with learning disabilities', which discusses research findings on interventions targeted at people with learning disabilities themselves; 'Interventions enhancing parents' and carers' roles', which considers research on strategies to enable carers to become more effective in advocating on behalf of those they care for; and 'Interventions enhancing practitioners' roles', which considers research targeting professional group roles in improve the health of people with learning disabilities.

Interventions with people with learning disabilities

Excluding 'poor' studies, 20 papers were identified that addressed interventions with people with learning disabilities directly. Papers reviewed fell broadly into the following topics; Health checks designed to identify and address unmet health needs; Health education; Weight and or fitness; Women's health; Smoking reduction; and Self-advocacy/communication. Each of these areas is summarised below.

Health checks

Ten papers reported on health check programmes. The health checks were conducted mainly in general practice settings, however one was carried out in the person's own home and another in day care facilities.

Findings:

- improvements in 'health strengths' (indicators of resistance to ill health, for example taking regular exercise) and decreases in 'health risks' (indicators of poor health, for example BMI $\geq$ 30, pain rated moderate or worse) using health risk assessment / intervention methodology from a US study.
- identification of high proportions of unmet needs. Much of this need was for preventative healthcare and health promotion and advice
- unmet needs reduced over subsequent checks
- successes in meeting needs may be masked by deterioration or continuing problems in other health areas
- health checks need to be conducted on a regular basis to effectively identify and address health need within the group
- ongoing health needs were evident in relation to sight and weight

Health checks in themselves did not directly improve particular health problems but acted to help both people with learning disabilities and their carers overcome problems in identifying and communicating health need, and provided a gateway to healthcare interventions that tackle health problems directly. As such they appeared to perform a key role in addressing inequity in health care provision for this population by circumventing barriers to health improvement imposed by cognitive and communication deficits.

Health Education

Seven papers described health education initiatives that involved some form of training, including classes, small group sessions and workshops.

Findings:

- Provision of a range of health promotion messages to children (up to 19 years) at two special schools was achieved by employing nurses on site, including information on puberty, weight and fitness, and with younger children role play visits for health consultations using toys. No evaluation was presented of the extent to which participants' behaviour/knowledge changed as a result of the intervention. However it covered issues important to the physical health of children that went beyond the usual school curriculum.

- A health 'diary' was developed for adults with learning disabilities in a pilot study. The diary was distributed after a 50 minute one-off training session covering advocacy principles and applications and assertiveness. Comment from participants, including 7 people with learning disabilities able to self-advocate, suggested that use of the package improved GP consultations, however little further information was presented.
- A study provided a training session on bodily knowledge and use of general practice, and developed a communication aid for use in discussing ill health with carers or general practitioners. Knowledge was found to be improved in the short and longer term, though most effective where an individual had an episode of ill health and used their knowledge and communication aid. This was described as a pilot study and so only limited information on the effectiveness of the intervention was available.
- HIV/AIDs awareness training courses were trialled with two groups of adolescents with learning disabilities. Authors described the school based training, which used students' own experiences and line drawings to explore issues relating to sex education, abuse and HIV/AIDs messages, as less mechanistic than a community leisure centre based programme. The latter used explicit slides and prosthetics to deliver sex education and HIV/AIDs messages. They concluded that these issues could usefully be introduced alongside other sex education topics.

Weight and Fitness

Weight and fitness is a particular concern for people with learning disabilities many of whom lead sedentary lifestyles where meals are a significant event in terms of marking the passage of time and providing a rewarding experience. Unhealthy diets are associated with risk factors for a range of conditions however the focus of current concern is the connection between Coronary Heart Disease, hypertension and excess weight. It must be noted, nevertheless, that a significant minority of people with learning disabilities experience difficulties stemming from being underweight and malnourished and that these individuals tend to be among those most severely disabled. However only one poor study addressed this issue and is therefore not included in this summary. Fitness, in particular cardiovascular fitness has been recognised as a bulwark against heart disease and as a resistance factor against a range of diseases.

Findings:

- One study suggested that adults with learning disabilities who took part in structured exercise programmes, devised by a Healthy Living

Co-ordinator, could reduce their weight over the longer term. Although there were no significant differences between the groups' weights after 6 months, the intervention group decreased their weight by an average of 1.5Kg, while the control group increased their weight by an average of 0.96Kg over 12 months.

- Activity and changes to diet tested in two further studies suggested similar benefits but gained over a shorter period of time. One described the health education learning programme (HELP) which consisted of training sessions on exercise, nutritional choices and stress reduction. After 8 sessions weight had reduced for 18.5% of participants by at least 5 lbs and health knowledge had increased by 58.8% for the whole group. The second study involved adults with learning disabilities but no mobility problems and also consisted of sessions on health eating and exercise. After 6 weeks an average weight loss of 3Kg was reported.

These studies suggest that, as with the general population, healthy eating and regular activity is most effective in reducing weight and therefore risk of developing associated health problems. It follows therefore that the physical health of people with learning disabilities can be improved through appropriate weight and fitness programmes.

Women's Health

These publications focussed on improving provision of breast and cervical cancer screening to women with learning disabilities.

Findings:

- Women with mild/moderate learning disabilities were successfully taught skills to cope with invasive procedures through practicing visits to clinics settings, learning about the equipment and staff involved and learning relaxation and assertiveness techniques. Significant health and coping knowledge gains were shown following the sessions however there was no significant change in health behaviour scores. Anecdotal evidence of women using skills in the longer term was reported.
- A study on cervical screening for women residing at a long stay hospital was conducted. 68% of those eligible attended appointments, however 29% were found physiologically 'unsuitable' for cervical screening, and a further 21% withdrew without having a test. Screening results from those who agreed to participate yielded similar results to those found in general population screening (87% 'normal', 11% 'inadequate', 2% 'abnormal'). Findings from the educational component of the first study suggest that the number of

women agreeing to have a smear test might have been increased had they been given appropriate preparation.

Several poor studies were found on this topic (see full report) which add to the impression that a range of initiatives are being implemented in an attempt to improve cancer screening for women with learning disabilities. There is evidence therefore of some success in providing knowledge and skills to assist more able women to make an informed decision about uptake of screening and tolerate invasive procedures.

Other Health Interventions

One publication was identified that covered direct intervention to reduce smoking.

Finding:

- The research suggested that the intervention, implemented with two men with mild/moderate learning disabilities living in an institutional setting, is an achievable outcome over an extended period of time (approx. 18 months in this case). The intervention linked two 'undesirable' behaviours (smoking and aggressive outbursts) using cigarettes firstly as a controlled reward and then substituting an alternative reward item in place of the cigarette.

This is an illustration of an intervention to improve health that goes beyond health education messages on smoking as a factor in risk of ill health. However there is no guarantee that this particular intervention would work in the same way in other settings, nor were the issues of choice and consent addressed in the study.

Self Advocacy / Communication

Four studies addressed issues relating to people with learning disabilities' communication and self-advocacy skills, and included some outcome data. Several of these studies had health education aims, however their documentary elements also provided opportunity for communication or advocacy improvement.

Findings:

- A pilot study suggested that people with learning disabilities were able to use a 'health diary' in which health information was to be routinely recorded. The aim of the file was to provide consistent quantitative information about health issues that could then be used in health appointments, it also included a section with health advocacy tips. Comments from participants suggested that the file was useful.

- A second pilot study tested an unstructured communication aid that helped people with learning disabilities to communicate about their health. Tentative evidence was provided that this aid helped the participants with learning disabilities, who had occasion to use the aid in the follow up period, to take a more active part in consultations with the GP.
- Another pilot study offered assertiveness and advocacy training in relation to women's health, as outlined above, and provided feedback comments that suggested the advocacy skills taught were being put into practice.
- A Health Status Interview Schedule, trialled with verbal or partly verbal people with learning disabilities was found effective in obtaining consistent quantitative information on a range of health issues.

The small amount of outcome data provided overall, suggests that the educational and documentary elements had the potential to impact on the ability of more able people with learning disabilities to take a more active part in health consultations. Most of these were pilot studies and as such more comprehensive evaluation studies may be forthcoming.

Interventions enhancing parents' and carers' roles

People with learning disabilities' difficulties in identifying and responding to the signs and symptoms of ill health mean that there is a greater reliance on those who come into regular contact with them, particularly carers, to fulfil this role. This is especially true for people with more severe learning disabilities who may be unable to take advantage of the health education training, information and communication/advocacy aids described above.

Nine studies identified here are also covered in the section on interventions with people with learning disabilities directly, that is health checks, weight reduction, health education and women's health. They were also included here because they provided some information on interventions designed to help carers identify where a person's health is, or is at risk of being, compromised.

Identifying health need

Two publications related to carers' roles in identifying and responding to health needs and described tools being developed.

Findings:

- A general health tool was found useful for eliciting information that carers might not provide without structured questioning. Participants were employed by the NHS but not all had health qualifications. It was not clear whether this structured questionnaire was designed for use in a particular setting, however comprehensive information is vital for identifying and responding to health needs and therefore such aids may provide a useful way to help carers provide appropriate observations regardless of setting.
- A nutritional tool proved useful in identifying nutritional adequacy and related problems among adults with learning disabilities but not for weight related risk, particularly underweight. Carers in this study were nurses at a long stay hospital, however it is arguable that the instrument could be used by carers in other settings.

Health Checks

A highly rigorous pilot study related to carer involvement in health checks. This study was undertaken in the USA however and so caution must be exercised in applying findings to the UK context. However as this was trial of a health screening tool and health information and advice it is reasonable to suggest that a similar intervention could operate in the UK.

Finding:

- A health profile was produced for adult participants with learning disabilities, based on a structured assessment carried out by a trained non-health assistant. This was followed up with relevant health education materials and advice to the person and their carer. Post intervention measures suggested that health risks (such as body max index > 30, or moderate to worse pain) decreased, and health strengths (such as taking regular exercise) increased following intervention. The tools developed are to be subject to further trials.

Women's health

A rigorous study, again in the US, provided training to women with learning disabilities on health examinations including information, and relaxation, coping and assertiveness skills. The training package incorporated joint training to carers in its design.

Finding:

- Attempts to include carers in the intervention were not as successful as the elements aimed at women with learning disabilities themselves. The authors suggest separate training for carers to focus on their particular needs in this process.

Health Education

One rigorous and one less rigorous study addressed health education to carers aiming to improve health in the people they look after.

Findings:

- Health diaries (see also above in relation to people with learning disabilities) that included personal information on the individual concerned and sheets for monitoring health data and appointments were provided. The package included a training session covering advocacy and assertiveness for people with learning disabilities and carers before diaries were distributed. Early feedback from this pilot suggested that the diaries were useful for carers as they were able to record relevant information in them and use this in health consultations. The extent to which advocacy training enhanced carers' roles is unclear in this study.
- Training on epilepsy and diazepam use was provided to carers in a less rigorous study. 95% of participants successfully completed written assessments on course content obtaining overall scores of 70% or more. However no information was provided on the impact the training then had on the individuals cared for.

The available evidence, therefore, suggests that training has been received positively by carers, however the longer term impact on the health of people with learning disabilities, has yet to be ascertained.

Interventions enhancing practitioners' roles

Eight papers addressed practitioner roles in improving the physical health of people with learning disabilities including five rigorous and three less rigorous publications. Publications identified involved nurses, general practitioners and teachers.

Nurses

Only one study, evaluating a health check protocol, was identified as enhancing the role of nurses.

Finding:

- The protocol was found to be a 'nurse-friendly' tool. Of the 35 people with learning disabilities assessed, 91% were referred to their GP. There was no information however on setting in which assessments

were conducted, the types of problem referred, or the outcome of the referral.

The literature on enhancing the roles of nurses was scant. There appears to be an urgent need for further initiatives, aimed particularly at mainstream NHS nurses, on enabling people with learning disabilities to access and use health services effectively.

General Practitioners

Two rigorous and four less rigorous publications were identified that addressed interventions to improve the physical health of people with learning disabilities by enhancing general practitioner roles. Research attempting to provide pertinent information to general practitioners had varying results.

Findings:

- A prompt card (containing information about specialist services and conditions commonly experienced by people with learning disabilities) placed in the note wallet of individuals selected at random did not appear to influence the preventative healthcare offered these patients compared to a control group.
- Personalised health information record cards were placed in the notes of patients with learning disabilities in eight general practices. No information was provided on the impact of the information on service delivery, healthcare to, or health improvement of the patients concerned, but it was noted that the card was 'regularly used' by some practices and that two practices were investigating ways of transferring the template to their computer systems.
- A rigorous Australian study (noted also above) involved compilation of a health diary which included information specifically aimed at general practitioners. A brief educational session was used to introduce the diary to GPs among others. However no information was given on how, or if the GP educational session differed from that given to other groups. No outcome data on this element of the study was available as this was a pilot of the tool and training package. The comments recorded suggested the tool had been 'advantageous' and would be useful with other patient groups as well, such as those with mental illness.
- A pilot study developed a communication aid to be used by people with learning disabilities both with their carers and their general practitioner. A copy of the communication aid was provided to the GP. Limited feedback suggested that the aid helped the person with learning disability take a more active part in the consultation process.

- Two reports of health check programmes, one UK and one Australian, suggested that GP's awareness of the health needs of patients with learning disabilities was improved as a result of the practice's, or their own involvement in health checks. The latter study also found the majority of general practitioners felt more aware of the availability of special services for people with learning disabilities in their localities.

Although research has tackled few of the possible 'solutions' proposed to help people with learning disabilities to overcome the barriers to accessing and using general practice effectively, the studies reviewed suggest that there are ways to enhance GP roles that are acceptable to both parties. The bulk of the 'successful' initiatives provided personalised, as opposed to general, documentary support to aid health consultations. As most studies were 'pilots', there remain questions as to their longer term success or sustainability.

Teachers

Only one rigorous study addressed teachers' roles in improving the physical health of children with learning disabilities. This study described the development of an intervention to improve teachers' knowledge of the health needs of their pupils with learning disabilities.

Finding:

- The range or extent of health education training to teachers in 2 special schools was enhanced, compared to 2 contrast schools, by the employment of a nurse on site. The nurses' prime responsibility was to respond to the continuing healthcare needs of children with learning disabilities and a range of physical health problems. However, their presence in the schools, not only relieved teachers and class assistants of performing healthcare tasks, but provided them with training on a range of issues including first aid, epilepsy, diabetes and meningitis. As with many other studies describing interventions there was no evaluation of the impact of the initiative on the health of the pupils they supported.

As teachers and classroom assistants spend extended periods of time with children with learning disabilities, the opportunities for health education and promotion are considerable. It is equally important that they are aware of the potential health needs of these children so that they may play their part in helping to identify needs as they arise. It is notable that no research was identified addressing the roles of other day care workers in improving the physical health of adults with learning disabilities.

Overall

The health improvement literature identified addressed in large measure issues relating to health promotion and prevention through health education, observation/monitoring and cancer screening. Health checks, and attempts to enhance practitioner knowledge in relation to the health of people with learning disabilities addressed to some extent the issue of early detection of need. The quality of evidence overall was not high but gave the impression that this is becoming a more active and rigorously researched field, and that there may be more substantial evidence forthcoming in the foreseeable future.

A literature review on the effectiveness of interventions to improve the physical health of people with learning disabilities

1. Introduction

Good health is a pre-requisite for achievement of potential and a fulfilling life. In the general population the wider determinants of health have been suggested to relate to socio-economic factors. That is, health status or risk has been associated with income, education and employment, as well as environment and lifestyle (Achieson, 1998 reported in Wanless, 2003). These determinants affect disabled and non-disabled populations alike however people with learning disabilities are more prone to a wide range of additional physical problems than the general population. Their health care needs, though not uniform, are likely to be both complex and long-term. Physical health for this group is additionally affected by severity of learning disability, presence of additional physical disabilities, type of learning disability (for example, presence of Down's syndrome), and age (e.g. Sutherland et al, 2002). Epidemiological studies predict increases in the numbers of people with learning disability both surviving the neonatal period and living into old age (Fryers, 1993; Carter & Jancer, 1983). New challenges therefore arise in relation to improving the physical health of people with learning disabilities due to both the size and the ageing of the learning disabled population.

People with learning disabilities may experience difficulties in recognising and communicating symptoms to carers and health professionals. People with limited communication are likely to rely heavily on the familiarity of a close carer to recognise symptoms or indicators of abnormal health; to secure access to health care facilities; to interpret and communicate with health professionals; and to support compliance with treatment regimes. Similarly many rely on others to facilitate access, use and compliance with health education and promotion regimes, preventative health measures and screening programmes.

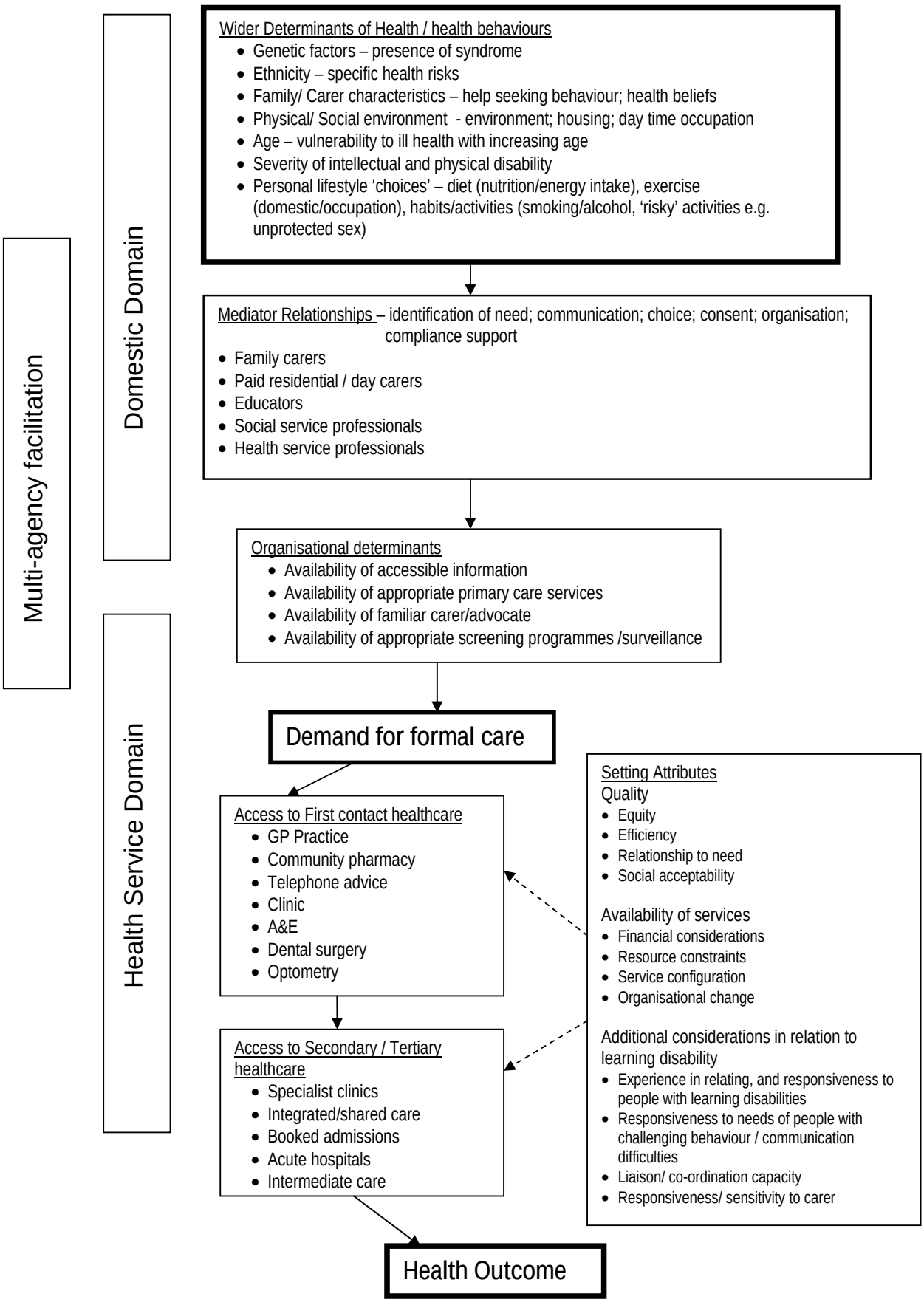
Evidence also indicates a higher prevalence of learning disabilities among ethnic minority communities; in particular, children with learning disabilities from South Asian families are disproportionately represented among all children born with learning disabilities (Emerson & Hatton, 1999; Office for National Statistics, 1996). Additional language and cultural beliefs may affect the uptake or effectiveness of interventions designed to improve the health of people with learning disabilities for those from minority ethnic populations.

Current NHS policies (DH 1997; DH 2000; DH 2003) emphasise the provision of equitable health services to the *whole* population of England. Similarly, policies for learning disability services (DH 2001) stress that people with learning disabilities should be able make full use of mainstream services (with appropriate support). More recently a further white paper (Choosing Health, DH, 2004) has highlighted the importance of preventative health care and health promotion in improving the physical health of the population including people with learning disabilities. General practices were expected to identify all people with learning disabilities who are registered with them by June 2004 and provide a Health Action Plan (HAP) for all who wish to have one by summer 2005 (DH 2001).

The HAP is a device though which health improvements may be mediated. In response to this initiative many people are receiving a health check at their general practice to underpin creation of their personal health action plan (Cobb, 2004). In some regions of the UK health professionals and researchers have taken the initiative to establish health check programmes on a more formal basis (Kerr et al 1998; Hanson, 2001). Other initiatives designed to improve health amongst this group include programmes to provide health education and communication aids for people with learning disabilities to improve their knowledge and communication about health issues with carers and general practitioners (Dodd, 1999), and provision of effective and acceptable information support systems to general practitioners to facilitate consultations with people with learning disabilities (eg Jones et al, 1997). There is an increasing emphasis on providing accessible information to people with learning disabilities that is likely to include information to support the health improvement agenda.

In establishing the effectiveness of interventions to improve the physical health of people with learning disabilities it is important to have an underpinning conceptualisation or model of the factors likely to influence health outcome. This conceptualisation can then guide literature searching along relevant trajectories and help to establish important gaps in knowledge. The authors adopted a model of ‘access to healthcare’, built on the work of Gulliford et al (2001), in an earlier review (Alborz et al, 2003) that also conceptually outlines issues that may be important in targeting and delivering effective interventions to improve the physical health of this group. This model has been revised to focus on issues identified in the literature as important in health improvement (see Fig. 1) and organised into three domains. The ‘Domestic’ domain includes the ‘wider determinants’ of health that is the personal and social variables that may influence uptake, compliance and effectiveness of different service

Figure 1: Pathway to Health for People with Learning Disabilities



delivery models for people in different circumstances. It also covers 'mediator relationships' with family or carers who support daily living and may play a central role in the success of health improvement activities.

The 'Multi-agency facilitation' domain spans Domestic and Health service domains and includes mediating relationships with professionals from a range of backgrounds such as education, social services and community health care who may have a role both in the identification of health need and support to access and use health improvement programmes.

The 'Health Service' domain includes primary, secondary and tertiary health service delivery. In terms of health improvement activities primary care has a key responsibility of health promotion and preventative healthcare in addition to their more traditional treatment role.

Communication presents a fundamental challenge to effective provision of health care for people with learning disabilities. Fig. 1 indicates that people with learning disabilities may rely on individuals with whom they have 'mediating relationships' to 'access' an intervention. Learning disability is likely to impede understanding of diagnosis and treatment requirements implying that third parties will be involved in ensuring compliance with medication or exercise regimes, or supporting health-promoting lifestyles. They are also likely to play a key role in helping health professionals to secure informed consent to treatment or participation where possible from the person they care for (Making Decisions, 1999). Effectiveness of any intervention may therefore depend to a greater or lesser extent on the on the continuity, expertise and responsiveness of relationships with these mediators.

Health screening/surveillance is a continuing need for people with learning disabilities, particularly where their disability carries associated risks of certain illnesses – for example, heart problems, hypothyroidism and early onset dementia are known to be more prevalent in people with Down's syndrome (e.g. Howells, 1989). Screening is likely to reflect the norms of the non-disabled population though health check programmes for people with learning disabilities are becoming more common. Infants and young children will be covered by universal screening and child health surveillance programmes, but local child health registers may not include information on more complex health needs or on health problems which occur after children reach school age (Glendinning et al, 2001). These issues, which are described in the model, provided a guide to literature searching and helped to highlight gaps in knowledge.

Health Improvement

Health improvement may be defined as avoiding preventable ill health through health promotion and preventive measures, as well as alleviating existing ill health by provision of appropriate and effective treatments. Health maintenance may also be viewed as relevant to this topic. It is not always possible to 'improve' or 'cure' a person's condition, for example for sufferers of epilepsy or diabetes, however maintaining that person's health at the optimum level for him or her may be viewed as a goal equally as important as avoidance or recovery from a health problem. Hence the term 'health improvement' in this case includes both 'improvement' and 'maintenance' facets.

Health improvement may be achieved in a variety of ways including improved living conditions, health education and promotion to individuals, health screening and improved treatments. Health education aimed at improving the physical health of people with learning disabilities can be delivered to a range of individuals from mainstream health professionals to carers as well as, in accessible formats, to people with learning disabilities themselves. Interventions to improve the physical health of people with learning disabilities may address one or more of these audiences. Health promotion, as in the general population is likely to include health screening, health checks, vaccination programmes but also, for this population, health action planning (HAP).

Sutherland et al (2002) describe a growing literature around barriers to adopting health promoting behaviours including environmental (limited access to leisure facilities); organizational (inadequate staffing to support activities) and policy (lack of clear guidance of responsibilities in relation to overcoming barriers). There is also some evidence on barriers and solutions to providing effective healthcare in general practice. Lennox et al (1997) through their research in Australia, identified several areas that general practitioners felt would improve the effectiveness of healthcare to this group. This included additional training or education; longer consultation times; enhanced involvement of parents and carers; continuity of both the carer accompanying the person with learning disabilities and the GP providing care so that a rapport might be established; better record keeping and proactive contact with allied professionals and services. Ziviani et al (2004) also consulted a range of people involved in promoting health for people with learning disabilities and produced a 'Model of cooperation - Meeting in the middle' that addressed barriers to effective consultations in general practice, the proposed solutions encompassed the general practitioner, person with learning disabilities and their advocate. This model proposed appropriate awareness and training on issues affecting the health care this group; improving organisational determinants

of healthcare (physical access, flexible appointments etc); improving preparation for consultations; appropriate 'cooperative' sharing of information during consultation; and appropriate referral and follow up from consultations. This work supports, from the UK perspective, the earlier findings by Lennox et al (1997).

Finally, work has been conducted at an European level on health improvement for this population. The POMONA project (Linehan et al, 2004) produced a set of indicators relevant to establishing the health status of people with learning disabilities across the EU. A number of these indicators address wider determinants of health that are beyond the scope of this review, including prevalence, living arrangements and income. Prevalence of learning disability has no bearing on this review. Learning disability is a characteristic of the population under consideration and so fluctuations in prevalence due to antenatal screening or improved antenatal care are irrelevant. Issues relating to poverty and housing are likely to affect the health of this group of people, who are amongst the poorest in the country (see for example Hatton and Emerson 2004), as they do other population groups, however the solutions to these problems do not lie within the remit of the NHS. Other indicators highlighted by the group are pertinent to the review and include epilepsy; body mass index; sensory impairment; mobility; physical activity; health checks; health promotion (women's cancers, hypertension, cholesterol, vaccinations); and special training. These issues were all considered in the review.

Aims

The aims of this review were to examine the literature on the effectiveness of interventions aimed at improving the physical health of people with learning disability across all age groups and levels of disability. To identify, evaluate and summarise evidence of specific, practical and effective interventions that aim to improve the physical health of people with learning disabilities.

2. Methods

Overview

In this review we gathered evidence on the range and effectiveness of interventions aimed at improving the physical health of people with learning disabilities. Following the methodology adopted in a recent literature review (Alborz et al, 2005), which is described in detail in two papers on literature review methodology (McNally and Alborz, 2004; Alborz & McNally, 2004), a three strand approach to literature identification was used involving: searches of electronic bibliographic databases; a brief consultation exercise; and a mail shot to researchers in the field and learning disability health professionals.

Broad inclusion/exclusion criteria for searching were initially set including: English language literature published from 1990 onwards relating to interventions to improve physical health; relating to people with learning disabilities of any age; using any study design; covering one or more dimension of the model; and relating to healthcare delivery in the UK, as well as Australia and New Zealand (which have systems similar to the UK) but including literature from other countries on interventions where healthcare delivery system had no bearing.

Bibliographic database searches

Searching used both natural language and thesaurus approaches to identify relevant literature to allow for inconsistencies in the indexing practices of bibliographic databases, whilst balancing the need for sensitivity and specificity. The electronic databases, libraries and websites searched are shown below in Table 1.

Additional references were also identified by checking the citations of all relevant papers collected (snowballing). However, time constraints dictated that full texts could only be obtained if they are easily accessible. For example we were not able to obtain theses or other publications through the British Library Document Supply service.

Consultation

Literature searching was supplemented by contacts with representatives of national organisations of and for people with learning disabilities and key researchers in the field including Prof. Mike Kerr in Wales. A meeting was arranged with three people with learning disabilities to discuss ‘Being Healthy’, unfortunately only one man was able to attend the discussion and time prevented us from rearranging discussions with the other volunteers. A seminar was also held with a group of practitioners, including nurses,

speech and language therapists, teachers and carers, as well as a parent, all of whom had personal or professional contact with people with severe or profound learning disabilities. These consultations provided confirmation of the relevance of terms used for literature searching and/or a source for unpublished reports relevant to the review.

Mail shot
A mail shot to researchers and professionals (described below) was undertaken in an attempt to obtain literature unlikely to be included in electronic databases.

Inclusion/exclusion criteria
A process of 'funnelling' (Hawker et al, 2002) was used to identify the core set of relevant publications to include in the review. That is, relevance was confirmed on receipt of the full text of publications. Relevant literature was given a preliminary quality screen to establish that it met standards for inclusion. Papers meeting standards were then fully evaluated.

Evaluation
A tool to evaluate quality was devised by two of the authors based on the work of methodological researchers such as Noblit & Hare (1988) and the Health Care Practice Research and Development Unit, University of Salford (2001) (Alborz & McNally 2004). This tool was used to organise identified literature. There is some agreement amongst researchers about the most important indicators of methodological and epistemological quality, many of which may be applied to both quantitative and qualitative research. As the literature around interventions to improve the physical health of people with learning disabilities was diverse in its methodology, though largely 'quantitative', this evaluation tool allowed the authors to employ specific criteria depending on whether the study had a quantitative, qualitative or mixed method focus, and then synthesise research findings.

Literature identification

Conventional Sources of Literature - Databases of Published Research

We conducted searches of the major bibliographic databases across all potentially relevant subject areas, including medicine, health services management, social science and education, as shown in Table 1 below. (A sample search is included as Appendix 1)

Table 1: Databases searched

Medicine/Health Medline (Index Medicus) Embase (Embase) Cochrane Library CINAHL (Cumulative Index to Nursing & Allied Health)	*Health Service Management* HMIC (Health Management Information Consortium) Health Development Agency
Social Science Social Science Citation Index ASSIA (Applied Social Science Index) IBSS (International Bibliography of the Social Sciences) CareData AgeInfo Sociological Abstracts PsychInfo	*Education* BEI (British Education Index) ERIC (Educational Resources Index)

We identified appropriate keywords and concepts and where possible used a combination of both free-text and thesaurus terms to ensure maximum sensitivity in retrieval. We identified a great deal of 'grey' literature during literature searching for the review largely through insensitivity in electronic databases that allowed searching only on the basis of very broad terms, for example 'learning disabilities'. Some of the material had already been identified in the earlier 'access' review. The ZETOC current awareness alerting service was used to identify recent literature published in key journals.

Research in Progress
We had already identified research in progress (up to 2003) by searching the relevant UK databases:
NRR (National Research Register)
CRIB (Current Research in Britain)
REGARD (Register of Economic & Social Research Council)
CORDIS (European Union)
REFER (DOH Electronic Register of Research Findings)

This was updated to look for projects funded between 2003 and 2005.

Additional sources of literature and evidence - Contacts

A number of contacts were invited to contribute to the literature by identifying and suggesting relevant literature. The contacts were found in 2 databases that had already been created for a recent literature review (Alborz et al., 2003). Both databases included a total of 321 contacts (excluding 41 duplicates in the first database & 5 duplicates between the 1st & 2nd database). Some of these contact details were not complete (addresses or e-mails were missing). To this were added contacts found from additional searching of the research registers. The databases included contacts identified as having conducted research in the health improvement field from grant-giving bodies, academics and researchers in the field of learning disabilities, medicine, or both, and professional bodies such as Speech & Language therapy LD Service. Relevant bodies and professional organisations included Mencap, the Nuffield centre and Norah Fry Research Centre. Further details of these organisations and individuals are shown in Appendix 2.

E-mails and letters were sent to contacts with a request to provide a copy of any publication of their research if it addressed issues in relation to the effectiveness of interventions to improve the physical health of people with learning disabilities (see Appendix 3 for a copy of the letter). They were also invited to suggest any literature known to them addressing the aforementioned issues.

A total of 135 e-mails were sent out to contacts for whom an e-mail address was available. A further of 172 letters were posted to people for whom an e-mail address was unavailable but a postal address was included in the database. Both a letter and an e-mail were sent out to 6 individuals. Table 2 presents the outcome of the attempts to identify further literature through the contacts.

Table 2: Material received from contacts made using a database of contacts

	e-mails	Letters	Overall Total
Sent out	135	172	307
Returned as non-deliveries / wrong address	109	14	123
Delivered	24	-	-
Responded	15	77	92
Notified that their research is	7	45	52

irrelevant			
Sent material or provided references	8	15	23

Of the 135 e-mails sent, 109 were returned as non-deliveries (delivery mail notification, error, delayed message and other similar automated e-mail receipts). A limitation of the databases and the use of e-mail as a preferred method of contact is that as the database had been created 3-4 years ago and many of the contacts had moved on to other posts, or had changed postal or e-mail addresses. For 24 of the e-mails, a confirmation of delivery was received. Fifteen individuals responded to the request. Seven reported that their research did not address any of the research issues under investigation and did not provided any further contacts or references. Two reported that their study was still in progress (1 was thesis and 1 stated that material on the research would follow). Eight people responded with suggestions, sent material in the post, copied the e-mail to another contact, or copied references/citations. One contact also provided their website address for searching further articles while another sent a CD-ROM with databases with further studies.

A total of 172 letters were posted. Fourteen were returned with 'wrong address' (either went to the wrong address or the addressee was not working at that address anymore). Forty-five returned the reply slip with no-related research messages and did not suggest any other sources (contacts, references, links). Of the 15 who provided references/sent material, 11 contacts sent a total of 14 papers/reports, 1 posted a CD database, 2 suggested further links or pointed to where possibly related research is available, 1 reported that the research although relevant was still ongoing.

Of the remaining postal contacts, 1 did not send material but offered to post his only copy of thesis, 2 reported that papers/reports were at the time in press, 1 replied that their study had not finished as yet and 2 contacts suggested other contacts or sources of information. We considered such material as was available at the time (November 2005) for inclusion in the review. (See Appendix 4 for a summary of research and professional contacts.)

Assessment of literature for inclusion in study

One of the team members scanned titles and abstracts generated by electronic database searches and excluded any articles obviously inappropriate to the subject area. Remaining titles were examined by two of the authors and classified as either 'not relevant'; 'possibly relevant'; and 'probably relevant – obtain paper'. As a large number of titles and abstracts were generated, inter-rater agreement was established for the first 300 titles. Having established a high rate of agreement the researchers examined sections of remaining titles separately but met to discuss those that were unclear. Early inclusion criteria were elaborated on over the period of inter rater assessment of titles for inclusion. The enhanced criteria used to guide selection are described in Appendix 5.

Evaluation of 'quality'

As noted above the identified research literature used a range of methodologies and so different quality criteria were employed depending on whether a study was quantitatively or qualitatively focused. As the review topic has a service development focus much of the published literature was not 'rigorous' in scientific terms, however, we have retained 'poor' studies if they remained the only example of their type. Throughout the review, their limitations are made clear.

The assessment of quantitative studies took into account the appropriateness of the research design, data sources and research instruments used and data collection procedures. Initial assessments considered whether confounding may offer an alternative explanation to the findings and whether the study builds on an existing body of research or generates new knowledge. Studies were rated as follows:

1. Little confounding or confounding controlled or large sample used. Data collected contemporaneously. Knowledge indicator met.
2. Main confounders partially controlled or shown to be low level. Wide evidence base and knowledge indicator met.
3. Confounders not controlled or measured, or measured and found moderate. Involves specific service or opinion only but knowledge indicator met.
4. Main confounders operating or likely to be involved. A single service and very small sample or knowledge indicator not met.

Qualitative research were assessed using standards developed by qualitative researchers including Popay, Rogers & Williams (1996) (see Alborz & McNally, 2004). These standards include whether emergent findings connect with existing bodies of theoretical knowledge or generate new understanding; validity; and adequacy. The latter two criteria will be judged according to:

1. *Data Quality* – relevance; clarity of description of data collection processes.
2. *Theoretical adequacy* – clarity of description; logic of analysis; imagination in interpretation; coherence; fairness; honesty; generalisability and transferability of findings.
3. *Policy relevance* – addressing issues of concern to practitioners and policy makers; empowering service users.

In applying these markers the primary focus will be the extent to which studies add to existing, or generate new, knowledge. In addition the studies given most weight will be those meeting the requirements for interpretive validity. Studies will be rated as follows:

1. All or most quality indicators met.
2. Main quality indicators met including knowledge indicators
3. Some lack of detail but meets knowledge indicators.
4. Lack of detail including knowledge indicators.

Snowballing

References in all obtained papers (identified through searching the electronic databases) were checked in order to identify other possibly relevant citations. Inevitably, this method resulted in identifying more references although often some of possibly relevant citations had already been identified in the electronic databases searched. An effort was made to quickly locate and obtain a copy of the newly identified paper but if this was not immediately accessible (through the electronic journal collection from the John Rylands University of Manchester Library) it was not chased further.

Papers identified

The following databases were searched between 24th August and 2nd September 2005. The number of records identified from each search are shown in Table 3, as follows:

Table 3: Number of records identified from electronic database searching

Medline	2874
Embase	3033
Cinahl	1067
Social Science Citation Index`	617
BEI	93
ERIC	163
HMIC	431
Social Care Online	693
Total before de-duplication and incorporating relevant references from Social Care Online	8269
Total following de-duplication and incorporating relevant references from Social Care Online	6087

2323 duplicates were removed.

Application of inclusion criteria, availability of publications, and inclusion on review of relevance based on the full text substantially reduced these numbers as shown in Table 4 below.

Table 4: Numbers of publications selected and retrieved for review

Titles and Abstracts from searching	6087
Reference remaining on application of initial inclusion/exclusion criteria	774
Available publications retrieved within time limit	250
References meeting inclusion criteria on consideration of full text	41

Electronic searching generated large numbers of publications relating to genetic indicators/interventions, for example to predict birth of a child with learning disabilities or prevent the birth of children with foetal alcohol syndrome. Other topics generated in substantial numbers were assessment of need among subgroups of people with learning disabilities.

Time pressures dictated that the team retrieve and evaluate publications that were easily accessible. These were largely more recent papers in e-

journals and references identified and collected in an earlier 'access to healthcare' literature review (Alborz et al 2003).

Selected publications

In selecting papers for review the authors retained a broad definition of 'interventions' that could be described as delivered through 'primary' care. The extent of any current or potential links between some non-general practice based practitioners and general practice is a matter for debate. The searching also revealed few publications examining the efficacy of interventions to improve physical health. A number of papers provided some outcome data, however none displayed the characteristics of large clinical trials common in the drug treatment literature. As a consequence the authors selected any publication describing an intervention designed to improve the health of people with learning disabilities for review. Where an intervention was covered in several publications, only those including some outcome data were selected. However in an attempt to describe the range of interventions being implemented to improve the health of this population a number of reports with no evaluative data were retained. These were included amongst those publications rated as methodologically 'poor'. The characteristics of selected papers are described in Table 5

Table 5: Summary of publications included (N=41)

Characteristic		Number included
Country of Study	UK	31
	Australia	2
	New Zealand	1
	Canada	1
	USA	6
Study design	Quantitative	28
	Qualitative	4
	Mixed	1
	Report	8
Age group	Children/Adolescent	4
	Adult/Older adult	27
	All	5
	Not recorded	5
Disability range	**M**ild/Moderate	6
	Moderate/Severe	1
	Moderate/Severe/Profound	1
	Severe/Profound	3
	All	10
	Not recorded	20

The final matrix of papers included was as follows:

Table 6: Distribution and quality of publications reviewed across pathways to health

Area	Highly Rigorous	Rigorous	Less Rigorous	Poor	Total*
Interventions with people with learning disabilities					
Health checks	2	2	4	1	9
Health education	-	2	2	3	7
Weight and fitness	-	2	1	2	5
Women's health	-	-	2	3	5
Other health interventions	-	-	1	1	2
Accessible information	-	-	-	1	1
Self-advocacy / Communication	-	3	2	1	6
Interventions enhancing parents and carers roles					
Identifying health need	-	-	2	1	3
Health checks	1	-	-	-	1
Women's health	-	1	-	-	1
Health education	-	1	1	2	4
Interventions enhancing practitioners' roles					
Nurses	-	1	-	-	1
General Practitioners	-	3	3	-	6
Teachers	-	1	-	-	1

Synthesis of identified publications has been organised using the above emergent headings and subheadings. This data is then followed by a summary of the intervention formats implemented.

3. Results

Overall 41 papers were identified as described in Table 6 above. In this section of the report tables showing reference details of the publications relating to interventions with people with learning disabilities; interventions enhancing parents' and carers' roles; and interventions enhancing Practitioners' roles, are presented. These are followed by detailed presentations of the context and findings of each study/publication in table format organised under the subheadings used in Table 6. The research in each subsection is then summarised. For clarity of interpretation the rigour of the studies referred to in the text is indicated by the use of different fonts. The identification number (ID) of highly rigorous papers is presented in '**bold'** font, rigorous studies in 'plain' font, less rigorous studies in '*italicised'* font, and poor studies in '*italicised and underlined'* font. The publications review used a variety of terms to describe the population under consideration. For the sake of consistency the description 'people with learning disabilities' is used throughout.

Interventions with people with learning disabilities

Literature was sought that covered interventions aiming to improve the physical health of people with learning disabilities through health education and promotion/surveillance, treatment, accessible information or self-advocacy.

Thirty one papers were identified that addressed these issues. However five papers related to two studies, as indicated in Table 7 below, each of which described a different intervention model. Eleven papers were poor in terms of academic rigour or were reports that did not evaluate the intervention in question.

Table 7: Publications describing interventions with people with learning disabilities

Final Rating	ID	Paper details	Study design	Age group	Disability range
1	**6995***	Aronow, H. U. and Hahn, J. E. Stay well and healthy! Pilot study findings from an inhome preventive healthcare programme for persons ageing with intellectual and/or developmental disabilities. Journal of Applied Research in Intellectual Disabilities 18(2), 163-173. 2005.	Quantitative	Adult	Mild/ Mod

Final Rating	ID	Paper details	Study design	Age group	Disability range
1	**7196***	Hahn, J. E. and Aronow, H. U. A pilot of a gerontological advanced practice nurse preventive intervention 23. Journal of Applied Research in Intellectual Disabilities 18(2), 131-142. 2005.	Quantitative	Adult	All
2	462	Ewing, G., McDermott, S., Thomas-Koger, M., Whitner, W., and Pierce, K. Evaluation of a cardiovascular health program for participants with mental retardation and normal learners. Health Education & Behavior 31(1), 77-87. 2004.	Quantitative	Adult	Mild/ Mod
2	2174	Newens, A. J. and McEwan, R. AIDS/HIV awareness training for young people with severe learning difficulties: an evaluation of two school programmes. Journal of Advanced Nursing 22(2), 267-275. 1995	Qualitative	Adolescent (11 to 19)	Severe
2	4597+	Martin, G. Annual health reviews for patients with severe learning disabilities. Journal of Learning Disabilities 7(1), 9-21. 2003.	Quantitative	Adult	Mod/ Severe
2	7287	Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F. M., and Purdie, D. M. ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. Health Promotion International 19(2), 167-175. 2004.	Qualitative	Adult	NR
2	7458	Ruddick, L. and Oliver, C. The development of a health status measure for self-report by people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 18(2), 143-150. 2005.	Quantitative	Adult	Moderate

Final Rating	ID	Paper details	Study design	Age group	Disability range
2	8002+	Martin, G. Evaluation of a nurse led annual review of patients with severe intellectual disabilities, needs identified and needs met, in a large group practice. Journal of Learning Disabilities; 8(3), 235-246. 2004.	Quantitative	NR	NR
2	8270	Chapman, Melanie J., Craven, Michael J, and Chadwick, Darren D. Fighting fit? An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. Journal of Intellectual Disabilities 9(2), 131-144. 2005.	Quantitative	Adult	NR
2	8420	Alborz, A. Swallow, A. and Hanson, D. *The role of health check programmes in improving access to mainstream NHS healthcare services for people with learning disabilities*. National Primary Care R&D Centre, University of Manchester (November 2005) www.npcrdc.man.ac.uk	Mixed	Adult	All
3	*567*	Moore, G., McConkey, R., and Duffy, M. The role of the school nurse in special schools for pupils with severe learning difficulties. International Journal of Nursing Studies 40(7), 771-779. 2003	Quantitative	Chldrn (up to 19)	Severe/ Profound
3	*697*	Marshall, D., McConkey, R., and Moore, G. Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. Journal of Advanced Nursing 41(2), 147-153. 2003	Quantitative	Adult	NR
3	*1352*	Barr, O., Gilgunn, J., Kane, T., and Moore, G. Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland. Journal of Advanced Nursing 29(6), 1482-1491. 1999.	Quantitative	Adult	Mild/ Mod

Final Rating	ID	Paper details	Study design	Age group	Disability range
3	*1427*	Shaughnessy, P. Better cervical screening for women with learning disabilities. Nursing Times 95(44), 44-45. 3-11-1999	Quantitative	Adult	Mod/ Severe/ Profound
3	*1429*	Bollard, M. Improving primary health care for people with learning disabilities. British Journal of Nursing 8(18), 1216-1221. 14-10-1999. (GENERIC)	Mixed	Adult	NR
3	*1454*	Webb, O. J. and Rogers, L. Health screening for people with intellectual disability: the New Zealand experience. Journal of Intellectual Disability Research 43(Pt 6), 497-503. 1999.	Quantitative	NR	All
3	*4976*	Peine, H. A., Darvish, R., Blakelock, H., Osborne, J. G., and Jenson, W. R. Non-aversive reduction of cigarette smoking in two adult men in a residential setting. Journal of Behavior Therapy & Experimental Psychiatry 29(1), 55-65. 1998.	Quantitative	Adult	NR
3	*6206*	Dodd, K. and Brunker, J. 'Feeling poorly': report of a pilot study aimed to increase the ability of people with learning disabilities to understand and communicate about physical illness. British Journal of Learning Disabilities 1999 Spring; 27(1), 10-15. 1999.	Quantitative	Adult	NR
3	*7312*	Lunsky, Y., Straiko, A., and Armstrong, S. Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 16(4), 247-253. 2003.	Quantitative	Adult	Mild/Mod
3	*7717*[+]	Cassidy, G., Martin, D.M., Martin, G. and Roy, A. Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary health care teams. Journal of Learning Disabilities; 6(2), 123-136. 2002.	Quantitative	All	All

Final Rating	ID	Paper details	Study design	Age group	Disability range
3	*8089*	Paxton, D. and Taylor, S. Access to primary health care for adults with a learning disability. Health Bulletin, 56(3), 686-693. 1998	Quantitative	Adult	All
4	*358*	Parry, C. and Jones, S. I can keep safe. Interview by Carol Davis. Nursing Standard 18(50), 20-21. 25-8-2004.	Report	Children (up to 19)	All
4	*1481*	Allan, E. Learning disability: promoting health equality in the community. Nursing Standard 13(44), 32-37. 21-7-1999	Quantitative	Adult	NR
4	*1853*	McRae, D. Health care for women with learning disabilities. Nursing Times 93(15), 58-59. 9-4-1997.	Report	Adult	NR
4	*3805*	Evers, S., Munoz, M. A., Vanderkooy, P., Jackson, S., and Lawton, M. S. Nutritional rehabilitation of developmentally disabled residents in a long-term-care facility. Journal of the American Dietetic Association 91(4), 471-473. 1991.	Quantitative	All	Severe/ Profound
4	*5270*	Schreiber, J., Marchetti, G., and Crytzer, T. The implementation of a fitness program for children with disabilities: A clinical case report. Pediatric Physical Therapy 16(3), 173-179. 2004	Quantitative	Children (up to 19)	NR
4	*5916*	We know best. Learning Disability Practice 2005 Apr; 8(3), 22-23. 2005	Report	NR	NR
4	*6071*	Brewster, J. Women's health in Doncaster. Learning Disability Practice 2005 Feb; 8(1), 29-30. 2005.	Report	Adult	NR
4	*6170*	Cowie, M. and Fletcher, J. Learning disabilities. Breast awareness project for women with a learning disability. British Journal of Nursing 1998 Jul 9-22; 7(13), 774-778. 1998.	Report	Adult	NR

Final Rating	ID	Paper details	Study design	Age group	Disability range
4	*6777*	Scott, E., Elvish, J., Luft, L., and Wilson, M. The development and use of a personal health resource. Learning Disability Practice 2005 Mar; 8(2), 27-31. 2005.	Quantitative	Adult	NR
4	*8201*	Taylor, G., Pearson, J., and Cook, H. Family planning for women with learning disabilities. Nursing Times 94(40), 60-61. 1998	Report	Adult	NR

* Two pilot arms of same U.S. study into different models of providing health checks for people with learning disabilities.
+ Papers all address provision of health checks at same general practice but use different methods of delivery over time.

Papers reviewed relating to interventions with people with learning disabilities fell broadly into the following topics; Health checks designed to identify and address unmet health needs; Health education; Weight and or fitness; Women's health; Other health interventions; Accessible information and Self-advocacy/communication. Each of these areas is described and summarised below.

Health checks

Ten papers reported on health check programmes. As noted above two of these reported on different aspects of the same study undertaken in the USA that piloted two models for implementing health education and checking, and three other papers covered different methods of health check delivery at the same general practice in the UK. Relevant findings from selected studies are noted in Table 8 below.

Table 8: Health outcomes for people with learning disabilities as a result of having health checks

ID	Population	Model	Outcomes
7196 Aronow & Hahn (2005)	70 pld aged 20-65 years (mean 41.3 median 41.5) 51% female. 76% White	Advanced Practice Nurse visits (2-5) over I year. Initial screen using a Comprehensive Geriatric Assessment protocol that evaluates physical, mental,	• Measured health risk changes from baseline (before 1st visit to retest after final visit 1 year later) Health risks reduced

ID	Population	Model	Outcomes
	14% Latino 10% other ethnic. 5% required assistance with all personal care and other activities such as using the telephone, cleaning or cooking. 18% were completely independent in all these activities	social, economic, functional and environmental needs and strengths. From this assessment the APN drew up a list of recommendations - including preventative healthcare, health promotion and referrals to other health professionals. The APN provided health education personally.	from mean 4.7 to 3.5 (t=3.31 p=0.002).
6995 Hahn & Aronow (2005)	201 adults Ethnicity: 65% white, 19% Latino, 8% african amer. 5% asian pacific, 3% other. Also, 59% employed day programme. 162 pld incuded in health improvement analysis.	Health risk appraisal completed by trained non-health assistant. Assessment coded and profile strengths & weaknesses created. This was paired with advice or congratulatory statement and mailout of appropriate health educational materials (accessible).	• Cautiously report retest following intervention indicated 'change in the direction of improvement'. That is a reduction in health risks and use of acute health services and an increase in health strengths. (Health risks- paired t=4.41, p<0.001; Health strengths - paired t=-3.68 p<0.001)
4597 Martin (2003)	71 adults invited, over 5 years of the programme. 16 people attended all 5 checks.	Afternoon sessions were set up with 20 minute appointments. A modified structured interview template was followed. The CLDT Nurse measured blood pressure, weight, urine checks, lifestyle and smoking/diet	• Initial referral rates to psychiatrists, CLDT and other colleagues tailed off after 2 years • there was a continuing need for primary care interventions particularly in relation

ID	Population	Model	Outcomes
		advice was given. Vaccination and screening/self-examination status were checked. The GP then covered sensory, digestive, skin, continence and locomotor problems following a structured checklist. A Health Action Plan was drawn up. Attendance and non-attendance over 5 years was ascertained from patient records. The "Action" column in the pro-forma was used to ascertain interventions	to sight and weight.
8002 Martin (2004)	53 people with LD (out of 58 invited, =91% response rate. (the sample is not described further)	Prior to check patients completed an agenda sheet. During the check, nurse discussed issues with patient & carer and completed a structured questionnaire, patient & carer were then seen by doctor & nurse & the implementation sheet was completed. The measure (evidence of effectiveness of intervention) is the calculation of needs met as a proportion of needs identified.	• Of 58 patients invited, 53 attended (attendance=91%) in 9 sessions. 5 patients had their checks outside booked sessions (eg home). • Total number of patients concerns & clinicians interventions where >= 1 action / interventions identified = 46 (87%). • Overall needs met = 81%. • Interventions were (in order of frequency): blood tests (thyroid & anaemia checks), earwax syringing, treatment (changes), screening (breast, cervical, testicular),

ID	Population	Model	Outcomes
			referral on eating/diet, orthopaedic surgeons & urine checks for bacteriology.
8420 Alborz (November 2005)	34 people with ld receiving health check every 2 years. Subgroup 18 people with ld (14 men, 4 women) received 3+ health checks so adequate time elapsed to examine impact of 2nd check - time lapse between 1st and 2nd 14-40 months (mean 25.28, SD 5.13)	Health checks on 34 items carried out approx every 2 years by practice nurse and ld nurse jointly.	• 4 (22%) no recorded health need at 2nd check (all had needs identified at first). • 15 people had one or more health need at 1st check that no longer caused concern at 2nd . • Continuing health needs evident in relation to weight, blood pressure, diet and exercise. • One or more emerging health needs for 10 people recorded
1352 Barr et al (1999)	373 people 20yrs+. 59% men, 20% with Down's syndrome.	Tests/examinations to establish cardiovascular status (weight, blood pressure, urinalysis); sexual health (breasts, testes); sensory deficits (eyes, ears, skin, hair/scalp); mobility (feet) and dental health. Staffing and setting unclear.	• Follow up survey indicated that 87% attendees followed up concerns raised during the review and some commented on subsequent improvements for the person with learning disability - no substantiation as part of research
1429 Bollard (1999)	65 health checks completed with 39 men 26 women (59% uptake) majority	30 minute, 34 item health check conducted in general practice. Care and reminder cards with referral info placed in clients notes held in practices.	• Reports some health improvement - reduction in severity of seizure; mood stabilised; slight improvement in hearing (less

ID	Population	Model	Outcomes
	accompanied by carer or key worker.		discomfort); less tired/more alert; 4kg weight loss over 3 months (2 - BMIs 39 and 41); reduction in urinary tract infections; improvement in mobility (weight bearing).
1454 Webb & Rogers (1999)	Pld resident in IHC facilities. 98% screened (1311) - Age, gender, severity of learning disability breakdown not given.	A summary protocol for introduction of check; outline for a social and developmental history/ form to record annual medication summary; syndrome specific checklist; Cardiff Checklist form (Martin Roy & Wells 1997); health goals record form	• 72.61% of those screened required health actions. • Most were health promotional activities and some reviews of existing treatments. • A 'noteworthy' number involved life-saving actions including fitting a pacemaker, surgery for melanoma and mastectomy for breast cancer
7717 Cassidy et al (2002)	69 adults identified and invited to attend, 35 attended on two occasions - 22 male, 13 female,	Health check protocol LD nurse checked height weight BP, fam history, alcohol and tobacco use, diet and phys exercise. GP checked sensory syst, musculoskeletal syst, skin and teeth and consulted re continence genitouringary funct and sexual health. Included examination by psychiatrist. Review of prescribed med - referrals req discussed and planned. Early stage of development of annual review programme at a	• Excluding behaviour probs and mood, 136 conditions found at 1st check of these 14% improved and 16% deteriorated by second check. • Improvement outweighed deterioration for sleep problems, mobility, bladder and a bowel continence. • Deterioration outweighed success for sight hearing skin problems and posture. • 86 health problems

ID	Population	Model	Outcomes
		large practice (see also 4597 6543 and 8002).	were continuing or newly detected at the second health check. • For those with weight problems average weight of 64.41kg at 1st check (22.6-112kg) reduced to average 62.71kg at 2nd (26.7-96.5). • Contacts with primary health care staff changed little (over 18 month period) and were higher than matched controls. • Authors note deterioration rooted in inadequate personal care or side effect of medication.
8089 Paxton & Taylor (1998)	People with ld over age 16 registered at 3 GP practices. 75 identified - 3 declined 1 in hospital not included - 71 remaining 32 women, 39 men , 13 living with family. 3 moved before feedback stage	Health screening assessment forms developed - completed using GP and/or hospital records for background info, and client interviews. Each pld screened and interviewed. Screening conducted at ATC or client's home. GP individuals and carers contacted after screening complete to get feedback (means not described)	• 60 health needs identified and referred to GP. • Mean contacts (incl telephone) in 12 mths 4.79. • None invited to attend GP epilepsy clinic made an appointment to do so • Many needs related to vision or hearing - low number followed up sight checks.

The most rigorous of the above studies **6995 7196** were concerned with piloting health check interventions rather than health outcome for the people screened. Nevertheless they produced outcome data suggesting improvements in 'health strengths' (indicators of resistance to ill health, for example taking regular exercise) and decreases in 'health risks' (indicators

of poor health, for example BMI ≥ 30, pain rated moderate or worse). Having established the feasibility of the tools and research methodology the authors intend to conduct full trials. A consistent finding across health check studies is the identification of high proportions of unmet needs. Much of this need appear to relate to preventative healthcare and health promotion [8002 8420 *1454*]. Several studies also indicated that unmet needs decreased over subsequent checks [4597 8002 8420], however there was also evidence that these successes may be masked by deterioration or continuing problems in other health areas [*7717*]. Several studies suggested that health checks need to be conducted in on a regular basis to effectively identify and address health need within the group [**7196,** 4597/7717 8420].

Many studies reported on the type and frequency of health needs addressed, however few report outcome data on health improvement. Given that the clinics occur annually or less frequently generation of such data may take a significant period of time. Health checks in themselves do not appear to directly impact on particular health problems but act to help both people with learning disabilities and their carers overcome problems with identifying and communicating health need, and provide a gateway to healthcare interventions that tackle health problems directly. As such they appear to perform a key role in addressing inequity in health care provision for this population by circumventing barriers to health improvement imposed by cognitive and communication deficits.

Health Education

Seven papers described health education initiatives that involved some form of training, including classes, small group sessions and workshops. Three 'packages' also included health files or diaries. The studies included two rigorous, two less rigorous and three 'poor' studies (two of these were reports with no evaluation but discussed interventions not covered in more rigorous studies). The third intervention was in development and so presented little data on outcomes. One rigorous study was also in a development phase but enough detail was presented to evaluate methodological rigour. We have not been able to identify any further publications on these tools to date.

Table 9: Health education studies involving people with learning disabilities

ID	Population	Model	Outcomes
2174 Newens& McEwan (1995)	2 special schools Group A: 6 M (16-18yrs), mix ability, Male nurse and male teacher leaders venue - nearby community health resource Group B: 9 (7M & 2F) (16-18yrs), female class teacher and female assistant leaders, venue - normal classrooms	observation (10 sessions, 5 per school, approx. 1-1½ hrs 1-2 tape recorded) Materials: Group A: life horizons. Slides demonstrating condom application and mechanics of sexual intercourse. Prosthetic penis for practice using condom. Discussion of the purpose of using condoms - avoid pregnancy and acquiring infections Group B: line drawings. Included discussion of rights - to say no - in range of circumstances. Use of incidents in students' lives as basis for discussion. Both introduced subject of HIV/AIDS in wider context of sex education	• issues about HIV/AIDs appeared well be understood by students with LD, • explicit nature of some material used aided discussion - no need for separation of the social aspects of personal & sexual relationships • some people dominate discussions -> caution on the use of specific techniques of focus group & answering questions of teacher. • Technique B felt more successful as less mechanistic. • Material in both groups acceptable & appropriate for students • No discussion of increased risk of HIV infection for homosexual males - controversial some parents concerned should not be discussed • Linking mechanisms of intercourse with risk of infections possibly create greater perceived risk than in reality.

ID	Population	Model	Outcomes
7287 Lennox et al (2004)	The study had several phases, and in total there were 22 people with LD. In piloting phase of the package was piloted with 2 groups: group 1 comprised 19 parents of adults with ID who use a non-government support service; group 2 comprised 7 people with ID (self-advocates) who use a non-government accommodation service.	Education session -. One-off session 50 mins long. Advocacy principles and applications, how to be assertive etc. Produced session plan part 1 for trainer (background, purpose, expected outcomes etc), 2 guidelines for delivering session, 3 worksheets and session evaluation sheet. Diary reinforced knowledge, attitudes and skills delivered in session. Diary-5 sections. Ring binder format with dividers 1 'All about me' 2 'Health advocacy tips'. 3 'For the doctor' - ideas how to work with people with ld, checklists of health probs assoc with syndromes etc. 4 'Medical records' - diagnoses, operations, medications, immunizations, allergies etc. 5 how diary developed and copies of record sheets to cover 5 year period.	The primary focus of the paper was to describe the development of the package, however • preliminary findings 2/3 advocates interviewed felt help them to be better advocates and • 50% reported relp with GP improved as a result of the training session. • Reported use of diaries to gain, maintain and ensure continuity of information betw patient and GP.

ID	Population	Model	Outcomes
567 Moore et al (2003)	4 schools. Two schools appointed full-time school nurses. Two further schools did not have access to school nurse on site but could access community nurses Pupils were aged from 3 to 19 years.	Record kept for full school yr of diff activities undertaken by school nurses (recorded on computer database). Telephone interviews with selected parents. Self-completion questionnaires for school staff and other health and social service profs in contact with project schools. No details on content of questionnaires. Epilepsy most common condition though sig less prev in one contrast school. 1/6 required medications to be admin in school. Dressing required in two schools - clinical tests, urine, weight, seizures, needed in all 4 schools. Number of chdn with PEG or NG feeding small and varied across schools as did number with catheters and tracheostomies.	• Variety of health promotion classes devised and presented by nurses in project schools though more in school B as nurse had more time. • Health promo included 3-6 sessions for 6 female students on 'becoming a teenage' and dealt with personal development, menstruation and hygiene. • Workbooks created were kept at home to involve families in reinforcing learning. • 10 weekly sessions held for 3 16-17 year olds on weight reduction, exercise and diet - used fitness suite at local leisure centre. • 'Well Teddy' clinics held for pupils 4-8 years old to improve compliance during school medicals and on visits to GPs and dentists - based around play with dolls and teddies. • Health promo included in curric for nearly all classes. • In contrast schs health promo covered by class teacher as

ID	Population	Model	Outcomes
			part of curric - primary focus hygiene and personal care.
6206 Dodd & Brunker (1999)	10 pld from three local residential homes. 5 men, 5 women aged 31-46 years all with verbal skills but variable degrees of comprehension and language use. 3 GPs providing primary health care to these individuals also participated	Training session (and communication aids) produced by authors - 'My body' file. Semi structured interview for users carers and GPs focussing on consultation and for pld bodily and illness awareness and knowledge of GP equipment. Pld also chose communication pics with meaning for them. Follow up evaluation cards also produced for use in natural setting after training.	• Reported improvements in knowledge of what to do when feeling ill, why and how to visit GP. • Majority retained this info at 6 month follow up. • Report marked increase in ability to recognise and relate to communication aid pictures and cards on severity and duration of symptom effective - again some reduction on follow up. • Use of aid in practice could not be established as participants taking part in this part of the study had no cause to visit GP in the six month gap.
358 Parry & Jones (2004)	The courses include groups of six children aged eight to 18 who have been referred because of concerns over their lack of personal safety skills.	The Keep Safe sessions start with issues of safety in the home, where the children compare irons, kettles and medicine bottles, for example, with cotton wool and cuddly toys. All concepts are represented visually because not all the children have functional literacy	• Use of interactive groups and peer teaching to help children learn about hazards. No evaluation available.

ID	Population	Model	Outcomes
		skills. Then move on to explore safety out of the home, … […] act out scenarios in role plays which are videoed, […] pictures cut from magazines to help the children make judgements etc…. They meet for two-hour sessions over four days, or for up to a fortnight, depending on individual learning needs.	
5916 no author (2005)	6 people supported and trained to deliver key messages such as healthy eating and healthy hearts, male and female cancers, smoking, sexual health and contraception.	Televsion game shows, chat shows and quizzes used as medium that is familiar to almost everyone. Created own games, icebreakers, role plays and dance and music sequences.	• Delivered > 150 workshops in day services, resid homes, colleges and adult ed centres. • Only paper reviewed where people with ld act as sole trainers (with support).
6777 Scott et al (2005)	Books distributed to 26 adults with ld (male and female - no figures given) 17 returned (65%). Reasons for non-completion from 5 - ill health, hosp	Health book in simple format - user friendly language. Provides baseline for health screening and essential info about person. Completion by person and carer together and used for health promotion.	Reported difficulty in getting feedback. List comments only. • Book used in variety of ways - resource for professionals, self-regulatory for self (using charts included). • Some problems with misunderstanding among resid staff as

ID	Population	Model	Outcomes
	admission, family difficulties (2), no time (paid carers).	Completed book contained - personal details; levels of abilities; general health status; space for comments from health profs and appointment sheets. Updated in partnership with indiv. To facilitate PCP as part of HAP. Encouraged to take to GP or other appointments to provide clinicians also more thorough knowledge of personal healthcare history. Session for carers about book and how to use found attendees could then pass info back to other carers - facilitating dissemination. After trial period questionnaire distributed to all staff participating (?parents).	to how much of book needed to be completed. • Felt empowered client. • Issues of confidentiality were raised due to worries about losing the book if it is taken to appointments. • In response to feedback reduced writing and increase use of pictures and symbols. • Included appointment pages. • Client comments suggested that it was most useful to remind them of an appointment or of important facts during GP consultations. • Reported that majority took ownership of the book and took it to appointments.

Three studies involved children and covered HIV/AIDs awareness training [2174], staying safe (preventing accidents) [358] and more general health promotion messages and preparation for health consultations [567]. These studies did not evaluate the extent to which participants' behaviour changed as a result of the intervention. They all described initiatives focusing on issues important to the physical health of the children involved, that are not normally available via the normal school curriculum.

Two studies included health 'diaries', one of which incorporated a brief training session. The latter study [7287] suggested that use of the package improved GP consultations, however this was a pilot phase for the model that is now subject to a formal RCT and presented little further information. The second study [6777] though poor in terms of methodological detail provided information on problems that may surface where such diaries/files are used by a number of carers who come into contact with an individual. Comments from carers suggested that diaries were time consuming to complete. The authors concluded this was due to misunderstanding about the extent to which the entire diary needed completion and/or that the person with learning disabilities should actively take part. These difficulties may have surfaced in the latter study but not in the first because they may have been covered in the brief training component of the intervention, which occurred before people with learning disabilities/carers were given the diaries [7287]. Comments from people with learning disabilities suggested that the diary was useful in helping them to remember important information and appointments [6777].

A further study [6206] involved a training session on bodily knowledge and use of general practice, and provided a communication aid for use in discussing ill health with carers or general practitioners. This was again a pilot of the methods but nevertheless produced some evidence that knowledge was improved in the short and longer term, though most effective were an individual had an episode of ill health and used their knowledge and communication aid.

The final study included was unique in being an educational programme addressing a wide range of topics delivered by people with learning disabilities themselves, with support [5916]. The high number of workshops they had delivered testified to the popularity of this type of event but, as with the programmes related to child health promotion mentioned above, the impact of this event was not evaluated.

Weight and Fitness

Weight and fitness is a particular concern for people with learning disabilities many of whom lead sedentary lifestyles where meals are a significant event in terms of marking the passage of time and providing a rewarding experience. Unhealthy diets have been shown to increase risk factors for a range of conditions however the focus of current concern is the connection between Coronary Heart Disease, hypertension and excess weight. It must be noted, nevertheless, that a significant minority of people with learning disabilities experience difficulties stemming from underweight and malnourishment. These individuals tend to be among those most

severely disabled. Conversely, fitness, in particular cardiovascular fitness has been recognised as a bulwark against heart disease and as a resistance factor against a range of diseases. We identified five papers addressing weight and fitness, two rigorous, one less rigorous and two poor studies.

Table 10: Weight and Fitness interventions involving people with learning disabilities

ID	Population	Model	Outcomes
462 Ewing et al (2004)	2 groups, one with ld, 1 without. 154 and 270 eligible, 19% and 30% drop out from ld and non-ld grps respectively. 21% and 34% incomplete data. Final sample 92 ld and 97 non-ld Age: mean=39.7 and 49.9, weight: mean=209.5 and 230, BMI: mean=35.4, and 38.4 and Race=46.7 and 68.8 non-whites, sex=54.4 and 84.5 female, diabetic=17.4 and 24.7	the Health Education Learning Programme (HELP) was used. It emphasises exercise, nutritional choices & reduction of stress. Cognitive restructuring was part of the programme (on top of exercise). 8 sessions Sessions= 90 mins long, also, home visits (2-4) to establish individual exercise programmes. The Behavioral Risk Factor Surveillance System (BRFSS) used to assess behaviour. Knowledge questions were asked pre- & post-intervention,	• Both people with and without learning disabilities showed differences and improvement but higher for the latter • BMI decreased by at least .75 (approx 5lbs) for 18.5% of participants with learning disabilities • Knowledge for ld group increased by 58.8% post-intervention • Change in exercise level post-intervention not statistically significant.
8270 Chapman et al (2005)	Group A: non-input: 50 LD in 3 day resource centres, didn't receive support from healthy living coordinator (HLC) to improve health. Mobile enough to stand on scales, mean age=43.32 yrs (older group)	use of measures to calculate BMI (body mass index) pre and post intervention. Physiotherapist intervention included home visits advice design of activity programme which also involved care	• Control group BMI increased by mean of 0.41 (0.966kg) in 12 months • Intervention group BMI decreased by mean 0.61 (1.519kg) after 12 months • No differences in either group after 6

ID	Population	Model	Outcomes
	Group B: input: 38 referred to HLC. Received support from HLC mean age=37.13 yrs (younger group). The input group higher initial weight. in total: 43% =f, 57%=m. vast majority classified initially as overweight or obese	staff and relatives. Gave health promotion info.	months • Significant main effect for input but not time. • Significant interaction between time and input
697 Marshall et al (2003)	464 people attended special health screening clinic 54% male, mean age 31 (10-68 years) 73% fully mobile 8% Down's syndrome. 79% living with family or in own accom. 122 people classed as obese and having hypertension referred to GP or given health promo advice. Follow up replies from 70 (57%) showed 29 (24%) no action taken. Study 2 involved 25 participants 68% male 32% Down's syndrome, 60% in 30s, 12% each in 40s 50s and 60s, 1 person under 20. 36% overweight, 12% obese, 32% very obese. 5 participants volunteered 3 normal BMI 2 underweight.	Adapted 'Activate' materials produced by the Health Promotion Agency in Northern Ireland. 1 nurse attended 10 training sessions. Covers healthy eating and exercise. Only 1 drop out. Two groups had 6 week programme, 1 group 8 week programme - sessions lasted about 2 hours. Weight measured at each session.	• Mean weight of participants needing to reduce (n=20) 85kg (SD19.4). After 6 weeks dropped to 81.6kg (SD17.9) – paired t=4.5, df=19, p<0.001 • Mean BMI 33.5 (SD5.9, 26-46) fell to 31.9 (SD5.4, 25-44) – paired t=5.26,df=19, p<0.001 • Two people moved to 'normal' BMI weight range, one 'obese' moved to 'overweight', and three 'very obese' moved to 'obese'. • No sig diffs in weight loss due to gender, Down's syndrome or age.
3805	Four female and 11	Physical	• After 6 months on

ID	Population	Model	Outcomes
Evers et al (1991)	male residents of long term care facility. Ages 7-27 severe physical and dev handicaps. Most common diagnosis cerebral palsy. Selected due failure to gain weight in previous 12 mths, clinical appear severe underweight, reported difficulties feeding.	measurements weight; tricep and suprailiac skinfold measure; arm circum; height. 3 day food record baseline preceding nutrition prog. Records analysed for nutrient composition. Energy and nutrient intake compared to RDAs. Individualized tray service provided. Indiv menu cards recorded amount served/eaten for each person. Record also of spillage/ vomiting to allow accurate measurement of intake. Portion sizes increased. Fluid snacks introduced. Food recipes modified by substituting higher energy version of common foods.	rehab programme sig increases observed for all anthropometric variables excl height. • All gained weight mean 2.7kg ($p<0.001$). • Prior to rehab 13% had intake at or above 2/3 RDA for all nutrients after 6 mths 40% met this crteria. • Difficult to increase fluid intake (556 ml/day - 716 ml/day after 6 mths). • 12 pld remained on prog after trial. • Review after further 6 mths showed 8 continued to gain weight (incl 3 who reverted to standard food service). 3 within 10% baseline weight - 4 lost weight.
5270 Schreiber et al (2004)	Case report 11 yr old girl mild mental retardation and hypotonia. 60in tall 127lb. Generally healthy and able in daily living and community activities. Participated in soccer and swimming prog. Pysio 2 x wk. No verbal communication.	Outcome measures - Energy expenditure index (EEI) - walking heart rate minus resting heart rate divided by walking velocity / beats per metre - Rating of perceived exertion (RPE) - Perceived Exertion Scale for Children, 10 point scale with colours	• Child completed 3 x 6 week sessions. • Marginal differences in scores after first 6 week programme but marked changes after 8 months. • Energy expenditure reduced from 0.874 before prog to 0.41 at follow up (8 mths). • Max heart rate during running test reduced

ID	Population	Model	Outcomes
		and facial expressions corresponding to level of exertion - and max running velocity - heat rate RPE and max velocity recorded over 40 metre 'run as fast as possible' trial. Easy to obtain and aided dev indiv prog. Likely to reflect changes due to improved fitness. Parents asked to complete home activity scale in relation to activity over 2 week period. 3 data collection points pre, after 6 weeks and after eight months.. Intervention group session with part individualised exercise section. Used volunteer high school / college 'coaches' who acted as motivator and assistant to children with higher levels of physical disability. I hour session 1/wk for 6 weeks. Some children completed several six 6 week sessions..	from 192 to 147. • Self rating of perceived effort reduced from 8 to 4. • Little information about exercise levels between intervention and follow up but anecdotal from parents suggested ongoing attendance for exercise activities

Four studies aimed to improve health by improving physical fitness and reducing weight. Two involved an activity programme alone [8270] [5270]. These studies suggested that adults and children with learning disabilities who took part in structured exercise programmes could reduce their weight or increase their fitness respectively but that substantial weight reduction or improvement in fitness occurred over the longer term. However the latter study was 'poor' being based on a single child and data collection occurring only before and after the first of 3 6-week sessions and then after 8 months. Two further studies that involved both activities and changes to diet [462] [697] suggested similar benefits but gained over a shorter period of time. These studies suggest that, as with the general population, health eating and regular activity is most effective in reducing weight and therefore risk of developing associated health problems.

Only one study addressed underweight/malnutrition [3805]. The people provided with the enhanced diet had all gained weight after 6 months, most of them continuing to gain for a further 6 months after the intervention period, partly due to continuing on the same diet but for 3 people even when they had returned to a standard diet.

These studies therefore suggest that the physical health of people with learning disabilities can be improved through appropriate weight and fitness programmes.

Women's Health

Six papers, two less rigorous and four poor, addressed women's health issues principally breast and cervical screening. Three of the publications reported no outcome data.

Table 11: Women's health studies involving women with learning disabilities

ID	Population	Model	Outcomes
1427 Shaughnessy (1999)	Women with moderate/severe ld aged 20-64 years and living in a long stay hospital who had no record of a smear in the previous 3 years and up to 70 years for	Not described. Assume standard smear taking procedure. Pilot screening session undertaken before main prog began 2 mths later and carried out over	• 45 women (36% of eligible) screened • 39 normal result • 5 inadequate smear • 1 abnormal result

ID	Population	Model	Outcomes
	those who had never had a smear. Some women had phys disabilities and therefore had to be assessed by physio re feasibility of carrying out procedure. 126 eligible 40 did not take part. 86 attended appt but 25 unsuitable for smear. 18 attended but withdrew co-operation (behaviour indicating withdrawal of consent).	several weeks.	
7312 Lunsky et al (2003)	Women expressing an interest or anxious/fearful of reg med care in the past. 39 interviewed 30 chose to participate. 3 considered inapprop because of limited comprehension. Other reasons for not beginning course included - inconvenient time (1) beh concerns (1), extreme discomfort with topic (1), lack of staff (1), changed their mind (2) - spec that healthy eating problematic for women suffering bulimia and Prader-Willi syndrome. 24 completed - 6	Session lasting 90 min with 10 min break in middle over 8 weeks in clin setting at Univ. Homework - practise. Stickers for attendance = small gift at end. 2 female co-leaders. Carers/supporters enc to participate so could follow up at home. 4 parts - 1) Health education. Risks specific to women/ health promo behs incl exercise, general safety, diet and hygiene. Discussion of anatomy and function of female body parts particularly breast/	• Whole group (n=22) sig gains in know (-3.31 p<0.005) healthy behaviours (-2.20 p<0.05) and coping (-3.50 p<0.005). • A sub group follow up test (n=16) knowledge (z=-2.67 p<0.01) and coping (z=2.62, p<0.01) gains remained however change in health behaviours scores was not sig. Authors sug due to high level of know in this area among group pre test compared to group as whole. • Anecdotal evid of participants using skills on own behalf

ID	Population	Model	Outcomes
	drop outs due to moving (2), behaviour (2), smoking in group (1), fear of examination (1). 2 women completed but unable to attend post-testing due staffing probs. 22 completed pre and post testing. 16 also completed follow up assessment after 10 weeks. Ages 20-65 mean 38. 12 lived semi-independently, six in group homes and 3 in large congregate care facilities. 1 lived with mother. 18 caucasian 4 african american.	pelvic care. Taught how med profs examine breasts/ pelvic area. Practiced self-breast exam with silicone model with lumps that could be felt with fingertips. Photos illustrations and video aids used. 2) Coping skills training - progressive muscle relaxation, relaxed breathing and guided visual imagery. Learned and practiced pain-coping strategies eg counting, breathing or saying coping statements. 3) Exposure to medical setting/ procedures. Gradual - videos of exam, touch some instruments used, visited gyn. clinic as group, role play procedures, opportunity to visit exam room and speak with nurse - reviewed exam, provided samples of gowns, etc. Invited to practice lying on exam table, opp ask questions prepared as homework. 4) Assertiveness/ empowerment training. Weekly role	and in support of others following intervention. • Challenges - attendance even with incentive not consistent - Evening presentation not ideal some may have been more attentive earlier in day. • 8 week course insufficient for people with intense fears but may be useful to run alongside individual therapy. • Unsuitable for women with more severe ld as would have difficulty completing role play and discussions.

ID	Population	Model	Outcomes
		plays - asking for help, describing probs, asking question to med profs. Both minor eg telling staff need new bra, and major - describing symptoms of illness to med practitioner eg lump rash or bleeding betw periods. Developed & practiced self-mantras to improve self-esteem and sense of autonomy. Evaluated thro' Women's Health Interview - 3 areas 1) health knowledge 36 items. 2) Health behaviour beliefs - 10 items. 3) Coping strategies assessed via photo of health prob scenario and asking how would deal with it.	
1853 McRae (1997)	Women with learning disabilities	A joint venture developed between a community learning disabilities team and local well woman and family planning services. A needs-led service - Informal and accessible clinic established for women with learning disabilities. eg.	• no formal evaluation of this is provided • the 'Wednesday Clinic' opened in 1994, to allow women with LD to make informed choices about their health needs. • The service was to be practical, & comprehensive & delivered in a

ID	Population	Model	Outcomes
		offered introductory visits, relaxation sessions & longer appointment times to allow pre-examination counselling. When pld couldn't attend on their own, careers & friends accompany them	relaxed, friendly environment' • Noted that 'evaluation & development of services takes place constantly' • Issues raised: women's health: well-women clinic, family planning, smear tests, breast examination, vaginal examination, contraceptives
6071 Brewster (2005)	Over 100 women attended day conference. 2/3 women with ld, others support workers and small no phc profs such as prac nurses and screening staff.	3 presentations 1) using 'books without words' gave info about cancer screening. 2) valuing people white paper - health action planning and role of screening for health. 3) description of research done by women with ld in preparation for drama about screening - Followed by workshops 1) breast health 2)importance of personal hygiene and going for smear. 3) issue of gaining informed consent. 4) special needs of women with ld going for smear and responses to needs. Finally performance of drama - humorous	• Open discussion to evaluate the day. • Several women with ld said had enjoyed the day.

ID	Population	Model	Outcomes
		and honest account of worries about prospect of having mammogram. Posters also available for participants to look at.	
6170 Cowie & Fletcher (1998)	Women with ld in Mulberry NHS Trust. 45% eligible women taken part. Ten nursing staff undertook training to implement scheme - increasing to 22. These staff arranged appts for women to attend clinics with a regular carer or arrange a home visit.	Attendance not compulsory and if considered prior or during examination would/did cause undue distress did not take place/continue. The training covered breast cancer prevention and breast awareness. After 7 months the scheme was evaluated and changes were made to policy and practice, including consultation with the trust's ethics panel regarding implementation of procedures.	• Audit of women living in residential care facilities who were eligible to receive national screening - found majority with hospital inpatient status had not been registered with service by their GP practice. This was corrected • A breast awareness service was set up with intention of educating service users to undertake self-examination or where not able to do this establish regular checks by a trained member of staff. • Service developed so that person other than carer undertook examinations and offered flexibility in terms of service delivery by offering clinic or home based appointments. The latter necessary for those for whom clinic facilities were unsuitable or where

ID	Population	Model	Outcomes
			transport difficulties. • 45% female service users receiving monthly checks at time of publication. Remaining eligible women will be included as more staff are trained. • States scheme adopted successful in improving provision and uptake of screening. •
8201 Taylor et al (1998)	125 clients with LD, 3 of them previously known to family planning service, 90% were known to community LD team.	This is a report of a joint service using the clinic services of the family planning medic, nurses & the community nurse. It opened in 1995 as a domiciliary service as well as a monthly clinic.	• Findings as result of the service opened: (reported informally): • 50% provided annual appointments for well-women checks, • 20% advice relating to prescription of contraceptives, • 30% counselling, • 1 client had breast lump that was treated, • issues in relation to sexual abuse were discussed. • Overall, the service filled in some gaps in provision.

These publications focussed on improving provision of breast and cervical cancer screening to women with learning disabilities. They used a variety of formats from a more traditional cervical screening service [1427] to 'needs led' women's health clinics that addressed a range of issues including smear tests.

Three publications suggested moves within services towards educational and screening provision to enable the women concerned by appropriately informing them of the need for this type of screening [1852] [8201] or teaching them skills to cope with invasive procedures [7312] . The day conference described above offered information to women with learning disabilities and those who support them, as well as health professionals. This was an educational session alone rather than a direct element of a screening programme.

Two studies focussed on increasing uptake of cervical or breast cancer screening [1427] [6170]. The study on cervical screening was able to report results based on those agreeing to take part. These clinics appear to have taken place on site at the long stay hospital where the women resided, however it is reasonable to suggest that similar results would have been obtain had clinics been held in primary care settings. Findings from studies with an educational components suggest that the number of women agreeing to have a smear test might have been increased given the type of preparation they suggest [e.g. 7312]. The study on breast screening focussed primarily on awareness, by women themselves, but where women were unable to do this monitoring provision of a service to ensure regular checks. They report that the scheme is successful in improving uptake of national screening but provide no figures to establish this.

Overall therefore the available evidence suggests a range of initiatives are being implemented in an attempt to improve cancer screening for women with learning disabilities with some evidence of success in providing knowledge and skills to them to assist more able women to make an informed decision about uptake of screening and to establish monitoring for women with more severe learning disabilities.

Other Health Interventions

Two publications were identified that covered very different interventions, one a service and another direct intervention to reduce smoking.

Table 12: General and smoking interventions involving people with learning disabilities

ID	Population	Model	Outcomes
4976 Peine et al (1998)	Two men - 46/47 years old both resident in 400 bed 'center' since childhood. Both displayed behavioural challenges in their communities that were related to smoking.	Behavioural programme designed to reduce cigarette smoking. Phase 1: Baseline - Access to cigarettes contingent on absence of challenging behaviours 1/hr - baseline at new residence. Continued until challenging behaviour stabilized approx 6 months. Phase 2: Introduced circular board with indicator spun to show reward - Man A board showing 12 options for hourly reward (2/12 = cigarettes; 1/12 = free choice of any reward - incl cigarette). Man B spinner with 6 sections (1 = cigarette, 1= ½ cigarette; 1 = free choice - incl 1 or ½ cigarette). If behaviour challenging w'in hour lost chance to spin. If behaviour challenging during spin lost chance to spin at end of next hour but gained access to reward for prior good	• Baseline period (6 mths) established a link between behaviour and access to cigarettes (1 cig per hr free of maladaptive behaviour). By last 8 weeks both men had optimised the no cigs they could obtain per hr. • Introduction of spinner reduced opportunities to gain access to cigs. • State some difficulties in interpretation of results as staff did not record 'choice' item, though stated cigs preferred. Also allowed to choose cig if spinner pointed to border between cig and other item. • Reported that towards end of phase 3 man B started to request items other than cig when spun to cig option (staff complied with request). • Suggest need to reduce access to cigs slowly to prevent turning to reliance on other people's cast off cig butts. Opportunity to gain cig needs to be greater than the attraction to this behaviour.

ID	Population	Model	Outcomes
		conduct after 15 min of good conduct. Phase 3: Man A one cig replaced (with agreement) by chance to go out in community with preferred staff. Man B full cig replaced by ½ (with agreement). Prog ended after 149 weeks but carried on informally by staff.	
1481 Allan (1999)	Attendees at two Adult Training Centres in Grampian Healthcare district. Clinics established at each Centre A analysis based on 30 consultations - 12 of which were carer consultations. Centre B based on 44 consultations all pld.	Pop in clinic run by specialist health visitor in learning disabilities available to give information and advice to attendees at centres and their carers. Frequency of clinics not specified. Interview recorded age, gender, type of consultation and outcome - health challenges (factors likely to affect health) included.	• 30 consultations at Centre A 12 of which concerned health of carers. • Centre B - 44 consultations all with service users. • Most people using service in 40s but more exaggerated in Centre A. • Each service user had at least one health need identified. • Majority consultations (41%) re weight loss/maintenance, healthy diet/lifestyle. Advice given on health eating and exercise for those in need, also weighed on reg basis to check progress. • Centre established healthy eating catering policy. All contributed to design healthy menus. • 18% consult related to bereavement and loss - no description of action taken. • 2.27% consultations req

ID	Population	Model	Outcomes
			crisis intervention - states required excellent commn. between multidisc team members for co-ordinated seamless service • 9% with epilepsy and wanted support with changes in seizure pattern, • side effects of drugs, • advice on dosage and use of Dosset boxes. • 11.3% consultations follow up and advice following discharge from hospital and clarification of treatments received. • Other issues menopause, dental health and diabetes.

The study of smoking reduction [4976] offered evidence that this is an achievable outcome over an extended period of time. However the men who participated were also challenging in that they became aggressive with others in regard to their smoking habit. The intervention here linked the two 'undesirable' behaviours using cigarettes firstly as a controlled reward and then substituting another reward item in place of the cigarette. Whether this is a service that can be adapted to be offered in or through general practice however is debatable. It is included here as an illustration of an intervention to improve health that goes beyond health education messages on smoking as a factor in risk of ill health.

The second study describes a 'pop in' clinic based in two day centres [1481]. The clinic is needs led but addresses general health issues rather than the women specific health clinics reported above. There is little information on outcome in what was methodologically poor study in research terms. However the author does list the types of issue that the specialist health visitor dealt with over an unspecified period of time. Provision of health care in specialist settings in not in keeping with the spirit of current health policy that people with learning disabilities should use mainstream healthcare services with appropriate support. However the author of this

paper argued that offering this service gave the centre users (and carers) ease of access to health advice.

Accessible Information

Only one study mentioned production of accessible information as an end in itself as opposed to the health files and diaries mentioned above that were described as health education 'packages'. However there was no information about the extent to which such leaflets were used or able to improve relevant knowledge for their target audience.

Table 13: Accessible information for people with learning disabilities

ID	Population	Model	Outcomes
5916 no author (2005)	Adults with learning disabilities	6 people supported and trained to deliver key messages such as healthy eating and healthy hearts, male and female cancers, smoking, sexual health and contraception.	• Supported in producing photo-story leaflets - making contact with venues arranging visits, finding out 'story' need to tell in leaflet, acting out stories and final design. Produced 12 leaflets about going to psychiatrist, GP and dentist amongst others. • Involved in design of hand-held medical records.

Production of information in more accessible formats has increased in recent years (for example accessible information is regularly produced by the Norah Fry Research Centre through its publication 'Plain Facts', and the Valuing people Support Team produce reports in an easy to read style). Nevertheless there appears little information on how helpful such documents are to those they are aimed at. Despite increasing levels of guidance on producing information for this group (see for example www.easyinfo.org) we identified no other information on leaflets/booklets as a means to improve the health knowledge of this population.

Self Advocacy / Communication

Five studies addressed issues relating to people with learning disabilities' communication and self-advocacy skills, four of which identified included some outcome data. Several of these studies are also noted above for their health education aims [7287 6206 7312], however their documentary elements also provided opportunity for communication or advocacy improvement.

Table 14: Self-advocacy and communication interventions for people with learning disabilities

ID	Population	Model	Outcomes
7458 Ruddick & Oliver (2005)	21 people with ld, either 'partly verbal or 'verbal. F= 13 women, M=8, mean age of 46.7 years (SD = 7.0s). Of those, 13 people with Down's syndrome and 8 with Id. All participants lived in staffed homes occupying between 4 and 12 residents, from six small towns in the West Midlands region.	Health Status Interview Schedule (adapting question items and response formats from a previous schedule) A Sensory Functioning scale A Memory Functioning question Schedule comprises 26 items divided into 8 areas, six make up sub-scales comprising more than one item. Variety of response formats (e.g. structured questions were followed by open comments, line drawings and faces to depict emotions, etc)	• Preliminary reliability data reasonable internal reliability for most scales (exceptions Mental Health and Sensory Functioning) • Overall, found personal questionnaire method effective in obtaining consistent quantitative info about range of health issues (current health, memory, eyesight and hearing). • People with LD able to utilize this format, method known to provide sensitive information that can measure changes over time).
7287 Lennox et al (2004)	In piloting phase of the package was piloted with 2 groups: group 1 comprised	Education session -. One-off session 50 mins long. Advocacy principles and applications, how to	• Study development of health ed/communication aid. • Interviews with pilot

ID	Population	Model	Outcomes
	19 parents of adults with Id who use a non-government support service; group 2 comprised 7 people with ID (self-advocates) who use a non-government accommodation service.	be assertive etc. Diary reinforced knowledge, attitudes and skills delivered in session. Diary-5 sections. Ring binder format with dividers 1 'All about me' 2 'Health advocacy tips'. 3 'For the doctor' - ideas how to work with people with ld, checklists of health probs assoc with syndromes etc. 4 'Medical records' - diagnoses, operations, medications, immunizations, allergies etc. 5 how diary developed and copies of record sheets to cover 5 year period...	groups suggested used diaries to gain, maintain and ensure continuity of information between patient and GP • Felt to be advantageous by advocates and GPs.
6206 Dodd & Brunker (1999)	10 pld from three local residential homes. 5 men, 5 women aged 31-46 years all with verbal skills but variable degrees of comprehension and language use. 3 GPs providing primary health care to these individuals also participated	Training and communication aids produced by authors. Discussion with 5 local GPs provided info on fundamental requirements for diagnosis formulation - site, severity, type and duration of pain and/or symptoms. Clear, computer generated colourful portrayals of info produced - 9 pictures for site of pain, 22 for types of pain, 5 point scale suing increasingly unhappy facial	• Pilot study • Follow up evaluation cards only returned for 3 people (set involving participant, carer and GP cards) - all from same residential home. 1 pld resid at another home not seen GP nor been unwell in 6 mths. Third home provided no info. • Cards returned showed patients able to take more active part in communicating with GP using

ID	Population	Model	Outcomes
		expressions for severity of pain/discomfort, drawing of six beds (how many mornings got up feeling pain) for duration of pain. Semi structured interview for users carers and GPs focussing on consultation and for pld bodily and illness awareness and knowledge of GP equipment. Pld also chose communication pics with meaning for them. Follow up (after 6 months) evaluation cards also produced for use in natural setting after training.	commmunication aid pack. • Found those with highest degree of knowledge / skill retention those who had occasion to use them during 6 mth period. • Marked increase in ability to recognise and relate to communication aid pictures after training phase - cards on severity and duration particularly effective - some reduction on follow up.
7312 Lunsky et al (2003)	Women expressing an interest in learning more about women's health or anxious or fearful regarding regular medical care in the past. 24 completed group interventions - 6 drop outs - 22 completed pre and post testing. 16 also completed follow up assessment after 10 weeks. Ages ranged from 20-65 mean 38. 12 lived semi-	Carried out over 8 weeks in clin setting at Univ. Session lasting 90 min with 10 min break in middle (healthy snacks to share). Assigned homework each week to practise skills and discussed next session. Stickers for attendance redeemed at conclusion for small gift. Part of programme Assertiveness and empowerment training. Weekly role plays - asking for help with health concerns,	• Anecdotal evidence of participants using skills on own behalf and in support of others following intervention.

ID	Population	Model	Outcomes
	independently, six in group homes and 3 in large congregate care facilities. 1 lived with mother. 18 caucasian 4 african american.	describing health probs, asking question to med profs. Some minor eg telling staff need new bra, more major - describing symptoms of illness to med practitioner eg lump rash or bleeding betw periods. Developed self-mantras to improve self-esteem and sense of autonomy - practiced reciting weekly.	
6777 Scott et al (2005)	Books distributed to 26 adults with ld (male and female - no figures given) 17 returned (65%). Reasons for non-completion from 5 - ill health, hosp admission, family difficulties (2), no time (paid carers).	Health book in simple format - user friendly language. Completed book contained - personal details; levels of abilities; general health status; space for comments from health profs and appointment sheets. Updated in partnership with individual. Encouraged to take to GP or other appointments to provide clinicians also more thorough knowledge of personal healthcare history. After trial period questionnaire distributed to all staff participating (?parents).	• List some comments - some used as resource for profs others as self-regulatory resource (using charts to remind to brush teeth etc), highlighted flexibility in usage. Some staff lacked info on aims, ie not just for acute episodes. Staffed houses miscommunication between staff re filling in book. • One client pleased, more confident when visiting GP used book as aide-memoire to update GP on current health. • Appointment sheets praised again aide-

ID	Population	Model	Outcomes
			memoire. • Carers reported majority clients took ownership of book and took to medical appointments.

Two interventions helped people with learning disabilities communicate health information, one through a structured accessible interview [7458] and the other through communication cards [6206] . The former study suggested that people with learning disabilities were able to use the took to provide consistent quantitative information about health issues. The second study tested a communication aid which was unstructured to allow people with learning disabilities to use them to communicate about their health. Small number of people were involved in both studies and so the results are tentative. A health book [6777] was also subject to piloting and provided some evidence that this documentary style aid is useful for more able people with learning disabilities. Comments on use of the book suggested that people with learning disabilities took ownership of the book and some used the information it contained as an aide-memoire.

Finally two studies offered assertiveness and advocacy training[7287 7312]. Both papers were concerned with trailing materials but provided feedback comments on the training that suggested the skills taught were being put into practice.

In all studies the number of participants was small. In the case of the rigorous studies this reflects that these were pilot phases concentrating on tool development. The small amount of outcome data provided overall, suggests that the educational and documentary elements had the potential to impact on the ability of more able people with learning disabilities to take a more active part in health consultations.

Interventions enhancing parents' and carers' roles

People with learning disabilities' difficulties in identifying and responding to the signs and symptoms of ill health mean that there is a greater reliance on those who come into regular contact with them, particularly carers, to fulfil this role. This is particularly true for people with more severe learning disabilities who may be unable to take advantage of the health education training, information and communication/advocacy aids described above. We therefore searched for information on interventions that sought to improve health for people with learning disabilities through enhancing the skills of or resources available to such individuals in the health of the people they are in contact with.

Thirteen papers addressed this issue. One highly rigorous, four rigorous, four less rigorous and four poor studies tackled a range of issues. One poor study described the development phase of a resource and not a 'trial' hence a lack of detail on implementation of the intervention, and another involved implementation of training to carers in support of a single individual. Two reports were also rated as 'poor' because they contained no substantive data that could be evaluated. The latter have been included only to give an indication of interventions that service providers are implementing that have the potential to impact on physical health.

Table 15: Papers addressing parent and carer roles in improving the physical health of people with learning disabilities

Final Rating	ID	Paper details	Study design	Age group	Disability range
1	**6995**	Aronow, H. U. and Hahn, J. E. Stay well and healthy! Pilot study findings from an inhome preventive healthcare programme for persons ageing with intellectual and/or developmental disabilities. Journal of Applied Research in Intellectual Disabilities 18(2), 163-173. 2005.	Quantitative	Adult	Mild/ Mod
2	462	Ewing, G., McDermott, S., Thomas-Koger, M., Whitner, W., and Pierce, K. Evaluation of a cardiovascular health program for participants with mental retardation and normal learners. Health Education & Behavior 31(1), 77-87. 2004.	Quantitative	Adult	Mild/ Mod

Final Rating	ID	Paper details	Study design	Age group	Disability range
2	7287	Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F. M., and Purdie, D. M. ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. Health Promotion International 19(2), 167-175. 2004.	Qualitative	Adult	NR
2	8002	Martin, G. Evaluation of a nurse led annual review of patients with severe intellectual disabilities, needs identified and needs met, in a large group practice. Journal of Learning Disabilities; 8(3), 235-246. 2004.	Quantitative	NR	NR
2	8270	Chapman, Melanie J., Craven, Michael J, and Chadwick, Darren D. Fighting fit? An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. Journal of Intellectual Disabilities 9(2), 131-144. 2005.	Quantitative	Adult	NR
3	*3326*	Bryan, F., Jones, J. M., and Russell, L. Reliability and validity of a nutrition screening tool to be used with clients with learning difficulties. Journal of Human Nutrition & Dietetics 11(1), 41-50. 1998.	Quantitative	Adult	NR
3	*7312*	Lunsky, Y., Straiko, A., and Armstrong, S. Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 16(4), 247-253. 2003.	Quantitative	Adult	Mild/ Mod
3	*7731*	Cole, C. and Pointu, A. An education programme for social care staff: improving the health of people who have a learning disability and epilepsy. British Journal of Learning Disabilities; 33(1), 39-43. 2005.	Report	All	All
3	*8005*	Matthews, D. The OK health check: a health assessment checklist for people with learning disabilities. British Journal	Quantitative	NR	NR

Final Rating	ID	Paper details	Study design	Age group	Disability range
		of Learning Disabilities 25(4), 138-143. 1997.			
4	6170	Cowie, M. and Fletcher, J. Learning disabilities. Breast awareness project for women with a learning disability. British Journal of Nursing 1998 Jul 9-22; 7(13), 774-778. 1998.	Report	Adult	NR
4	6621	Naphine, A. Empowering people with diabetes who have learning disabilities. Journal of Diabetes Nursing. Spring; 5(1), 19-22. 2001.	Qualitative	Older Adult(60+)	Moderate
4	6777	Scott, E., Elvish, J., Luft, L., and Wilson, M. The development and use of a personal health resource. Learning Disability Practice 2005 Mar; 8(2), 27-31. 2005.	Quantitative	Adult	NR
4	7407	Pegg, J. Better health: Improving health promotion and health care for people with a learning disability. Health & Social Care in the Community 9(3), 179-180. 2001.	Report	NR	NR

The issues covered reflect those addressed in the section on interventions with people with learning disabilities directly, that is health checks, weight reduction, health education and women's health, but also included some information on interventions designed to help carers identify people whose health is, or is at risk of being, compromised.

Identifying health need

We identified three publications relating to carers' roles in identifying and responding to health needs. Two rigorous studies were developing tools to aid identification on needs, one relating to general and one nutritional health. The carers in the latter study were nurses at a long stay hospital, however it is arguable that the instrument could be used by carers in other settings.

Table 16: Interventions enhancing carer roles in identifying health need

ID	Population	Model	Outcomes
3326 Bryan et al (1998)	35 randomly selected people - 18 female, 17 male aged between 30 and 82 years (mean 56yrs) and living in staffed houses forming part of a long-sty hospital. Mild to severe ld people with profound physical disabilities excluded. Each person assessed by 3 nurses who knew them well and 3 dieticians (non-specialist)	NST designed to assess risk in 3 areas - nutritional adequacy - weight - nutrition related problems eg constipation or swallowing difficulties. Revised edition incorporating changes indicated by pilot. Ticking certain sections placing the person in the 'at risk' category. If assessment shows person in 'at risk' in any section then person/carer prompted to seek help in first instance from doctor and members of multidisciplinary team.	• Good reliability for assessment of risk relating to nutritional adequacy • Moderate agreement re nutrition related problems • Not satisfactory with regard to measurement of weight related risk. Not surprising due complicated area no weight-height standard for pld. Only mod agreement in assessment re weight among dieticians - use variety of methods bmi, standard weight-height charts and visual assessment. • Limitations due diff nurses evaluating participants and dieticians not familiar with work with pld. • State malnutrition difficult to assess, no single objective marker further complicated in field of ld because lack pop specific standards.

ID	Population	Model	Outcomes
8005 Matthews (1997)	Instrument development in 3 phases. Phase 1 - Delphi groups 10 experts who developed the items for inclusion in the tool. Phase 2 - testing validity that is whether the tool identified a greater number of health needs than carers could identify without its guidance. Involved 40 carers employed by NHS - volunteers- 4 residential social work quals, 4 qualified Community Nurses, 12 qualified nurses empl in resid care settings, 20 unqualified or social work qualified staff employed in resid care settings. Phase 3 - inter-rater reliability 15 clients assessed by groups of 2-3 individuals independently. Assessors 16 nurses and 18 care assistants. 8 x 2 raters, 6 x 3 raters. No information on those assessed.	Phase 1 developed tool devised to assess medication, side effects and review; circulation and breathing; perception of pain; digestion and elimination; skin; feet; ears/hearing; sexuality issues; lifestyle risks; body dimension and measurements; epilepsy and management; urinary syst.; physique and mod; oral hygiene; eyes/vision; mental health; sleep. Includes categorical/continuous /ordinal response options - y/n questions included D/K option to avoid unhelpful guessing. 155 items 27 factual (name age height/weight etc) 88 - female 86 - male. Assessment tool developed to consist of 115 items Delphi group felt it was comprehensive but manageable. Featured all key areas identified. Compared to a blank sheet requesting carers to describe person's current state of health in as much detail as possible.	• Found identified additional relevant info in all 40 clients range 3-27 items (mean 7.75). Nothing on unstructured data collection sheet that wasn't covered by instrument • Inter-rater reliability calculated for 15 clients. Agreement varied between 84.1% to 97.68%. Satisfactory. Mean incidence of discrepancy 7.54% (6.6 items). Discrepancy occurred over total of 55 items therefore not an issue with unreliability of particular items. • Unqualified staff more likely to use D/K than qualified staff (6.2 vs 3.4 mean D/Ks). Suggest due to unqualified staff less willing to take responsibility for use of judgement on various items

ID	Population	Model	Outcomes
7407 Pegg (2001)	Care staff working with people with learning disabilities	Based on ideals of 'The Health of the Nation' self study pack in 6 workbooks. 1) Intro to health and illness and people with ld - identification of need and access to healthcare. 2) Opportunity to develop skills and knowledge required in identifying signs of possible illness - observational strategies and commn techs. Practical tips for interacting with health profs who may not have exp of working with pld. 3) How can prepare pld for poss med treatment - ensuing person fully understands what about to experience and understand own role in helping mainstream healthcare profs to understand pld's needs. 4) Health promotion issues - how to apply knowledge to promote sense well-being and reduce ill health. 5) Causes of inequality in provision of healthcare and how can reduce opportunity for discrimination. 6) Skills in identifying relp between direct	• Assessed as well structured and helpful by reviewer. Suggests useful for new entrants to the service. No evaluation based on people who actually completed course

ID	Population	Model	Outcomes
		and indirect causes of ill health. Each unit examines impact of underlying conditions such as Down's syndrome, epilepsy the ageing process + practical tips to help person achieve better qual of life. Plain English same structure used throughout.	

The general health tool [8005] was found useful for eliciting information that carers might not provide without structured questioning. It was not clear whether this tool was designed for use in a particular setting, however comprehensive information is vital for identifying and responding to health needs and therefore such aids may provide a useful way to help carers provide appropriate observations. The nutritional tool [3326] proved useful in identifying nutritional adequacy and related problems but not for weight related risk, particularly underweight. This was the only study found to target people with severe / profound learning disabilities specifically despite their particular need for interventions to improve physical health due to greater levels of health risk and communication difficulties.

The third publication reviewed a study pack [7407] which provided information and advice on identifying health need and working with and, preparing individuals for consulting medical practitioners. There was no evaluative data on the package and it is noted that the workbooks do not form part of the Learning Disabilities Awards Framework (LDAF) materials on the Mencap website [accessed 21.11.05] from which this package may be obtained. It would seem particularly appropriate that this type of carer education should form part of LDAF certification.

Health Checks

Only one highly rigorous pilot study [6995] related to carer involvement in health checks. This study provided carers with a health profile, based on a structured assessment carried out by a trained non-health assistant, and relevant health education materials and advice. The authors report some

data suggesting that health risks following intervention decreased and health strengths increased. The tools developed are to be subject to further trials.

Table 17: Health check studies reporting on carer roles

ID	Population	Model	Outcomes
6995 Aronow & Hahn (2005)	201 adults ID (=> 32yrs=170, <32yrs=31), residence private residency/group homes (not nursing homes) [responses sought from pld, where carers present sought direct questions participants, if unable to respond proxy responses obtained]. Assigned to treatment group after base line. M=106, F=95. Mean age 41 (19-79). Ethnicity: 65% white, 19% Latino, 8% african amer., 5% asian pacific, 3% other. Also, 59% employed day programme. 162 pld incuded in health improvement analysis.	Health risk appraisal carried out by trained assessor. Feedback / assessment coded to produce profile of Health risks and strengths. This information sent to person with ld / carer paired with advice to address need or congratulatory statement on health strengths (eg taking regular exercise) and mailout of relevant health educational material (accessible). For many people responding to this information will have involved input from their carer, but no specific analysis here	• Some evidence of health improvement over mean=309 days (18-581 days). • Report that retest indicates change in direction of improvement. Reduce risks & use of acute health services. Increase in health strengths. Sign change in total health strengths, risks, life sat. number of recent falls, self report pain & emergency room visits. • Related to issues around ID health needs but also focuses on health strengths or factors likely to help guard against avoidable ill health. • Only a pilot allowed authors to concentrate on tool development for use with people with poor lit skills.

Women's health

One rigorous study [7312] sought to provide training to women with learning disabilities related to health examinations including information and relaxation, coping and assertiveness skills. The training package incorporated joint training to carers in its design. However authors did not find this aspect of the intervention as effective as the elements aimed at women with learning disabilities (see above). They suggest separate training for carers to focus on their particular needs in this process.

Table 18: Women's health studies reporting on carer involvement

ID	Population	Model	Outcomes
7312 Lunsky et al (2003)	Women expressing an interest in learning more about women's health or anxious or fearful regarding regular medical care in the past. 24 completed group interventions - 6 drop outs. 16 also completed follow up assessment after 10 weeks. Ages ranged from 20-65, mean 38. 12 lived semi-independently, six in group homes and 3 in large congregate care facilities. 1 lived with mother. 18 Caucasian 4 African American.	Carried out over 8 weeks in clin setting at Univ. Session lasting 90 min. Assigned homework each week to practise skills and discussed next session. Carers/supporters encouraged to participate so could follow up at home. 4 components - 1) Health education 2) Coping skills training. 3) Exposure to medical setting and procedures. 4) Assertiveness and empowerment training.	• Biggest challenge promoting staff involvement. Many not used to playing active part in therapy - crucial to ensure that participants practice and use skills in everyday life. • Suggest further training may be necessary for staff to ensure comfortable with process and motivated.

Health Education

One rigorous, one less rigorous and two poor studies were identified that addressed health education to carers that aimed to improve health in the people they look after.

Table 19: Health Education studies reporting on carer involvement

ID	Population	Model	Outcomes
7287 Lennox et al (2004)	In piloting phase of the package was piloted with 2 groups: group 1 comprised 19 parents of adults with ID who use a non-government support service; group 2 comprised 7 people with ID (self-advocates) who use a non-government accommodation service.	Education session for advocates -. One-off session 50 mins long. Advocacy principles and applications, how to be assertive etc. Diary reinforced knowledge, attitudes and skills delivered in session. Diary-5 sections. Ring binder format with dividers 1 'All about me' 2 'Health advocacy tips'. 3 'For the doctor' - ideas how to work with people with ld, checklists of health probs assoc with syndromes etc. 4 'Medical records' - diagnoses, operations, medications, immunizations, allergies etc. 5 how diary developed and copies of record sheets to cover 5 year period..	• Preliminary findings: the package has been enthusiastically received. • 2/3 of the advocates interviewed indicated that the diary had helped them to be better advocates • Half said their relationship with their GP had improved as a result of the training session. • Used diaries to gain, maintain and ensure continuity of information between patient and GP and vice versa • felt to be advantageous by advocates and GPs.
7731 Cole & Pointu (2005)	Care staff of 173 persons with learning disabilities	Training programme. Both practical & written assignments. On successful completion, participants receive	• In 2002, 97 social care staff completed Basic Epilepsy awareness. 99% of sample found training relevant to

ID	Population	Model	Outcomes
		certificate from local PC trust, valid for 2 years. 1st session = epilepsy awareness (morning session), 2nd session related to administration of rectal diazapam (afternoon session). No instrument appended but some examples are provided.	their practice • 173 written assessments & evaluation forms were analysed • (95.4%) passed with mark equal or above 70%
6621 Naphine (2001)	I adult, female, LD, 72 yrs, type II diabetes, underweight & poor appetite	Ed. Package for staff, including: information, guidelines, procedures, practical skills, monitoring documentation.	• Benefits for home staff included increased knowledge, esteem, and motivation • Benefits for professionals included agreed roles & responsibilities, contribution of specialised knowledge in coordinated way, greater understanding about other areas of expertise • It also discusses barriers that were faced, how they were overcome, and the benefits that followed from the package--for the person with ld, the home staff and the professionals involved. • The intervention

ID	Population	Model	Outcomes
			• allowed the LD person to control her diabetes, this leading to better physical health as well as empowerment for her. • It is implied that PH is increased through this empowerment.
6777 Scott et al (2004)	Books distributed to 26 adults with ld (male and female - no figures given) 17 returned (65%). Reasons for non-completion from 5 - ill health, hosp admission, family difficulties (2), no time (paid carers).	Health book in simple format - user friendly language. Completed book contained - personal details; levels of abilities; general health status; space for comments from health profs and appointment sheets. Updated in partnership with individual. Encouraged to take to GP or other appointments to provide clinicians also more thorough knowledge of personal healthcare history. After trial period questionnaire distributed to all staff participating (?parents).	• Some staff lacked info on aims, ie not just for acute episodes. • Staffed houses - appeared to be miscommunication between staff re filling in book. • Staff said time consuming due need to complete with client (misunderstanding re amount needing to be completed with client). • Liked adaptability to client needs. • Thought empowered client. • Issues raised about confidentiality and worries might get lost if taken to appointments.

Two of the identified publications [7287] [6777] related to health diaries (see also above in relation to people with learning disabilities). Both diaries included personal information on the individual concerned and sheets for monitoring health data and appointments. In one study [6777] difficulties were reported in completion of the diary by staff. However no such difficulties were found in

the rigorous study [7287] this may be due to the brief training session delivered to carers and people with learning disabilities where appropriate, before distributing the diary.

Two other publications related to maintaining the health of people with epilepsy [7731] or diabetes [6621]. The authors of the publication on epilepsy training and diazepam use reported that a high number of participants successfully completed written assessments on course content. However there is no information on the impact the training then had on the individuals they care for. The second study involved carers and professionals looking after a single individual with diabetes [6621]. The authors report increased knowledge for carers but unsubstantiated claims that empowering the person improved her physical health.

Interventions enhancing practitioners' roles

Eight papers addressed practitioner issues in improving the physical health of people with learning disabilities including five rigorous and three less rigorous publications.

Table 20: Papers involving interventions to enhance practitioner roles

Final Rating	ID	Paper details	Study design	Age group	Disability range
2	567	Moore, G., McConkey, R., and Duffy, M. The role of the school nurse in special schools for pupils with severe learning difficulties. International Journal of Nursing Studies 40(7), 771-779. 2003	Quantitative	Chdn (up to 19)	Severe/ Profound
2	1771	Jones, R. G. and Kerr, M. P. A randomized control trial of an opportunistic health screening tool in primary care for people with intellectual disability. Journal of Intellectual Disability Research 41(Pt 5), 409-415. 1997	Quantitative	Adult	All
2	7287	Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F. M., and Purdie, D. M. ask for it: development of a health advocacy intervention for adults with intellectual disability and their general	Qualitative	Adult	NR

Final Rating	ID	Paper details	Study design	Age group	Disability range
		practitioners. Health Promotion International 19(2), 167-175. 2004.			
2	8231	Wakefield, S., Hunt, G., and Hunt, C. Community nurse learning disabilities: a case study of the use of an evidence-based screening tool to identify and meet the health needs of people with learning disabilities. Journal of Learning Disabilities; 5(1), 9-18. 2001.	Qualitative	Adult	NR
3	*1429*	Bollard, M. Improving primary health care for people with learning disabilities. British Journal of Nursing 8(18), 1216-1221. 14-10-1999.	Mixed	Adult	NR
3	*4453*	Lennox, N. G., Green, M., Diggens, J., and Ugoni, A. Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. Journal of Intellectual Disability Research 45(Pt 3), 226-232. 2001	Quantitative	Adult	All
3	*6206*	Dodd, K. and Brunker, J. 'Feeling poorly': report of a pilot study aimed to increase the ability of people with learning disabilities to understand and communicate about physical illness. British Journal of Learning Disabilities 1999 Spring; 27(1), 10-15. 1999.	Quantitative	Adult	NR
3	*7824*	Goldsmith, S., Cooray, S., Johnston, F., and Williams, G. Good practice, general practice: identifying the health needs of people with learning disabilities. Journal of Clinical Governance, Leicester 8(2), 83-88. 2000.	Quantitative	All	All

Publications identified involved nurses, general practitioners and teachers.

Nurses

Only one study was identified that covered facilitation of identification of health needs by nurses. This rigorous study employed a particular health check protocol to help nurses to identify health needs. As a result 91% of those assessed were referred to their GP. There was no information however on setting in which assessments were conducted, the types of problem referred, or the outcome of the referral.

Table 21: Study on intervention to enhance nurse role in identifying health need

ID	Population	Model	Outcomes
8231 Wakefield et al (2001)	35 adults with LD, m=13, f=22. Mean age=39 yrs, range 17-65. 32 lived at home with their families, 3 in staffed group homes.	the OK Health Check	• OK health check proved to be a comprehensive & nurse friendly tool for a systematic approach to assess health needs. • Out of the 35, 32 people (91%) were referred top a GP by their community nurse.

General Practitioners

Two rigorous and four less rigorous publications were identified that addressed interventions to improve the physical health of people with learning disabilities by enhancing general practitioner roles. Two rigorous studies involved a GP note prompt and a health education package. Less rigorous studies also included examples of the above but additionally studies on health check programmes.

Table 22: Studies reporting interventions to enhance GP role

ID	Population	Model	Outcomes
1771 Jones & Kerr (1997)	19 practices approached six agreed five of which used handwritten	Audit of case notes at start of study and after 6 months of the card being inserted	• No difference in consultation patterns. • No sig difference

ID	Population	Model	Outcomes
	medical records suitable for insertion of prompt (29 GPs). Pld identified by practice staff on advice and with assistance of one of the researchers. Identified 111 pld from 5 practices (56 male, 55 female) randomly allocated to active and controlled groups. No sig diff in age, sex marital status, cause or severity of ld, med condition or specialist consultations. Mean age 41 years (18-72 range). Two married, two divorced or separated, degree of ld estimated for those where enough info available - 28 mild ld, 39 severe (comb mod, sev, prof). 30 people had Downs syndrome. Mean consultation rate over prev 4.5 years 4.0 per yr (gen pop 3 times for men, 5 times for women - 5 and 7 times for under 5s and over 75s). People identified randomly allocated to active and control groups.	in 'active' patients notes	across a range of health promotion issues. • Main preference was for consultations in the surgery and within surgery hours. • Health promotion more likely to have been given to patients who had joined the practice in the last 4 years than in those prior to that date. • Use of the prompt card was not found to be effective in increasing access to targeted or specifically appropriate services eg Down syndrome patients still only had around 50% uptake for testing for thyroid function in a group known to be at risk.

ID	Population	Model	Outcomes
7287 Lennox et al (2004)	The study had several phases, and in total, there were 22 people with LD. These were split such as: in the 'consultation with advisors & focus group' phase, there were 9 people (including 2 with ID, 2 support workers, 2 parent advocates, 2 advocacy organization representatives and 1 occ. therapist). Later, to determine the format & content for an intervention package, 15 focus groups were held with 101 people (8 with ID, 85 supp. workers, 3 parents, 2 psychologists, 1 GP, 1 volunteer & 1 sister). In piloting phase of the package was piloted with 2 groups: group 1 comprised 19 parents of adults with ID who use a non-government support service; group 2 comprised 7 people with ID (self-advocates) who use a non-government accommodation service.	Education session for advocates and GPs -. One-off session 50 mins long. Advocacy principles and applications, Diary reinforced knowledge, attitudes and skills delivered in session. Diary-5 sections. Ring binder format with dividers 1 'All about me' 2 'Health advocacy tips'. 3 'For the doctor' - ideas how to work with people with ld, enhances primary care initiatives, checklists of health probs assoc with syndromes etc. 4 'Medical records' - diagnoses, operations, medications, immunizations, allergies etc. 5 how diary developed and copies of record sheets to cover 5 year period..	• 2/3 advocates interviewed said it had helped them become better advocates. Half said their relationship with their GP had improved as a result of the training session. Use of diaries to gain, maintain and ensure continuity of information between patient and • felt to be advantageous by advocates and GPs. • GPs commented would be useful with other groups too such as people with mental disorders • Describes educational package designed for GPs also but not included in pilot nor specific mention in description of session documentation/guidance.

ID	Population	Model	Outcomes
1429 Bollard (1999)	65 adults with LD (out of 110, =59% of those invited) (m=39, f=26). Age=22-78. Most accompanied in health checks by carers.	A) Survey questionnaire for GPs after 12 months (13 returned, 76% response rate) re level of knowledge of health needs & services for P with LD. B) 30-mins health checks with adults with LD (34-itemised health check card & brightly reminder card with referral info). C) identification of health needs & appropriate treatment (eg. referral, etc). D) creation of general database for com. Nurses to access & update health check info.	• when questioned towards the end, 100% of GPs were able to identify how many people with LD were registered at their practice, • 46% felt project made them more aware of health needs of people with LD, • 77% felt more aware of the special services for LD in the locality.
4453 Lennox et al (2001)	45 self-selected GPs from previously postal surveyed GP (1000) randomly selected from Health Insurance Commission database. Characteristics of larger group representative of GPs generally. Each GP ident ps with ld (aged 19+) and 3 randomly selected by investigators to be approached for consent to	GP self evaluation form (T1 and T2); synopsis of lit T1; Audit of notes (T1 and T2).; comp health assessment booklet T2. Booklet dev by authors in collaboration with others in field. Two part - first user/carer completed current and past med history incl screening and preventive activities such as immunization. Second part GP	• Comprehensive Health Assessment useful method of increasing or clarifying GPs' awareness of patients' health & opportunity to reassess needs. • It can possibly used as comprehensive summary of person's health and kept in person’s notes. • It provided an opportunity to clarify and update aspects of care which may

ID	Population	Model	Outcomes
	participate. 15 GPs completed all components of study (drop out rate 66%). 38 patients completed project (21 female, 17 male) 7 excluded because not ld. Age range 22-68 mean 40 years	completed at consultation aimed at general check but emphasising disorders commonly suffered by pld	not be the GP's main responsibility but which the GP can help to facilitate.
6206 Dodd & Brunker (1999)	10 people with ld from three local residential homes. 5 men, 5 women aged 31-46 years all with verbal skills but variable degrees of comprehension and language use. 3 GPs providing primary health care to these individuals also participated	Training and communication aids - 'My Body' file and 'Feeling Poorly' communication aid - produced by authors. Discussion with 5 local GPs provided info on fundamental requirements for diagnosis formulation - site, severity, type and duration of pain and/or symptoms. Clear, computer generated colourful portrayals of info produced - 9 pictures for site of pain, 22 for types of pain, 5 point scale using increasingly unhappy facial expressions for severity of pain/discomfort, drawing of six beds (how many mornings got up feeling pain) for duration of pain. Semi structured interview for users,	• Follow up evaluation cards only returned for 3 people (set involving participant, carer and GP cards) - all from same residential home. 1 pld resid at another home not seen GP nor been unwell in 6 mths. Third home provided no info. • Cards returned showed patients able to take more active part in process of accessing and communicating with GP using communication aid pack. Found those with highest degree of knowledge / skill retention those who had occasion to use cards during 6 mth period.

ID	Population	Model	Outcomes
		carers and GPs focussing on consultation, and for people with ld bodily and illness awareness and knowledge of GP equipment. People with ld also chose communication pictures with meaning for them. Follow up evaluation cards also produced for use in natural setting after training.	
7824 Goldsmith et al (2000)	8/9 primary health care teams. Consent to access notes obtained from patients guardians/carers - 123 letter and info sheets sent, 117 (95%) granted permission. Records of 102 people included in final audit (one practice withdrew and so 15 could not be audited). Included 16 aged 16 and under (10 male) 86 aged 17 and over (48 male)	Data collected from records held by the GP and notes for individuals accessing specialist nursing. Retrospectively audited for 18 month period.	• The audit resulted in the development of a health information record card • The card constituted a minimum data set to assist practitioners to focus on the health needs of people with LD & highlighted areas of unmet needs. • health information record card contained key info and was designed to fit in Lloyd George Wallet. • it is noted that 'the card is already being regularly used by some of the participating practices, 2 of the GPs who participated in the

ID	Population	Model	Outcomes
			audit are also currently investigating ways of integrating the template of the record card onto their computerised systems in the practice' (p.87).

Research attempting to provide pertinent information to general practitioners had varying results. A prompt card placed in the note wallet of selected individuals with learning disabilities [1771] did not appear to influence the preventative healthcare offered to patients with learning disabilities. A less rigorous study [7824] reported on the development health information record cards also placed in the notes of patients with learning disabilities, however no information was given on the impact of the information on delivery or healthcare to or health improvement of the patients concerned. Authors noted that card 'regularly used' by some practices and that two practices were investigating ways of transferring the template to their computer systems.

Two studies described training packages primarily designed for people with learning disabilities but having elements of training for general practitioners. One rigorous study [7287] involved compilation of a health diary which included information specifically aimed at general practitioners. A brief educational session was used to introduce the diary to people with learning disabilities, carers and GPs however no information was given in the paper as to how or if the GP educational session differed from that given to other groups. The report suggested that the session was general so that it met the informational needs all groups. No outcome data on this element of the study was available as this was a pilot of the tool and training package. The paper included only comments to the effect that the tool had been useful. The second study [6206], also a pilot, involved development of a training session for people with learning disabilities and a communication aid to be used by people with learning disabilities both with their carers and their general practitioner. A copy of the communication aid was provided to the practitioner. Limited feedback suggested that the aid helped the person with learning disability take a more active part in the consultation process.

Finally two reports of health check programmes, one involving GP participation in screening [4453] and the other describing a practice nurse led model [1429], suggested that GP's awareness of the health needs of patients with learning disabilities was improved as a result of the practice's, or their own involvement in health checks. The latter study also found the majority of general practitioners felt more aware of the availability of special services for people with learning disabilities in their localities.

Teachers

Only one rigorous study described an intervention aimed at improving teacher's knowledge of the health needs of their pupils with learning disabilities. This study suggested that the range or extent of such training in special schools was enhanced by the employment of a nurse on site. This nurse's prime responsibility was to respond to the continuing healthcare needs of children with learning disabilities and a range of physical health problems. However, their presence in the schools, not only relieved teachers and class assistants of performing healthcare tasks, but provided them with training on a range of issues including epilepsy and diabetes. As with many other studies describing interventions there was no evaluation of the impact of such initiatives on the health of the people they supported.

Table 23: Study reporting on intervention enhancing teachers' roles in improving health

ID	Population	Model	Outcomes
567 Moore et al (2003)	4 special schools. Two schools appointed full-time school nurses. Two further schools did not have access to school nurse on site but could access community nurses Pupils were aged from 3 to 19 years. Epilepsy most common condition though sig less prevalent in one contrast school. 1/6 required medications	Record kept for full school yr of diff activities undertaken by school nurses (recorded on computer database). Telephone interviews with selected parents. Self-completion questionnaires for school staff and other health and social service profs in contact with project schools. No details on content of questionnaires	• In project schools administration of medication. PEG feeding and suctioning, mouth care, catheterisation etc carried out by nurses. In contrast schools carried out by teachers, parents and classroom assistants. • In project school B nurse provided short training sessions to teachers

ID	Population	Model	Outcomes
	to be admin in school. Dressing req in two schools - clinical tests, urine, weight, seizures, needed in all 4 schools. Number of chdn with PEG or NG feeding small and varied across schools as did number with catheters and tracheostomies.		and assistants on diabetes, epilepsy, First Aid and meningitis. • Nurses in both project schools trained staff on summer activity schemes on epilepsy management. • In contrast schools training provided by health visitors or community paediatric nurses on PEG feeding and catheterisation. Clinical MO also provided training in one school.

Overall

Overall therefore we were able to identify literature on a range of interventions however evaluation of impact on health was rare. Several of the most recent studies described pilots designed to assist in the development of intervention tools suggesting that rigorous evaluation studies are to follow. However the authors note that follow up from other pilots conducted six to seven years ago *e.g. 6206* have not been followed by large(er) scale evaluation studies.

Summary and Conclusions

The literature reviewed, as documented above, demonstrates attempts to provide healthcare to improve physical health through instruments/ documentation; training programmes and special clinics or services which take a variety of formats. These are summarised in Table 24 below.

Table 24: Types of intervention identified in the literature and target groups

Clinic/service (paper ID)	Intervention	Target group
Instruments/ documentation		
1771	GP Note prompt	GPs
3326	Nutrition screening tool	Carers / nurses
7287	Health Diary	People with ld /carers/ practitioners
7458	Health Status interview	Adults with ld
8231	OK Health Check protocol	Nurses
6206	Health file / communication aid	People with ld /carers/ GPs
7824	Health record card	GPs
5916	Photo-story leaflets	Adults with ld
6777	Health Diary	People with ld /carers/ practitioners
Education/ Training		
2174	HIV/AIDs awareness	Adolescents with ld
7287	Health advocacy	People with ld / carers / GPs
567	Health management issues	Special Education Teachers (SLD)
6206	Basic body knowledge	People with ld
7312	Women's health, coping skills	Women with ld
7731	Epilepsy / Diazepam use	Carers
358	Hazard perception	Children with ld
6071	Cancer day conference	Women with ld /carers/practitioners
6170	Breast awareness	Women with ld / carers
6621	Diabetes management	Carers

Clinics / services		
Women's health		
1427	Cervical screening clinic	Women with ld
1853	Needs led - cancer, family planning	Women with ld
6170	Breast screening clinic / home	Women with ld
8201	Cancer, family planning clinic/ home	Women with ld
Weight and fitness		
462	Fitness	Adults with mild/mod ld
8270	Weight and fitness	Adults with ld
697	Obesity	Adults with ld
3805	Underweight/malnutrition	Adults with ld
5270	Fitness classes	Children with ld
Health check programmes		
6995	Domestic Health Risk Assessment (HRA)	Adults with ld
7196	Nurse led domestic HRA	Adults with ld
4597	CNLD/GP health check clinic	Adults with ld
8002	Practice nurse/GP clinic	NR
8420	Practice nurse/CNLD clinic	Adults with ld
1352	Nurse led clinic	Adults with ld
1429	Practice nurse led clinic	Adults with ld
7717	CNLD/GP/Psychiatrist clinic	Children and Adults with ld
8089	Nurse led home/day centre check	Adults with learning disabilities
Health advice and information		
1481	Pop in clinic	Adults with ld / carers
Smoking reduction 4976	Domestic behavioural intervention	Adults with ld

Apart from health check programmes, the emphasis was on interventions to improve the physical health of more able people with learning disabilities where the aim of services is to empower the individual by facilitating self-advocacy and communication with health practitioners. In these circumstances it is reasonable that training programmes and documentary aides, such as diaries, should be targeted at those able to benefit from them. However, for the more severely disabled who rely most heavily on the facilitation provided primarily by their carers, but also on health

practitioners themselves, we identified little research into health improvement. Similarly, little research was identified into interventions to improve the physical health of children with learning disabilities, of any ability level.

As noted above much of the more rigorous research was at the pilot stage. Several of these authors commented that their intervention was to go on to full trial, however we could identify no further reports on these interventions to date. Consequently we have reported on the literature that was available and included some reports that contained no evaluative data to inform the reader of the range of interventions that are being implemented across healthcare and other services without making claims to efficacy.

In reviews of this type, where timescales are short, the literature is limited to that which can be obtained most easily. As indicated above, in the time available we were only able to obtain a third of the publications thought 'potentially' relevant. Although it is unlikely in any event that we would have been able to obtain copies of all these references, it is probable that the number of papers included in the review could have been doubled. However there is no guarantee that the research would have been any more rigorous.

Nevertheless the evidence available suggests that with appropriate adaptation to more visual or kinaesthetic (active/practical/task related) learning styles and skill practice, more able people with learning disabilities can benefit from the same types of health improvement interventions that are recommended for the general public. The interventions identified related primarily to lifestyle issues and health need identification. In terms of the model that guided the review, much of this activity occurred in the domestic and multi-agency facilitation domains. Very little literature was identified in the Health domain.

Most interventions were targeted at the person with learning disabilities themselves. Interventions that enhanced carer roles often included this as a secondary aim to an intervention with a person with learning disabilities. Very few studies addressed need to enhance the roles of practitioners in improving the physical health of people with learning disabilities. Lack of attention to the roles of carers and practitioners is a considerable omission, particularly in relation to the physical health of the most severely disabled people in this population who are also likely to have the greatest level of health need (e.g. van Schrojenstein Lantman-de Valk et al 1997).

The most prevalent intervention with people with learning disabilities aiming to improve physical health was the comprehensive health check. These

health checks, which covered the health indicators proposed as particularly important for people with learning disabilities by the POMONA project (Linehan, 2004), appeared to perform a key role in addressing inequity in health care provision. This was achieved by the use of screening to circumvent barriers to health improvement imposed by cognitive and communication deficits, which make health need identification for people with learning disabilities, and their carers, difficult. However several different models of service delivery were presented, most of which occurred in general practice but not all involved direct input from the general practitioner. Therefore, although the value of performing health checks has been demonstrated the most effective model has not been established.

Other facilitators of health improvement identified in the literature included, continuity of carer from carers, nurses and general practitioners (Lennox et al, 1997; Ziviani et al 2004). Trials of health records, files or diaries suggested that these documents had the potential to provide a safety net for people who are likely to be cared for by a number of different carers and practitioners over their lifetime. This type of intervention is likely to be very important for this population among whom even the most able is likely to have difficulty recalling their own past medical, or health, history. None of the research identified addressed the issues raised by Sutherland et al (2002) in relation to health promotion. These issues of responsibility for ensuring health promotion needs are met, adequate staffing to allow participation in health promotion activities, and access to community leisure facilities did not appear in the literature reviewed. This re-emphasises the point made above that interventions aiming to improve the health of people with learning disabilities tend to be narrowly focussed on the individual, rarely taking account of the role of their wider support network, both health and non-health.

Lennox et al (1997) and Ziviani et al (2004) through their consultations with general practitioners and other primary healthcare staff also note a number of issues affecting general practice roles in improving the health of this population. Flexibility and double length appointments were proposed as necessary for this patient group but none of the research identified addressed this issue. Training for general practitioners was also seen as key, however only two studies involved any actual training directly to general practitioners and these were ‘tool’ focussed and brief. Finally none of the literature reviewed discussed links between mainstream and specialist learning disabilities services in providing expertise in development of interventions to improve the physical health of people with learning disabilities.

In summary, improving the physical health of people with learning disabilities, as with the general population, will include health promotion and preventative measures to enable them to avoid preventable illness; measures to ensure early detection of health need to ensure implementation of treatment as early as possible to avoid acute illness; and effective management of existing long-term conditions. The health improvement literature identified addressed in large measure issues relating to health promotion and prevention through health education, observation/monitoring and cancer screening. Health checks, and attempts to enhance practitioner knowledge in relation to the health of people with learning disabilities addressed to some extent the issue of early detection of need. However few studies addressed health improvement or maintenance for people with additional long-term health conditions, aiming to ensure optimal health status. The quality of evidence overall was not high but gave the impression that this is a field that is becoming more active and rigorously researched, and that there may be more substantial evidence forthcoming in the foreseeable future.

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Appendix 1

Search terms devised for OVID Medline and adapted for searches in other databases.

1. learning adj (difficulty or difficulties).tw.
2. (learning disable$).tw.
3. (learning disabilit$).tw.
4. (learning deficien$).tw.
5. learning impair$.tw.
6. developmental$ adj (difficulty or difficulties).tw.
7. (developmental$ handicap$).tw.
8. (developmental$ retard$).tw.
9. (developmental$ disable$).tw.
10. (developmental$ disabilit$).tw.
11. (developmental$ deficien$).tw.
12. (developmental$ impair$).tw.
13. (intellectual$ handicap$).tw.
14. (intellectual$ retard$).tw.
15. (intellectual$ disable$).tw.
16. (intellectual$ disabilit$).tw.
17. (intellecctual$ deficien$).tw.
18. (intellectual$ incapacit$).tw.
19. (intellectual$ impair$).tw.
20. (mental$ handicap$).tw.
21. (mental$ retard$).tw.
22. (mental$ disable$).tw.
23. (mental$ disabilit$).tw.
24. (mental$ deficien$).tw.
25. (mental$ incapacit$).tw.
26. (mental$ impair$).tw.
27. Exp Mental Retardation/
28. Exp Mentally Disabled Persons/
29. Exp Learning Disorders/
30. OR/27-29
31. exp Health Promotion/
32. exp Health Education/
33. exp Health Status/
34. exp Health Behavior/
35. exp Health Services/utilization
36. exp Health Services/supply and distribution
37. exp Health Services Accessibility
38. exp Preventive Health Services
39. exp Communication Aids for Disabled

40. exp Speech Recognition Software
41. exp Socioeconomic Factors
42. Randomized Controlled Trails/methods
43. exp Appointments and Schedules/
44. health check$.tw.
45. health action plan$.tw
46. health improvement$.tw.
47. screening.tw.
48. goal planning.tw.
49. (target$ adj setting).tw.
50. program$ planning.tw.
51. health gain$.tw.
52. OR/31-51
53. 30 AND 52
54. editorial.pt.
55. letter.pt.
56. 62 OR 63
57. 54 NOT 57

Limit to English Language
Human
1990-2005

Appendix 2

Contacts identified as conducting research in health improvement field

The databases included contacts from grant-giving bodies, academics & researchers in the field of learning disabilities, medicine or both, professional bodies such as Speech & Language therapy LD Service. Relevant bodies & professional organisations included the Mencap, Nuffield centre and Norah Fry Research Centre.

Organisations included:
NHS Trusts (various), health centres, Hospitals, Learning Disabilities Services, Psychology Services, Services for People with Learning Disabilities, Learning Disabilities Partnership, Community Learning Disability Teams.

Researchers & academics from:
University of Sheffield, St Georges Hospital Medical School, University of Edinburgh, University of Northumbria at Newcastle, University of Glasgow, University of Essex, University of Wales, University of Leicester, University of Cambridge, University of Newcastle upon Tyne, University of Kent at Canterbury, University of Dundee, University of Sterling, University of Kent, MMU, University of York, University of Plymouth, University of Exeter, University of Southampton, University of Bristol, University of Surrey, University of Oxford, University of Reading.

The above academics came from the following departments/ centres:
Department of Education, Psychology Departments, Department of Genetics, Departments of Psychiatry, University College London, University of Essex, Social Services Department, School of Nursing & Midwifery, Department of Child Health.

Also, individuals such as psychiatrists, psychologists, clinicians, Nurse Facilitators, clinicians, Community Nurse, Speech & Language Therapists.

Appendix 3

Letter/email to contacts

<<Name>>
<<Address>>

Dear <<Name>>

Re: Review of the effectiveness of interventions to improve the physical health of people with learning disabilities

We have recently been funded by the Disability Rights Commission to conduct the literature review above. We are, of course, keen to identify as much of the relevant literature as possible but as keyword searching of relevant electronic databases is notoriously problematic we have decided that, in order to be thorough in our searching, we should also contact researchers whose recent work may have addressed issues in interventions to improve the physical health of people with learning disabilities.

We understand that you recently undertook a study entitled:
<<Study Title>>

Would you please let us know if your study addressed 'interventions to improve the physical health of people with learning disabilities'. If it did we would be grateful to receive a copy of any related publications from this work, or details of how we might obtain a copy. If not, would you please return the 'Not Applicable' slip enclosed for our records.

We are also keen to hear about any other publications (papers, reports etc) that you feel should be included in the review, or other researchers who you feel we should contact in relation to this work. Self addressed envelopes are enclosed for your convenience.

Your time and assistance with this review is greatly appreciated and will be acknowledged. However, we will need to access all the information by the end of October; therefore, we would appreciate an early response.

Yours sincerely,

Alison Alborz
Lecturer in Complex Learning Disabilities

Appendix 3

Reply slip

To:

Afroditi Kalambouka
Research Associate, ESI,
School of Education,
The University of Manchester

Tel. 0161 2753266
e-mail: afroditi.kalambouka@manchester.ac.uk

Researcher: <<Name>>

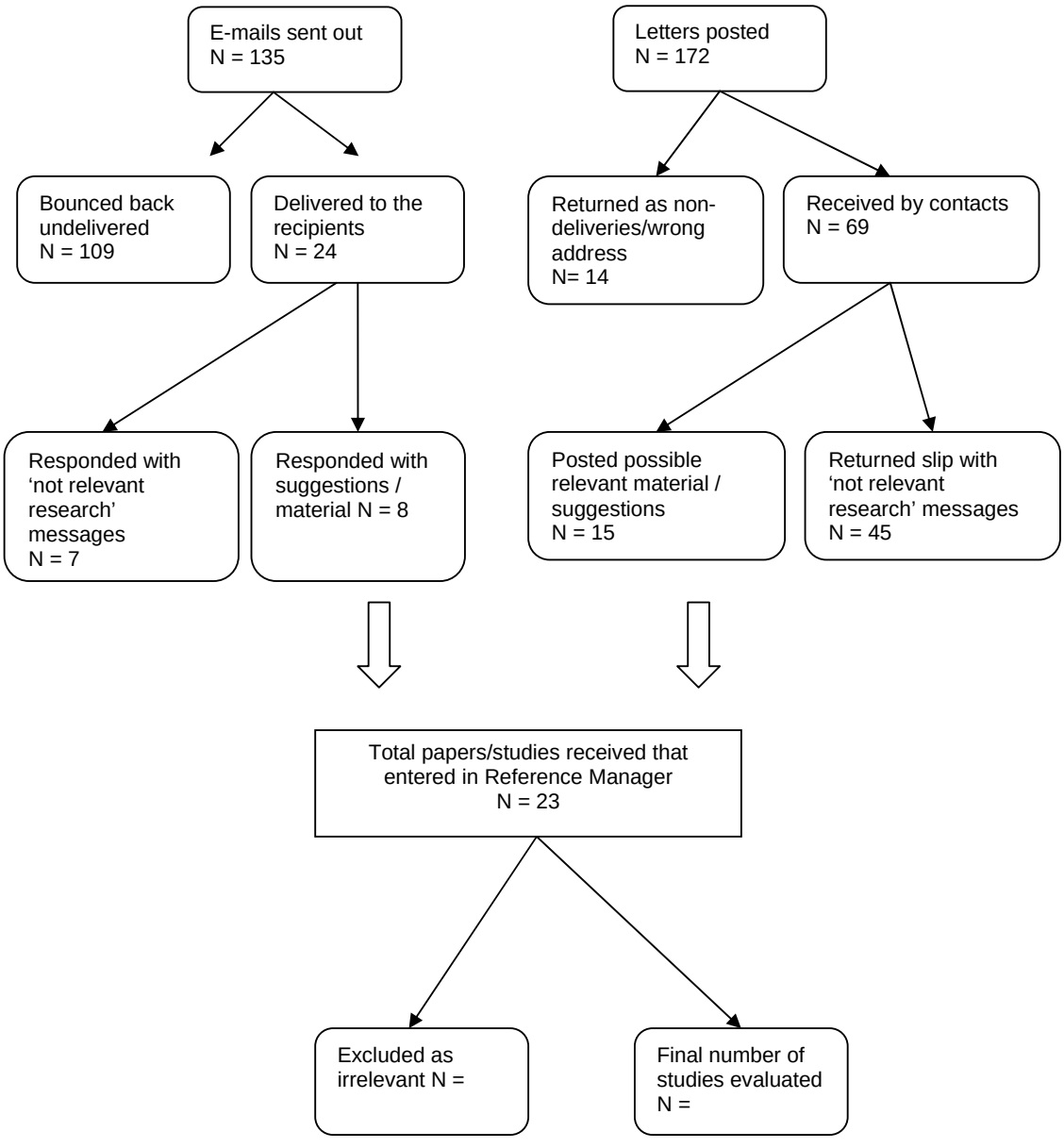
Project: <<Study Title>>

Sorry, our research did not address 'interventions to improve the physical health of people with learning disabilities'.

Signed
……..

Appendix 4

Result of contacts with professionals and researchers



Appendix 5

Expanded inclusion / exclusion criteria

	Include	Exclude
1	**Learning Disability**	• Screening for learning disability or specific syndromes • Genetic basis of • Prevention of • Prevalence studies
2	**Physical Health** • Health Education • Carer facilitation of • Health benefits of employment/vocation/ leisure	• Mental Health • General education • Social care • Employment/vocation
3	**Intervention** • Leaflets/guides to health or health services • Health needs assessment tools/interventions • Communication aids / therapies	• No intervention with person with ld or carer that impacts on person's health • Consumer satisfaction surveys • Service quality rating tools • Leaflets/guides to non-health issues/services • Needs assessment studies • Communication aids in non-health specific contexts
4	Primary health care service delivery • Hospital as primary care diagnostic service • 'Community healthcare' e.g. health visitors / physiotherapy / speech and language therapy • Learning disability healthcare services	• Hospital – unless re inappropriate referral • Hospice • Dental – unless link to phc • Optical – unless link to phc
5	Health care delivery system in UK (incl Eire) / Australia / NZ / Canada	Healthcare delivery in US or other countries using non-UK type system
6	Challenging behaviour related to ill health / pain	Challenging behaviour per se Challenging behaviour as mental health

Appendix 6

Papers included in the review

Final Rating	ID	Paper details	Study design	Age group	Disability range
1	**6995**	Aronow, H. U. and Hahn, J. E. Stay well and healthy! Pilot study findings from an inhome preventive healthcare programme for persons ageing with intellectual and/or developmental disabilities. Journal of Applied Research in Intellectual Disabilities 18(2), 163-173. 2005.	Quantitative	Adult	Mild/Mod
1	**7196**	Hahn, J. E. and Aronow, H. U. A pilot of a gerontological advanced practice nurse preventive intervention 23. Journal of Applied Research in Intellectual Disabilities 18(2), 131-142. 2005.	Quantitative	Adult	All
2	462	Ewing, G., McDermott, S., Thomas-Koger, M., Whitner, W., and Pierce, K. Evaluation of a cardiovascular health program for participants with mental retardation and normal learners. Health Education & Behavior 31(1), 77-87. 2004.	Quantitative	Adult	Mild/Mod
2	567	Moore, G., McConkey, R., and Duffy, M. The role of the school nurse in special schools for pupils with severe learning difficulties. International Journal of Nursing Studies 40(7), 771-779. 2003	Quantitative	Childr en (up to 19)	Severe/ Profoun d
2	1771	Jones, R. G. and Kerr, M. P. A randomized control trial of an opportunistic health screening tool in primary care for people with intellectual disability. Journal of Intellectual Disability Research 41(Pt 5), 409-415. 1997	Quantitative	Adult	All
2	2174	Newens, A. J. and McEwan, R. AIDS/HIV awareness training for young people with severe learning difficulties: an evaluation of two school programmes. Journal of Advanced Nursing 22(2), 267-275. 1995	Qualitative	Adole scent (11 to 19)	Severe
2	4597	Martin, G. Annual health reviews for	Quantitati	Adult	Mod/

Final Rating	ID	Paper details	Study design	Age group	Disability range
		patients with severe learning disabilities. Journal of Learning Disabilities 7(1), 9-21. 2003.	ve		Severe
2	7287	Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F. M., and Purdie, D. M. ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. Health Promotion International 19(2), 167-175. 2004.	Qualitative	Adult	NR
2	7458	Ruddick, L. and Oliver, C. The development of a health status measure for self-report by people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 18(2), 143-150. 2005.	Quantitative	Adult	Moderate
2	8002	Martin, G. Evaluation of a nurse led annual review of patients with severe intellectual disabilities, needs identified and needs met, in a large group practice. Journal of Learning Disabilities; 8(3), 235-246. 2004.	Quantitative	NR	NR
2	8231	Wakefield, S., Hunt, G., and Hunt, C. Community nurse learning disabilities: a case study of the use of an evidence-based screening tool to identify and meet the health needs of people with learning disabilities. Journal of Learning Disabilities; 5(1), 9-18. 2001.	Qualitative	Adult	NR
2	8270	Chapman, Melanie J., Craven, Michael J, and Chadwick, Darren D. Fighting fit? An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. Journal of Intellectual Disabilities 9(2), 131-144. 2005.	Quantitative	Adult	NR
2	8420	Alborz, A. Swallow, A. and Hanson, D. *The role of health check programmes in improving access to mainstream NHS healthcare services for people with*	Mixed	Adult	All

Final Rating	ID	Paper details	Study design	Age group	Disability range
		learning disabilities. National Primary Care R&D Centre, University of Manchester (in press)			
3	*567*	Moore, G., McConkey, R., and Duffy, M. The role of the school nurse in special schools for pupils with severe learning difficulties. International Journal of Nursing Studies 40(7), 771-779. 2003	Quantitative	Children (up to 19)	Severe/ Profound
3	*697*	Marshall, D., McConkey, R., and Moore, G. Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. Journal of Advanced Nursing 41(2), 147-153. 2003	Quantitative	Adult	NR
3	*1352*	Barr, O., Gilgunn, J., Kane, T., and Moore, G. Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland. Journal of Advanced Nursing 29(6), 1482-1491. 1999.	Quantitative	Adult	Mild/Mod
3	*1427*	Shaughnessy, P. Better cervical screening for women with learning disabilities. Nursing Times 95(44), 44-45. 3-11-1999	Quantitative	Adult	Mod/ Severe/ Profound
3	*1429*	Bollard, M. Improving primary health care for people with learning disabilities. British Journal of Nursing 8(18), 1216-1221. 14-10-1999. (GENERIC)	Mixed	Adult	NR
3	*1454*	Webb, O. J. and Rogers, L. Health screening for people with intellectual disability: the New Zealand experience. Journal of Intellectual Disability Research 43(Pt 6), 497-503. 1999.	Quantitative	NR	All
3	*3326*	Bryan, F., Jones, J. M., and Russell, L. Reliability and validity of a nutrition screening tool to be used with clients with learning difficulties. Journal of Human Nutrition & Dietetics 11(1), 41-50. 1998.	Quantitative	Adult	NR
3	*4453*	Lennox, N. G., Green, M., Diggens, J.,	Quantitati	Adult	All

Final Rating	ID	Paper details	Study design	Age group	Disability range
		and Ugoni, A. Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. Journal of Intellectual Disability Research 45(Pt 3), 226-232. 2001	ve		
3	*4976*	Peine, H. A., Darvish, R., Blakelock, H., Osborne, J. G., and Jenson, W. R. Non-aversive reduction of cigarette smoking in two adult men in a residential setting. Journal of Behavior Therapy & Experimental Psychiatry 29(1), 55-65. 1998.	Quantitative	Adult	NR
3	*6206*	Dodd, K. and Brunker, J. 'Feeling poorly': report of a pilot study aimed to increase the ability of people with learning disabilities to understand and communicate about physical illness. British Journal of Learning Disabilities 1999 Spring; 27(1), 10-15. 1999.	Quantitative	Adult	NR
3	*7312*	Lunsky, Y., Straiko, A., and Armstrong, S. Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 16(4), 247-253. 2003.	Quantitative	Adult	Mild/Mod
3	*7717*	Cassidy, G., Martin, D.M., Martin, G. and Roy, A. Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary health care teams. Journal of Learning Disabilities; 6(2), 123-136. 2002.	Quantitative	All	All
3	*7731*	Cole, C. and Pointu, A. An education programme for social care staff: improving the health of people who have a learning disability and epilepsy. British Journal of Learning Disabilities; 33(1), 39-43. 2005.	Quantitative	All	All
3	*7824*	Goldsmith, S., Cooray, S., Johnston, F.,	Quantitati	All	All

Final Rating	ID	Paper details	Study design	Age group	Disability range
		and Williams, G. Good practice, general practice: identifying the health needs of people with learning disabilities. Journal of Clinical Governance, Leicester 8(2), 83-88. 2000.	ve		
3	*8005*	Matthews, D. The OK health check: a health assessment checklist for people with learning disabilities. British Journal of Learning Disabilities 25(4), 138-143. 1997.	Quantitative	NR	NR
3	*8089*	Paxton, D. and Taylor, S. Access to primary health care for adults with a learning disability. Health Bulletin, 56(3), 686-693. 1998	Quantitative	Adult	All
4	*358*	Parry, C. and Jones, S. I can keep safe. Interview by Carol Davis. Nursing Standard 18(50), 20-21. 25-8-2004.	Report	Children (up to 19)	All
4	*1481*	Allan, E. Learning disability: promoting health equality in the community. Nursing Standard 13(44), 32-37. 21-7-1999	Quantitative	Adult	NR
4	*1853*	McRae, D. Health care for women with learning disabilities. Nursing Times 93(15), 58-59. 9-4-1997.	Report	Adult	NR
4	*3805*	Evers, S., Munoz, M. A., Vanderkooy, P., Jackson, S., and Lawton, M. S. Nutritional rehabilitation of developmentally disabled residents in a long-term-care facility. Journal of the American Dietetic Association 91(4), 471-473. 1991.	Quantitative	All	Severe/ Profound
4	*5270*	Schreiber, J., Marchetti, G., and Crytzer, T. The implementation of a fitness program for children with disabilities: A clinical case report. Pediatric Physical Therapy 16(3), 173-179. 2004	Quantitative	Children (up to 19)	NR
4	*5916*	We know best. Learning Disability Practice 2005 Apr; 8(3), 22-23. 2005	Report	NR	NR
4	*6071*	Brewster, J. Women's health in Doncaster. Learning Disability Practice	Report	Adult	NR

Final Rating	ID	Paper details	Study design	Age group	Disability range
		2005 Feb; 8(1), 29-30. 2005.			
4	6170	Cowie, M. and Fletcher, J. Learning disabilities. Breast awareness project for women with a learning disability. British Journal of Nursing 1998 Jul 9-22; 7(13), 774-778. 1998.	Report	Adult	NR
4	6621	Naphine, A. Empowering people with diabetes who have learning disabilities. Journal of Diabetes Nursing 2001 Spring; 5(1), 19-22. 2001.	Qualitative	Older Adult(60+)	Moderate
4	6777	Scott, E., Elvish, J., Luft, L., and Wilson, M. The development and use of a personal health resource. Learning Disability Practice 2005 Mar; 8(2), 27-31. 2005.	Quantitative	Adult	NR
4	7407	Pegg, J. Better health: Improving health promotion and health care for people with a learning disability. Health & Social Care in the Community 9(3), 179-180. 2001.	Report	NR	NR
4	8201	Taylor, G., Pearson, J., and Cook, H. Family planning for women with learning disabilities. Nursing Times 94(40), 60-61. 1998	Report	Adult	NR

Keywords: Health inequalities; Interventions; Learning disabilities; Literature review