

## **Executive Summary**

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

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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 improving 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.

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## **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 mass 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.

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## **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.

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