A health toolkit for people with learning disabilities

AUTHORS Cath Hunt, BSc, RGN, RNMH, is practice development nurse, learning disabilities; Paul Rankine, BA, PGCE, RNMH, is senior community nurse, Daventry community team for people with learning disabilities; Ros Blackmore, MSc, BSc, RNMH, is community nurse, Northampton community team for people with learning disabilities; all at Northamptonshire Healthcare NHS Trust.


People with learning disabilities are likely to have greater health needs than the majority of the population but are less likely to access health services and receive treatment. This article reports on a local initiative to develop a toolkit that people with learning disabilities can use to help them address their health needs through a simple health check and a health action plan.

People with learning disabilities are likely to have greater health needs than the majority of the population but are less likely to access health services and receive treatment. This article reports on a local initiative to develop a toolkit that people with learning disabilities can use to help them address their health needs through a simple health check and a health action plan.

The project

The past 10 years have seen increasing interest in improving the health of people with learning disabilities in Northamptonshire, following the implementation of the Community Care Act (Department of Health, 1990). Locally the focus has been on supporting those whose physical and mental health needs are greatest and who therefore come into contact with specialist learning disability services.

A health action plan steering group was set up as a subgroup of the partnership board that coordinates the implementation of Valuing People (DH, 2001). The aim of the group was to work together strategically to see how health action plans could be developed and implemented to reach all people with learning disabilities. The steering group had representation from:

- People with learning disabilities;
- Carers;
- The community team for people with learning disabilities;
- Health staff, including a doctor from public health;
- Social care staff;
- Advocacy organisations, including the patient advice liaison service;
- Local PCT associate directors and project managers.

Examples of good practice that had been developed by services in other regions were examined and it was agreed that the group would oversee the development of a simple health check and a health action plan. This would be combined into a user-friendly, personally held booklet, which could be seen as a toolkit for health.

A three-step programme developed the tool through focus groups, refined it through a pilot scheme, raised awareness and provided training.

Key principles

Three key principles underpin the work:

- Collaboration – with people with learning disabilities, their families, carers and local services;
- A person-centred approach – keeping the person at the centre of the development (DH, 2001);
- Empowerment – helping access mainstream services rather than reliance on specialist services.

Developing the tool

A focus group was formed by eight volunteers with learning disabilities and facilitated by two members of the steering group. The group provided ideas and...
Focus groups were set up consisting of 18 volunteers with learning disabilities from three day centres, who gave feedback on the prototype booklet developed by the first group. The groups agreed on simple and easy language with large print and pictures.

The focus groups also advised on who could best carry out the role of health facilitator. This is an important role involving helping the person complete the health check and drawing up a health action plan. The groups agreed that family members, carers and professionals would be best suited to the role.

Advice about developing the booklets was also sought from carers, families, advocacy organisations and primary healthcare teams. Links were forged with practice nurses, GPs, opticians and dentists to seek advice and to provide feedback on the prototype booklet. A flow chart was developed with support from a parents’ advocacy organisation to make the process easier to understand (Fig 1).

### Refining the tool

Once the health check and booklet were developed 30 people with learning disabilities were asked if they would like to take part in a pilot. The participants lived in a wide range of settings, including their own homes, social care, private and voluntary homes, and specialist healthcare facilities. Most consented to take part, with only one person declining. They chose their health facilitator and then were visited by steering group members to explain health action plans and the role of the health facilitator using DH guidelines (2002). The health check and booklet were also discussed in detail.

After a month an evaluation questionnaire was sent out and feedback collected. Participants accessed a range of primary and specialist healthcare teams as a result of completing the booklet (Table 1, p36). Outcomes included accessing further screening assessment and health promotion services including:

- Blood tests;
- Cervical smear tests;
- Visual and hearing assessment;
- Dental check-ups;
- Podiatry assessment;

### REFERENCES


It took approximately 12 months to develop the booklet and deliver the awareness training. One difficulty was in accessing primary healthcare staff’s ‘protected learning time’ as this was understandably booked up well in advance.

The main concern from all involved was who would take on the health facilitator role. In the focus group stage, people with learning disabilities felt that family members, carers and professionals should take on this role and this was reflected during the pilot scheme. Matthews (2003) suggests that a direct carer may interact with the person with a learning disability every day and is therefore in the best position to recognise changes in behaviour and health. Families and carers are usually very influential in the lives of people with learning disabilities and it is often difficult to bring about any change if they are not involved. However, Singh (1997) found that only 19% of unpaid carers and 33% of paid carers received information about healthcare. Therefore, it can be seen that training is required if health facilitators are to be effective.

A major concern was the resource implications for delivering this training across the county to such large numbers of people. Combining the awareness training with training on person-centred planning and teaming up with the independent sector and social care and health services made it more cost-effective and logistically easier to organise.

It was recognised that it was impossible to develop a tool that all people with learning disabilities could use independently as they use different forms of communication, have different ways of understanding information and have different support needs. However, the booklet can also be adapted to meet individual needs, for example by providing a taped version for a person with a visual impairment.

### REFERENCES


### TABLE 1. HEALTH SERVICES ACCESSED

<table>
<thead>
<tr>
<th>TYPES OF SERVICE ACCESSED</th>
<th>NUMBER ACCESSING SERVICE</th>
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<tbody>
<tr>
<td>Practice nurse</td>
<td>10</td>
</tr>
<tr>
<td>Dentist</td>
<td>10</td>
</tr>
<tr>
<td>Optician</td>
<td>8</td>
</tr>
<tr>
<td>CTPLD</td>
<td>7</td>
</tr>
<tr>
<td>Podiatrist</td>
<td>7</td>
</tr>
<tr>
<td>GP</td>
<td>6</td>
</tr>
<tr>
<td>Speech and language therapist</td>
<td>4</td>
</tr>
<tr>
<td>Dietitian</td>
<td>3</td>
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<tr>
<td>Orthopaedic consultant</td>
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</tr>
</tbody>
</table>

### Development

- Breast awareness;
- Healthy eating advice;
- Exercise advice;
- ‘GP-prescribed’ access to a local gym.

Remarks were positive. One respondent said: ‘It helped me think about what I need to do about my health.’ A health facilitator said: ‘It is good to clearly identify health needs and actions to be taken by whom and when.’ There were positive comments about support from primary healthcare services. The dental service was praised and its disabled access appreciated. However, some respondents in residential homes found it difficult to access services.

Results showed that the health check and booklet were simple, easy to understand and covered an extensive range of health issues. The use of pictures was appreciated. However, some feedback suggested that some of the questions were vague and used childish language. Several people said that there was not enough space for changes in health to be recorded and the layout could be improved.

Further changes were made to the booklet including producing it on yellow paper, providing removable rather than bound pages, using larger print and providing tick boxes.

### Awareness training

Awareness training packs were developed and accessed by approximately 800 people with learning disabilities, their families and carers. A person-centred approach to training was taken. This was rolled out across the county by healthcare and social services and an independent sector organisation. People were told they could obtain the booklet from the community team for people with learning disabilities (CTPLD). If they needed support to complete it, they could contact the team.

It was important to ensure that primary healthcare teams were aware of this project, so training was provided for 100 primary care staff on definitions and prevalence of learning disability, common health conditions, government strategy, HAPS and health facilitation, barriers and solutions to accessing services, and the role of the community team.

### Discussion

Developing the scheme with the involvement of people with learning disabilities has been very positive and well received. They were vocal, assertive and clear about what they wanted, despite initial concern from some carers and professionals that they would not be able to participate in this type of work.

Greater links have been forged between specialist learning disability services and PCTs. While partnership working in this way is very positive, it has to be recognised that it takes time and targets must be set accordingly.