

**Secondary Healthcare
for
People with a Learning Disability**

**A report completed for the Department of Health
by
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1. Introduction

Background

This report has been completed on behalf of the British Institute for Learning Disability (BILD) following a commission by the Department of Health. The report contributes to the development of the national strategy for people with a learning disability and aims to:

1. Analyse the strengths and weaknesses of the current provision of secondary healthcare for people with a learning disability in England.
2. Identify good practice in the provision of secondary healthcare for people with a learning disability.
3. Develop guidance to facilitate the development of good practice in this field throughout the NHS.

Note that the term 'secondary healthcare' in this report refers to specialist medical and surgical treatment in hospitals, outpatient clinics, and accident and emergency departments. It excludes psychiatric services.

The proposal involved work with four NHS regional offices (London, Northern and Yorkshire, Trent, and West Midlands), and it was anticipated that workshops and conferences would be organised in each of these regions to bring together people with a learning disability, family and professional carers, professionals and managers in hospital services, members of community learning disability teams, and commissioners. The National Development Team (NDT) was commissioned by the Department of Health to carry out a similar programme of work on the primary health care for people with a learning disability.

Secondary healthcare and learning disability

There is now a considerable body of research which shows that people with a learning disability have higher levels of health need than the general population (Lindsey 1998). Evidence that many people with a learning disability have problems in accessing healthcare and consequently have disorders which are undiagnosed and untreated has led to a series of policy initiatives to improve the effectiveness of primary health care for this group of people (Lindsey and Russell 1999). There is now an increasing body of research on which approaches are most effective in promoting the most effective primary health care for people with a learning disability (eg. Whitfield et al. 1996, Martin et al. 1997).

Less attention has been paid to the experiences of people with a learning disability in non-psychiatric secondary healthcare, and there is little data on the use of these services or on which forms of intervention are most effective. However, a recent record linkage study has estimated that people with a learning disability occupy about 0.4% of acute non-psychiatric hospital beds, with much higher bed occupancy among those living in the community (either at home or in residential homes) than among those still in NHS institutions (Morgan et al. 2000).

Some small-scale studies have identified a range of problems experienced by people with a learning disability when they are admitted to non-psychiatric secondary healthcare:

- < *Poor communication.* There are several reports of people with a learning disability not receiving appropriate information about the reasons for their admission or the medical treatment or surgical procedures, and not being asked for consent. In some cases, the carers were spoken to directly rather than any attempt being made to determine the patient's level of understanding or ability to consent (Mental Health Foundation 1996, Hart 1998).
- < *Fear and distress.* People with a learning disability report fear while in hospital, aggravated by a lack of information in a form they can understand and limited emotional support from general nurses (Mental Health Foundation 1996, Hart 1998).
- < *Lack of appropriate care.* Hospital routines and facilities may not be appropriate for the specific needs of people with a learning disability. There are reports of patients being asked to choose meals from written menus, not receiving assistance with feeding, being cold or in pain because they were unable to ask for help (Hart 1998, Lindsey et al. 1993). Specialist health services such as audiology or optometry may not be available to people with a learning disability in some areas (Department of Health 1999).

Many of these problems are also experienced by people with other disabilities, particularly failures to communicate with the patient, and the inappropriate nature of hospital routines and facilities (Beardshaw 1988, Biley 1994). It has been proposed that this results from the limited opportunity to develop clinical skills in work with people with a learning disability in medical and other health professional training and the consequent failure to confront stigmatising attitudes among professionals (Barr 1997, Shanley 1995).

Policy

Over the preceding decade, the Department of Health has emphasised the importance of providing a high quality of healthcare for people with a learning disability through inclusion in mainstream services, facilitated by additional support where required (eg. NHS Executive 1992). The Health of the Nation for People with Learning Disabilities (Department of Health 1995) recommended that:

“People with learning disabilities should have access to all general health services... with appropriate additional support as required to meet individual need... Any problems in obtaining health care for people with learning disabilities should be identified, and solutions found”.

The Department has been less specific on the what this additional support should comprise, and what solutions are preferred. However, Signposts for Success included the following recommendations as part of a much wider set of proposals for improving the health of people with a learning disability:

- < Training of staff, particularly in communication skills, in which people with a learning disability, their carers and advocates have a substantial input.
- < Provision of appropriate illustrated information about hospitals, including the use of introductory visits and videos.
- < Planning for hospital admission and clinic attendance, with attention to the needs of carers, and arrangements for the provision of personal support.
- < Access to quiet waiting areas and minimal waiting-times.
- < Guidelines for hospital staff, including information about local sources of advice and contact-persons in specialist services.
- < Personal and portable health records for people with a learning disability (Lindsey 1998).

These proposals have stimulated greater awareness of the needs of people with a learning disability in hospital, generating a series of local initiatives. The aim of this paper is to contribute to the development of innovative solutions which can substantially improve the experiences of people with a learning disability in hospital.

2. Data-collection

Conferences and workshops

The limited extent of previous research in this field resulted in this study being exploratory, with the aim of defining key issues and identifying local innovations and solutions. The proposed programme of research therefore used the focus group method, in which a facilitator works with a group of participants to define a shared perception of key issues, using a mixture of plenary and small group problem-solving methods. It was proposed that the participants in each group would include people with a learning disability, their supporters, family and professional carers, senior managers and professionals in hospital services, commissioners, and members of CLDTs. The range of participants and the need to include people from several districts required the use of conferences of up to 40 participants, rather than the smaller focus groups traditionally used in this type of research.

Both this project and the parallel project on primary care carried out by the NDT encountered major problems in organising conferences in four NHS regions, within the time-scale of the research. This resulted from the demands placed on the limited resources available to regional offices by the other tasks needed for the development of the national strategy. It ultimately proved possible to organise three meetings by the end of June:

1. A conference in Sheffield for Trent NHS Region on 31 May 2000. This had about 40 attenders, including people with a learning disability and their supporters, family carers, professionals from community learning disability teams (CLDTs), hospital clinicians and senior professionals, managers of hospitals services, and health authority commissioners. After a description of the aims of the conference, the facilitators (SC and DM) gathered personal experiences for people with a learning disability about their experiences as inpatients, outpatients, or as patients in A&E departments. This was expanded by the accounts of family and professional carers, and was followed by a series of presentations on innovative local services in different parts of the Region. The Conference concluded with a series of workshops, which made recommendations for supporting people with a learning disability in hospital, improving outpatient and A&E care, and for improving the quality of inpatient nursing care in hospital. Margaret Flynn (who is responsible for completing the parallel project on primary care) also acted as a facilitator. The authors acknowledge with gratitude the work of Roger Wallis (Trent Regional NHS Office) for his work in organising this conference.
2. A conference in London for London NHS Region on 27 June 2000. This was similar in membership, numbers and format to the Sheffield Conference, but had

workshops focussing on improving information to patients with a learning disability and to hospitals about patients, providing support for people with a learning disability in hospital, and implementing change. The authors acknowledge with gratitude the work of Wendy Wallace (London Regional NHS Office) for her work in organising this conference.

3. A workshop at the Royal Shrewsbury Hospital on 15 June 2000. This included eight people including patients and former patients with a learning disability, the head of nursing, a family carer, the CLDT head, and a member of a support agency for people with a learning disability. This discussed a similar range of experiences and topics as the conferences, and focussed in particular on information and support issues. The authors acknowledge with gratitude the work of Rick Robson (Shropshire's Community and Mental Health Services NHS Trust) in organising this workshop.

Other sources

Other sources of information used in the preparation of this report included:

1. Attendance at a meeting of the Department of Health's Users Forum, which analysed the problems experienced by people with a learning disability in accessing secondary healthcare, and reviewed a range of solutions.
2. Collection of material relating to the secondary healthcare of people with a learning disability, including several examples of hospital policy statements, information leaflets, health authority commissioning policies, and guidance material for people with a learning disability. The London Region of the NHS began developing a learning disability strategy in advance of the Department of Health, and the reports developed as part of this exercise were particularly useful.

The authors gratefully acknowledge the advice of Sally Mallard (West Midlands Regional NHS Office) and Phil Sculthorpe (Northern and Yorkshire NHS Regional Office).

3. Results

Hospital experiences

Both conferences included detailed accounts of the experiences of people with a learning disability in inpatient and outpatient care, and in A&E departments. Their overriding memories were of being fearful and sad, of being ignored by staff, of not understanding why tests were being performed or what treatment was being undertaken, and frustration and anger at what was being done to them. There were some instances of more positive experiences (particularly at the workshop in Shrewsbury), but the key problems can be summarised as follows.

1. Poor communication

The conferences identified poor communication as a central problem with hospital care for people with a learning disability. This included:

- < *Limited skills among hospital staff in communicating with people with a learning disability.* People with a learning disability and carers reported instances of physicians and surgeons who used pictures and explained treatments and/or operations in easy English before obtaining consent from the patient. A more frequent comment, however, was that hospital staff appeared unfamiliar and embarrassed in dealing with people with a learning disability. Individual members of staff sometimes showed reluctance to talk directly to the patient, explain the reasons for the admission to them, or determine the extent to which they understood and could give consent. In other cases, hospital staff failed to make use of the specialist knowledge of the carer in how to recognise idiosyncratic non-verbal signs (such as signs of anger or distress), or to explain the side-effects of medication.
- < *Inadequate information about the hospital before admission.* Several people with a learning disability reported that they would have appreciated more information before elective admissions. This could have taken the form of videos or booklets with photographs and large-print text.
- < *Inadequate information about hospital procedures.* There were several reports from both people with a learning disability and their carers of inadequate information about diagnosis and treatment. Waiting times in A&E departments were a further cause of frustration, particularly when coupled with a lack of information. One report is typical. A person with a learning disability told of how he had gone to hospital at 9.30 a.m. and had waited until 5.30 p.m. before being treated. No explanations were given and no one explained to him why there had been such a delay.

- < *Poor transmission of information within the hospital.* Hospital staff noted examples of how referrals to diagnostic and treatment services within the hospital (such as radiotherapy) failed to indicate that the patient had a learning disability. This gave limited opportunity for staff to prepare the patient or consult a carer about the most appropriate way of conducting such procedures as scanning or taking blood.
- < *Poor information at discharge.* Several people with a learning disability said they had not been told what would happen to them at discharge, and some had been told to find their own way home even though they had little experience or skill in using public transport.
- < *Limited information about choices within hospital.* A common experience of people with a learning disability attending the conferences and the workshop was being presented with a written menu for hospital meals with no other assistance in making a choice. Other facilities in the hospital were not explained, and patients felt too intimidated to express their wishes to ward staff.

2. Fear and distress

Many examples were offered during the conferences of how hospital admission had been a traumatic and fearful experience. This occurred because of the usual fears of illness and death, but was made worse for people with a learning disability because of their unfamiliarity with hospitals and the lack of any comprehensible information from hospital staff about what would happen to them.

Attendees at the conferences reported varying experiences in the extent to which staff provided support to them. Some people with a learning disability said they received support from doctors and nurses. But others said they had received little emotional support to help them deal with their feelings of anxiety and distress. No-one appeared to regard it as their job to comfort the sick. After they became used to being in hospital, they became bored and disoriented, but they received little engagement from nursing staff in a way that was meaningful and easily understood.

3. Poor quality of care

Carers and professionals at the conferences noted that hospitals experienced difficulties in making 'concessions' to the individual needs of inpatients with a learning disability. For instance, one family carer stayed in hospital with her daughter who had scoliosis. It was easier for her to use a settee rather than a chair, but there was no chair available and no room in the ward for a settee. Crowded hospital wards (even in new hospitals) meant that there was little space between beds, and no room to manoeuvre a wheelchair. Similar lack of flexibility was reported in meeting special needs with feeding,

resulting in some patients missing food and drink. Lack of adapted facilities in hospital for patients with profound and multiple disabilities meant that one patient went six weeks in hospital without a bath.

Family carers at the conferences said that hospitals could be made more responsive, but only after sustained assertiveness. One carer (whose daughter had been in hospital several times) usually succeeded after a few days in getting her moved to a side-room in the ward. Another family carer had persuaded the hospital to mark clearly on the front cover of her daughter's medical notes that she must not be kept waiting (because impatience was expressed violently). This did not always work, and a refusal by receptionists to move her daughter to the front of the queue usually led to violent and destructive incidents in hospital waiting-rooms.

Some attenders gave examples of people with a learning disability receiving an inferior quality of medical treatment, which they assumed reflected the low expectations of clinicians about this group of patients. There were examples of a lack of attention to epilepsy, and a failure to prescribe appropriate medication. Low expectations and unresponsiveness among ward staff had resulted in failures to manage bedsores, starvation of patients and dehydration. The latter occurred because staff had assumed that the patient had refused drink or food simply because they had not touched what was put in front of them).

Carers' experiences

Carers at the conferences noted that hospitals seemed to expect them to be present throughout the stay of a patient with learning disability. This was not always possible because of family circumstances, and it would be necessary in such cases for community learning disability services to provide support. Support for inpatients who live in residential homes is usually provided by a member of the home staff. This can be costly, and it was common for the NHS trust managing the hospital to require payment from the CLDT (NHS trust or local authority) or the residential home. The home might in turn seek to offset this cost by charging the authority purchasing the residential care for the inpatient. There were reports of hospitals refusing to admit a patient for elective treatment until these financial arrangements had been confirmed. This could result in substantial delays in treatment.

Family carers reported examples of where they had collaborated effectively with hospital staff to provide information about the person with a learning disability, and shared care in an efficient way. But others were concerned that the hospital expected them to be with the inpatient for prolonged periods. They were also concerned that if they did not support the patient, no-one else would provide comfort and ensure the patient's basic care needs were met. Carers were reported that they often provided

long-term support with limited assistance from hospital staff, and little access to hospital facilities. This made the provision of support by family carers particularly stressful, and carers at the conferences emphasised that the responsibility of care for people with a learning disability in hospital should be shared by nursing staff.

Hospitals

Senior managers and professionals from hospital services who attended the conference noted a number of problems they experienced in providing effective care for people with a learning disability:

- < *Poor information on admission.* There might be limited information from the patient's GP, the CLDT, or the residential home even in the case of elective admissions. Emergency admissions presented particular problems because it was often not clear who should be contacted. It was found that professional carers could sometimes be 'poor historians' when it came to reporting the medical history of the patient.
- < *Limited staff training in the needs of people with a learning disability.* Few hospital staff had had the opportunity to develop skills in working with people with a learning disability during their professional training. It was proposed that the effectiveness of nursing staff in dealing with patients with a learning disability was impeded by the limited numbers of trained nurses on many hospital wards, and the definition of other care staff as having a primarily domestic rather than care role.
- < *Risk to other patients.* Nurses reported difficulties in dealing with the challenging behaviour presented by some people with a learning disability. It was understood that this often resulted from pain, fear, or an inability to communicate, but there was concern that it could seriously worsen the quality of care for other patients or, in extreme cases, pose an active risk.
- < *Consent.* The increasingly litigious atmosphere in healthcare made clinicians particularly wary of consent issues. This tended to predispose them against invasive treatments.

Solutions

The conferences and workshops provided data about many local initiatives and ideas or improving the hospital care of people with a learning disability. This was particularly the case at the workshop in Shrewsbury, where there was evidence of a sustained and comprehensive approach. There was clearly a local creative energy evident in the Trent regional conference, producing several innovative local services. This was less so in the London, where the fragmentation of health and social care in the city into 32 boroughs

and 16 health authorities presented active and committed professionals, managers, and carers with a clear obstacle to the generation of solutions.

Shropshire's Community and Mental Health Services NHS Trust and the Royal Shrewsbury Hospital (RSH) have a comprehensive range of support for people with a learning disability and their families at a time of hospital admission. Family carers who need to be in hospital to accompany an inpatient with a learning disability can receive support from a carers' support group ('Helping Hands') and from volunteers at the RSH. Individual patients have a portable 'patient passport', which summarises key information and prevents the need for repeated explanations. A hospital admissions sheet has been developed to collect information about a patient from daycare and residential units before a hospital admission. A comprehensive guide ('Helping Hands') has been produced for nursing staff in the RSH on learning disability. A learning disability unit located near the RSH is a source of training and advice to hospital staff. A 'Health for All' questionnaire has been developed in a form accessible by many people with a learning disability, to assess their views of the quality of healthcare they receive. For details, contact Rick Robson, Shropshire's Community and Mental Health Services NHS Trust 01743 261181 (Fax 261446).

The main solutions proposed and discussed at the conferences and workshops were as follows.

1. Improved information

There were a wide range of initiatives which aimed to improve the transfer of information between patient, carer, hospital, and community services:

- < *Patient-held data.* Several districts are implementing 'communication passports', which include a photograph of the person, together with information about key contacts, communication, and health needs. A variation that is more appealing to some people with a learning disability is the Medi-ID or Medalert pendant. This is widely-used by a range of people who may need emergency medical care, and includes either engraved information or a pull-out paper strip.
- < *Preparation for admission.* There were a number of examples of programmes designed to prepare people with a learning disability for an elective hospital admission. These included a combination of videos, accessible information booklets, and more sustained desensitisation programmes. Several districts had developed information booklets and videos quite independently, and without reference to equivalent material developed by bodies such as the RNIB. Another proposal is to use pre-admission nursing visits before inpatient admission to

collect information about the patient and carer support, and explain what it involves to the person with a learning disability.

- < *Information to accompany the patient into hospital.* These included information sheets which were completed by carers (family, residential or daycare), and which summarised key personal, communication, and medical information about the person with a learning disability. This would accompany them to hospital in the case of elective admissions, or could be sent rapidly to the A&E department in case of emergencies. This could be supplemented by life books, which summarise the life and interests of the patient, and which is kept by the bedside. It alerts ward staff to the needs of the patient, their likes and dislikes, and reminds everyone that the bed is occupied by a person and not an illness or disability.
- < *Training programmes for clinical and healthcare staff in communication.* There were a few examples of CPD programmes which aimed to improve the skills of hospital staff in communicating with people with a learning disability. These involved the participation of people with a learning disability (including a group of actors), carers, and staff from the CLDT and other specialist services. The aim was to ensure that the information given to patients with a learning disability and their carers was appropriate to their levels of understanding. This required that doctors should introduce themselves, listen, be flexible, be inclusive, avoid jargon, and give extra time to people with communication difficulties and their carers. Augmentative and alternative communication (AAC) methods were required for patients with limited or no verbal skills.

Harrogate Health Care NHS Trust have published a guide for hospital staff which describes the problems often experienced by people with a learning disability in hospital, what staff can do to communicate, provide support, and deal with disturbed behaviour, as well as contact arrangements with the CLDT. For details, contact Kevin Millar, Harrogate Health Care 01423 889624.

- < *Improved information about choices while in hospital.* Attenders at the conferences proposed that AAC methods should also be used to enable inpatients with a learning disability to exercise choices in meals (pictures or symbols for food and not just names), while named nurses should identify themselves personally to the inpatient and leave a photo by the bed.
- < *Improved transfer of information within hospital.* This required improved hospital information systems, which enabled staff to maintain multi-disciplinary computer-based records. These enable staff in diagnostic and treatment facilities to access information about an individual patient with a learning disability and arrange for additional support when needed.

2. More effective support arrangements

Some proposals aimed to improve the quality of support available to inpatients with a learning disability, and the experience of family and professional carers providing support:

- < *Clearer responsibility for funding.* Attendees at the conferences recommended that liability for funding support for inpatients with a learning disability should rest with the NHS trust managing the hospital, in the same way that the hospitals would meet the additional costs of caring for other communication minorities such as the deaf or people who do not speak English.
- < *More collaborative working with family carers who support inpatients with a learning disability.* It was recommended that hospitals do not expect family carers to be present on a 24 hour basis, that they be included in handovers and case planning, and that they be invited to use staff facilities in the hospital.

Birmingham Heartlands NHS Trust have developed a clear one-page set of guidelines for ward staff in the care of people with a learning disability (Rush 1996). This emphasises that “Any care delivered by outside carers or relatives is to be seen as goodwill on their part and not an obligation. Communication is essential so that hospital nursing staff evaluate the effectiveness of the care delivered, whoever delivers it. If carers and relatives choose to assist, their welfare must be considered eg. relieving them for breaks if necessary”.

- < *Specialist support teams.* Some districts had proposed to develop specialist teams to support inpatients with a learning disability, either hospital or community-based. These aim to provide support where family or professional carers can not do so, and operate on a 24-hour basis. An example is shown in the box below.

Birmingham Specialist Community Health NHS Trust has proposed to set up an acute response team of experienced learning disability nurses and support workers to offer practical assistance to patients in an acute setting or advice to acute nursing staff on appropriate approaches and interventions. The team would be on call 24 hours a day, every day, and be available to all hospitals in the City. Additional support would involve training acute staff, providing guidelines, and liaison with community services. For details, contact Miriam Somerville, Birmingham Specialist Community Health NHS Trust, 0121 627 8195.

3. Improving the quality of care

Key proposals made in the conferences included:

- < *Improving the hospital environment.* It was agreed that hospital environments should be made more comprehensible for people with a learning disability and other communication minorities by using pictorial symbols, photographs, and colour codes. It was suggested that it might help every patient and visitor if, for instance, a symbol of an eye replaces the difficult word 'ophthalmology' in hospital signs. There need to changes to hospital design standards to allow more space for wheelchairs, and more facilities for family carers. All hospitals need a store of equipment that can be used for inpatients with profound and multiple learning disabilities.
- < *The inclusion of programmes to develop skills in work with people with a learning disability in all medical and health professional training.*

St. George's Hospital Medical School in London has reviewed the content of its medical and nursing degrees to identify the sessions relating to learning disability. These were brought together as part of a coherent programme to develop clinical skills in communicating with and diagnosing people with a learning disability. A company of actors with a learning disability take part in a play demonstrating their experience of healthcare services, while other actors are used in standardised clinical examinations (OSCEs). For details, contact Professor Sheila Hollins.

- < *Changes in the organisation of inpatient nursing.* Attenders at the conferences proposed that the difficulties experienced by inpatients with a learning disability reflected broader problems in the resourcing and organisation of inpatient nursing. Greater flexibility in the delivery of inpatient care requires higher ratios of trained nurses to patients, and a more effective definition of the role of other ward staff.
- < *Access to expertise.* Some districts had designated a member of the CLDT to liaise with hospitals, be their point of contact for advice on management, and ensure that information had been passed between the hospital, the patient, carers, and community services. An alternative model proposed in one district was for the hospital to appoint an admissions co-ordinator with responsibility for identifying patients with a learning disability and for liaising with specialist teams.
- < *The development of new specialist clinical services.* It was proposed that the very specialised health needs of particular groups of people with a learning disability would inevitable pose problems for generic services, indicating a need to develop new specialist teams as centres of excellence.

North Derbyshire Community Healthcare Service have developed a specialist pain service in collaboration with a consultant anaesthetist with the Northern General Hospital Trust in Sheffield. It has been found that a high proportion of people with a learning disability and associated physical disorders suffer prolonged pain, and that this can be a key factor in self-harm and challenging behaviour. For details, contact Roger Hutchinson, North Derbyshire Community Health Care Service, 01246 565007.

- < *Alternatives to hospital care.* One proposal at the London conference was to investigate the wider use of hospital-at-home and telemedicine for people with a learning disability. This would enable patients to be treated in more familiar surroundings among carers who were aware of their distinctive needs and patterns of communication.

Achieving change

There was therefore broad agreement at the conferences and workshops about the most appropriate pattern of services that would provide a high quality of secondary healthcare for people with a learning disability. But attendees were less sure of the most effective way to achieve change in hospital services. The formal commissioning route had proved useful in several districts in raising awareness of the healthcare needs of people with a learning disability, and in building networks across health and social services. However the formal strategy development groups that operated within regions and districts tended to function as conveyor belts of guidance from the Department of Health, rather than as means of mobilising expertise and building local alliances for change.

Leicestershire and Rutland Healthcare NHS Trust completed a review of the services it provides for people with a learning disability. This has developed a health checklist to be completed by a specialist nurse or social worker for all people on the learning disability register, alignment of community learning disability nurses with PCGs, guidelines for staff in residential homes on the information they need to provide to people due for admission, and a set of clinical audit standards. For details, contact Joan Hawkins, Leicestershire and Rutland Healthcare NHS Trust 0116 225 5207 (Fax 5214)

Another approach to establishing networks was to use a more informal and inclusive model. This links professionals with an interest in improving the health of people with a learning disability by collecting and publishing information about local initiatives to improve healthcare, promoting good practice, and organising conferences.

The Midland Access to Health (MATH) Group is one of the longest-standing informal networks. It has organised conferences on the health needs of people with a learning disability, and has published *The West Midlands Regional Directory of Learning Disability Practice* in collaboration with the NHS West Midlands Regional Office. Similar bodies inspired by MATH have been established in other parts of the country. For details, contact Martin Bollard, Coventry Healthcare NHS Trust, 024 76 559758 (Fax 251914).

An alternative route, which was followed in most districts, was to build links with key personnel in local general hospitals, to promote changes in clinical practice. In some cases, a small number of staff within individual hospitals and NHS trusts had championed the need for improved services for people with a learning disability, using audit procedures to identify shortfalls in services. However, changes achieved by this route could be 'fragile', in the sense that they depended on the commitment of one or two key staff, and could be reversed when those members of staff left.

Central Sheffield University Hospitals have developed an audit programme to measure and improve the quality of care provided for inpatients with a learning disability. This began with meetings with community learning disability nurses to identify problems and solutions. A smaller focus group was set up which prepared a series of audit tools and care protocols, as well as resource packs on learning disability for each ward. The focus group is also developing an integrated care pathway for the care of people with a learning disability. For details, contact Mrs. R. Bollands, Royal Hallamshire Hospital, 0114 271 1900.

One new approach recommended by some attenders at both conferences was to use facilitation. The use of an appointed facilitator to work within clinical teams to has been effective in improving primary healthcare for people with a learning disability (Martin et al. 1997). A facilitator would be appointed to work within a general hospital specifically to collaborate with clinicians to develop policies and clinical practices that achieve improved communication, support and care for people with a learning disability.

4. Recommendations

The discussions in the conferences and workshops indicate that a broad consensus exists among people with a learning disability, their family and professional carers, clinicians and managers about the kind of services needed to provide a high quality of secondary healthcare for people with a learning disability. Their proposals correspond to those in *Signposts for Success*, and emphasise the need for a range of measures to improve communication, to support patients with a learning disability in hospital, and to improve the quality of healthcare. Most of these proposals require sustained incremental change, but some have more far-reaching implications. In particular:

1. The lack of clinical skills in work with people with a learning disability found among hospital staff indicates that the universities and royal colleges need to ensure that professional training provides an opportunity to develop skills in work with people with a learning disability. Among staff in post, there is a need for an equivalent programme of continuing professional development.
2. The inflexibility of inpatient care experienced by many people with a learning disability (which echoes equivalent surveys of people with other disabilities) indicates that hospital services are often unresponsive to variations in need and unable to provide adequate nursing care for patients who are unable to assert their needs. This raises questions about the staffing levels in many hospital wards, and also the allocation of responsibilities between different grades of ward staff.
3. The fragmentation of the NHS on a district (and more recently PCG basis) is a disincentive for the development of services with specialist skills in meeting the health needs of small groups in the population. This means that, even in the largest cities in the country (or in the case of London, the largest city in the EU), health services are unable to take advantage of economies of scale. As a result, there are few clinical teams which specialise in the (non-psychiatric) medical and health problems experienced by adults with a learning disability. Fragmentation also results in the misuse of scarce management resources, with each health district attempting to develop its own information leaflets for carers and its own policy statements on the healthcare of people with a learning disability.

The problems in sustaining improvements in hospital care reported by attenders at the conferences indicate the difficulties in promoting longstanding change in clinical practice in the NHS. Over the last two decades, major changes in services for people with a learning disability have resulted mainly from local initiatives by entrepreneurs in the public and independent sectors who have exploited loopholes in social security

regulations or, more recently, in the funding of further education (Cumella 1998). A key strategy for developing change in services should therefore involve empowering champions of change and enabling them to network effectively together.

It is therefore proposed that the Department of Health consider the following policy options:

- < *To require that NHS trusts to meet the cost of support for inpatients with a learning disability in the hospitals they manage.* This would reduce administrative work, avoid delays in admission, and state unambiguously to hospital services that the effective healthcare of people with a learning disability is a core responsibility. Support costs should be met from hospital-wide budgets, rather than ward or unit budgets.
- < *To identify beacon sites in each region as development centres in providing secondary healthcare for people with a learning disability.* These sites would be funded as mini-HAZ sites, to provide training for other hospital services in the region, and to collect, assess and recommend best practice.
- < *To fund clinical effectiveness research into the facilitation model for improving hospital care.* This would involve tendering for an action research programme using a development of the facilitation model pioneered in primary healthcare (Martin et al. 1997).
- < *To fund BILD to develop a website recording information about initiatives in secondary healthcare.* This would expand the databases developed by MATH and similar bodies, and would facilitate links between people with a learning disability, carers, professionals and managers who have a commitment to improve the secondary healthcare of people with a learning disability.

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