

# **IMPROVING THE HEALTH OF PEOPLE WITH LEARNING DISABILITIES IN THREE LONDON BOROUGHs: AN AGENDA FOR ACTION**

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## **Introduction**

Improving health and health services, tackling health inequalities and ensuring effective services to people at risk of serious disadvantage are key national priorities. Since the publication of the national strategy for people with learning disabilities (Department of Health 2001), their health and health care have been a particular focus of policy attention. This is now given specific force through the requirements on Learning Disability Partnership Boards; 'Liberating the Talents: Helping Primary Care Trusts and Nurses to deliver *The NHS Plan*' (Department of Health 2002); the 'Discharge from Hospital: pathway, process and practice' (Department of Health 2003); the resource pack, 'Working Together' (Gregory et al 2003); and the 'Health Needs Assessment Report: People with Learning Disabilities in Scotland' (NHS Health Scotland 2004), all of which recognise that while NHS agencies have the major responsibility for good and fair health services, better health is everybody's business.

Anticipating these policy requirements, a multi-stakeholder 'Health Alliance', (formerly under the umbrella of the Merton, Sutton and Wandsworth Health Authority), provided a focus for local review and action on improving the health of people with learning disabilities. The Health Alliance commissioned us to undertake a study of strengths and weaknesses in current provision and use this in facilitating the development of a programme of local action. This paper seeks to share this work with a wider audience.

Recent structural changes, particularly in the NHS, hinge on pursuing a results-oriented agenda. The main responsibilities now rest with the South West London Strategic Health Authority, the three Borough Learning Disability Partnership Boards, the two Primary Care Trusts and all health service provider agencies, working in partnership with each other and their local communities. Accordingly, the Health Authority proposed the creation of more local Health Alliances, as sub-committees of the Partnership Boards and with Primary Care Trust leadership. This proposal identified three main streams of work:

- promoting healthy lifestyles,
  - improving the healthcare experiences of people with learning disabilities in primary care, and
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- improving the healthcare experiences of people with learning disabilities in acute care.

As our contribution to this work, we summarised the agenda for health improvement and identified the key responsibilities of the main agencies involved. This was designed to be a resource to the local Health Alliance groups and an action check-list for the mainstream agencies charged with achieving better health and health care for the local population.

## **The challenge of ‘Health for All’**

The general determinants of ‘Health for All’ are well established. Biology plays an important part, so too does our environment, our experiences and lifestyle. To manage our health we have to understand our bodies and the importance of health promoting behaviours. We need to access good quality primary, acute and specialist health care. And if we need support, it is important that someone is there to coordinate our health care and facilitate health promoting opportunities. We need action to reduce health inequalities; action to challenge discrimination; better access to mainstream primary and acute health services; and better coordination and support through, inter alia, health advocacy.

International, national and local research confirms that people with learning disabilities have poor health as reflected in extra morbidity and premature mortality; have difficulty getting to use the health services other people use; and often report poor experiences of health care when they do use the NHS. Further, all these problems are more likely among people from Black and ethnic minority communities.

Our own diagnostic work identified six themes in local health experiences:

- the typically short-term nature of health promotion initiatives;
- the lack of experiential knowledge of working with people with learning disabilities in most mainstream services;
- the use of specialist services and community teams as alternatives to mainstream health promotion and primary care;
- the significant gaps in the health services that are available to people with learning disabilities;
- the lack of sensitivity of acute hospital services, both out-patient and in-patient, to the requirements of treating and supporting people with learning disabilities well; and
- the endemic under-investment in making services and information about them accessible to people with learning disabilities and ensuring their understanding and proper consent to treatment.

As Wendy Perez, the self-advocate member of our team says,

*There’s a lot to do. It seems to me that people with learning disabilities need to have a better knowledge of their health needs like what to eat, having a healthy lifestyle and how to prevent getting ill, because prevention is better than cure.*

*My GP, the Primary Care Team and the health professionals in hospital I see have known me since I was young. This is the way it should be for everyone. We’ve learned together. Even making mistakes along the way, like they used to talk to my Mum and Dad and not me, but we’ve managed to sort them out.*

*Possibly GPs don’t know who’s got a learning disability or how to pick up the signs that someone may need help understanding, thinking things through, knowing the system and asking good questions. They need our help.*

*It's better for people to know things. If we didn't have a learning disability, people would tell us anyway! If we don't get told things, it will come back to haunt all of us! Schools should teach things outright and not keep things back. In normal schools, they have health biology and sex education. In special schools, that's a taboo subject as they don't think people with learning disabilities will have relationships.*

*So much has to change. People with learning disabilities have to have higher expectations and services have to move with the times.*

### **The agenda for health improvement**

Nationally, the commitment to improving health and reducing inequalities, the NHS Plan and the increasing number of National Service Frameworks provide strong policy support for local action. Against this background, the local studies offer a range of foci for making progress. What follows does not seek to be comprehensive but does address each of the main areas of health identified above, in the form of action plans, organised according to the short and medium term agenda. (The local version of this agenda also identified valued examples of current practice on which further local action might build.)

<b>Box One</b>		
<b>Lifestyle, health promotion and managing one's own health</b>		
Possible Priorities		
<b>Issues</b>	<b>Short Term</b>	<b>Medium Term</b>
Understanding my body and living healthily	Map what is happening now in educational and leisure settings  Identify and promote what is valued and effective  Improve the quality and availability of accessible health information  Create local directories of what is available and make these widely accessible	Promote a positive health curricula in schools, colleges, day services and people's accommodation and support services  Develop people with learning disabilities as mentors  Promote better access to general health and leisure facilities
Improving access to mainstream health promotion and disease prevention	Plan National Service Framework implementation to ensure the proper inclusion of people with learning disabilities  Ensure accommodation and day service contracts address healthy living matters e.g. on diet and exercise	Monitor the impact of National Service Frameworks on health processes and outcomes  Encourage the contributions of people's relatives and friends to this agenda  Monitor providers' delivery of support to healthy living
Enhancing everyday opportunities and support for healthy living		Improve the availability of flexible transport



**Box Three**

**General acute health care**

Possible Priorities

<b>Issues</b>	<b>Short Term</b>	<b>Medium Term</b>
Improving access to, the sensitivity of, and support during, episodes of acute care	Identify acute care champions in each Trust  Establish methods for identifying patients with learning disabilities  Develop plans for people with learning disabilities in hospital which are strongly influenced by relatives and others who know them well  Explore scope for offering person to person supports for people admitted to hospital in contracts with accommodation and support services  Support (i) Access Committees and (ii) the Patient Advice and Liaison Services in focusing on patients with learning disabilities	Support the top management in acute Trusts in using evidence from short-term initiatives to plan and deliver a culture change programme  Gather case study material to outline the determinants of outcomes for patients with learning disabilities, and feedback to managers  Focus on disability in basic and post-basic professional training

**Box Four**

**Mental health (including specialist learning disability) mental health services**

Possible Priorities

<b>Issues</b>	<b>Short Term</b>	<b>Medium Term</b>
<p>Improving access to, sensitivity of, and support during inpatient mental health care</p> <p>Maintaining and improving mental health specialist advice and consultation within primary care</p> <p>Developing specialist assessment and intervention services for people with mental health or challenging needs across the three boroughs</p> <p>Developing specialist psychological therapy services for people with any degree of learning disability</p>	<p>Develop protocols for opening up the full range of mental health services to people with learning disabilities with appropriate learning disability specialist expertise</p> <p>Ensure the appropriate use of Care Programme Approach</p> <p>Design joint learning events and programmes for Community Learning Disability Teams, Community Mental Health Teams, Crisis Teams, Assertive Outreach Teams and members of the Local Implementation Team</p>	<p>Support senior managers in the mental health trust to plan and deliver learning disability-friendly areas within inpatient services</p> <p>Gather case study material on the determinants of outcomes for patients with learning disabilities and feedback to managers</p> <p>Design and deliver a local service response to minimise out-of-area placements e.g. supported accommodation; and opportunities for planned breaks</p> <p>Ensure availability of specialist learning disability mental health 'beds'</p>

**Box Five**

**Specialist learning disability health services**

Possible Priorities

<b>Issues</b>	<b>Short Term</b>	<b>Medium Term</b>
Creating borough-based Community Learning Disability Teams which properly link health and social care skills through local authority leadership  Developing new ways of working with specialist mental health services in the Mental Health Trust	Reshape specialist health care contributions to promote full use of mainstream NHS services  Raise mental health awareness and skills in a range of community services and good liaison with Mental HealthTrust services  Involve mainstream health, social care and voluntary sector organisations in the design and development of valued service responses to people with learning disabilities	Improve specialist assessment and treatment for people with complex health needs living in the community  Establish routinely available shared training opportunities for specialist professionals working in the same localities

## **Responsibilities for action**

The Learning Disability Partnership Boards in each Borough have the widest multi-agency representation and are well-placed to act as champions for change across the whole of this agenda. Their health task groups particularly benefit from PCT leadership. These Boards have the distinctive asset that people with learning disabilities and family members are directly represented in their work. However, the Partnership Boards are not themselves statutory agencies and the main responsibility for delivering better health and health services rests with the new health agencies and their partners in local government and more widely. As a brief guide we outline the relevant responsibilities of each main body.

### Learning Disability Partnership Boards

The three borough Partnership Boards have an overview across the whole of this agenda although action must necessarily be taken through other agencies. Reflecting this overview, local proposals draw on 'Valuing People' to identify eight specific responsibilities:

- Challenging discrimination in healthcare services;
- Ensuring National Service Frameworks include people with learning disabilities;
- Ensuring the availability of Health Facilitators for people with learning disabilities;
- Ensuring that people with learning disabilities are registered with GPs;
- Ensuring all local people with learning disabilities have a Health Action Plan;
- Building on good practice in local primary care services (e.g. Department of Health 1999);
- Ensuring all mainstream hospital services are accessible;
- Providing guidance to local healthcare agencies with respect to issues of consent to treatment for people with learning disabilities.

We would add that, because of their wide membership, including social care agencies, housing and support providers and links to employment and leisure services, Learning Disability Partnership Boards, with additional public health expertise, are especially well-placed to pursue the agenda for tackling inequalities and promoting health summarised in **Box One**.

### Primary Care Trusts

While Learning Disability Partnership Boards are the local champions for people with learning disabilities, the Primary Care Trusts are the champions for health of their local population. Their task is to convert the strategic statements of the Department of Health into local realities. They have lead responsibilities in promoting health, improving equity, shaping the local health system and themselves providing good quality primary and community services. Learning Disability Partnership Boards and Primary Care Trusts, with the involvement of people with learning disabilities, are together therefore the main agents across the whole of the agenda set out above.

We summarise these PCT responsibilities as:

- Working closely with Learning Disability Partnership Boards to ensure delivery of responsibilities listed for the Boards;
- In their commissioning role, ensuring the commitment of general acute health care, mental health and specialist learning disability mental health services,

and specialist learning disability health services to addressing the agenda in **Boxes Three, Four and Five**;

- In their commissioning and providing roles, ensuring delivery of the agenda for primary care and coordination in **Box Two**;
- Promoting the involvement of people with learning disabilities in the emerging Forums and in developing this agenda, training staff and reviewing service quality;
- Ensuring Clinical Governance arrangements prioritise accessible and effective services to potentially marginalized groups;
- Continuing to develop the Primary Care Trusts' capability to carry out these responsibilities.

#### NHS Provider Trusts

The acute hospital Trusts (St. George's and St. Hellier) have a duty to work with the Primary Care Trusts and the Learning Disability Partnership Boards to deliver on relevant aspects of the responsibilities set out above and take a leadership role in relation to the agenda in **Box Three** (general acute health care). It should be noted that our own work indicated that people with learning disabilities and their families were often most critical of their experience in acute hospitals.

Similarly, the St. George's and South West London Mental Health Trust has a collaborative role with the Primary Care Trusts and Learning Disability Partnership Boards in relation to mental health matters and a leadership role, most particularly in relation to the agenda in **Box Four** (Mental health and specialist learning disability mental health services).

#### South West London Strategic Health Authority

The Strategic Health Authority (SHA) has different functions from its NHS predecessors and a considerably larger population. The ways the SHA can best work with Primary Care Trusts and other health services providers are still emerging. Our analysis suggests five main foci for its overview and leadership:

- Developing a sector-wide (now across six London boroughs) approach to improving the health of people with learning disabilities, including performance management arrangements and the pursuit of equity;
- Ensuring that weaknesses in local capacity, for example to serve people with additional complex needs, are addressed through more local agencies;
- Offering a mediating role when local agency disagreements (e.g. in relation to funding complex care packages) undermine effective delivery;
- Ensuring the successful implementation of national policy on long stay hospitals; and
- Sustaining a sector-wide approach to staff training and development through the Workforce Development Confederation.

While we do not expect readers to be concerned with the detail of progress in the three London boroughs, we hope this paper will provide a useful resource and stimulus to review and action planning elsewhere.

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