



Institute for applied health and social policy
LEARNING DISABILITY PROGRAMME

ACTION GUIDE SUMMARY

valuing health for all

Primary Care Trusts
and the
Health of People with
Learning Disabilities



KING'S
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Current national policies and local delivery plans offer the chance of better health for everyone and a step-change in the quality of health services. Primary Care Trusts have the key local role in ensuring this happens for all in their populations. People with learning disabilities have relatively poor health compared with their fellow citizens and often experience less good access to appropriate services.

This Action Guide is addressed primarily to:

- Executive leadership in PCTs
- Senior staff with specific learning disability leadership roles
- Primary care teams
- Community staff with learning disability expertise
- People with learning disabilities and others engaged with them in health advocacy
- PCT partners in the Learning Disability Partnership Boards and Strategic Health Authorities

Drawing on the lessons from recent experience in 12 PCTs across England, it offers these readers an invitation to work together to ensure people with learning disabilities are part of the *all*.



KEY FINDINGS

Goals

Ensuring people with learning disabilities are included alongside other local citizens in local strategies to:



IMPROVE PATIENT ACCESS

DELIVER BETTER SERVICES AND OUTCOMES

IMPROVE THE EXPERIENCE OF SERVICE USERS

REDUCE HEALTH INEQUALITIES

STRENGTHEN NHS CAPACITY

ENHANCE NHS LOCAL ACCOUNTABILITY

DEVELOPING PCT CAPACITY

- Planning with Learning Disability Partnership Board allies
- Establishing senior internal leadership for the health of people with learning disabilities
- Including the needs of people with learning disabilities in NSF and other local health improvement strategies
- Using staff with learning disability expertise to promote mainstream inclusion
- Ensuring routine information systems track learning disability health issues
- Investing in practitioner and staff training for inclusive practice
- Strengthening two-way communication with people with learning disabilities and their families

INVOLVING PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Improving peoples' health and health experience through:

- Ensuring registration for all with a GP and dentist
- Providing easy to understand health information
- Offering individuals their own Health Action Plan
- Fostering appropriate and respectful treatment

Listening to the views of people with learning disabilities and their families through:

- Surveying their health experience
- Supporting health advocacy
- Engaging people with learning disabilities in staff training and service audit

ADDRESSING THE HEALTH FOR ALL AGENDA IN MAINSTREAM SERVICES

- Addressing health inequalities in partnership with others
- Collecting and using data about health of people with learning disabilities
- Including a learning disability perspective in NSFs and Cancer Plan implementation
- Surveying access to health services and acting on the results

RESHAPING SPECIALIST CONTRIBUTIONS FROM COMMUNITY LEARNING DISABILITY TEAMS

Reviewing community teams and the roles of specialist health professionals and:

- balancing individual interventions with help for other services to do their jobs better
- ensuring specialists work with mainstream health services *and* learning disability services
- developing the health facilitation role
- supporting the introduction of health action plans.

checklist

What the PCT can do

- Nominate a 'lead' person with sufficient seniority to ensure that the health of people with learning disabilities is included in PCT priorities and Local Delivery Plans; that the health dimension is included in the commissioning of learning disability services, and that the PCT is well represented in the Learning Disability Partnership Board.
- Use *Improvement, expansion and reform: ensuring that 'all' means 'all'* to select appropriate targets. Encourage learning disability specialists to contribute to the implementation of NSFs, Cancer Plan, etc.
- Address the health inequalities experienced by people with learning disabilities through health improvement plans (e.g. via Local Strategic Partnerships) and equity audits
- Identify a senior practitioner (probably a GP or nurse) who can act as a 'champion' in professional forums such as the PEC and the clinical governance committee. Their role could include identifying any concerns of practitioners about working with people with learning disabilities
- Make sure that people with learning disabilities are registered with GPs and dentists. Support provision of a variety of health information in accessible forms
- Check that the development of information systems (such as practice registers) includes appropriate coding of learning disability (Read code E3), so that better data on health and access may be collected for future use
- Invite people with learning disabilities to make a presentation to the PCT Board about health and access to health services, perhaps to introduce the topics of Health Action Plans and health facilitation. Draw on the expertise of specialist learning disability services to support these initiatives
- Include people with learning disabilities and family carers (including people from black and minority ethnic communities) in surveys and other means of listening to patient and public views (e.g. PALS, Patient Forums). You could commission a local self advocacy group to conduct service audits
- Make sure that training and development plans support both 'awareness raising' and 'in depth' training on specific appropriate topics (you could involve self advocates as co-trainers)

What primary health care teams and secondary health services can do

- Ask one person in the practice or service to take a special interest and make sure that the health of people with learning disabilities is included in (not additional to) your main priorities
- Invite representatives of the community learning disability team to a practice meeting or clinical governance forum to discuss:
 - the health needs of people with learning disabilities who are registered with the practice or use your services
 - any concerns you have about working with people with learning disabilities (for example: consent; communication; people arriving at the surgery or hospital without proper information)
 - how the specialists can support you to do your job (for example, helping you to include people with learning disabilities in your access and screening targets)
- Collaborate with the PCT and specialist services to introduce Health Action Plans
- Ensure that practice and hospital information systems capture information on the health of people with learning disabilities, combining clinical data (such as risk of heart disease) with Read code E3 (learning disability)
- Use the data to audit health risks and access to appropriate interventions (for example as part of action on National Service Frameworks)
- Involve people with learning disabilities and family carers in practice or service audits and Patient Forums
- Include learning disability awareness in your training plans. Invite people with learning disabilities to talk about their experiences

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