

learning disability workstream report

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summary

The services for Adults with Learning Disability (LD) has been established as a separate workstream in the Northamptonshire review of services.

The importance of all those with LD, and their carers, receiving the appropriate care and support which is afforded to others in the community is a major theme.

To live in the community, and have choice and control over your life as a human right, requires an integrated approach, and involvement of users and carers in the planning of services.

Service users and carers have identified where the barriers are and commissioners and providers need to take note.

The implementation of Valuing People , and the current consultation on Valuing People **NOW**, will continue to drive the future vision for people with LD, with the NHS focus on keeping people healthy, reporting on health of people with LD, and improving information and advocacy services, alongside the other priorities of inclusion in the community, access to housing and making change happen.

A joint strategic needs assessment will strengthen the integration of Local Authority and health which is necessary for effective outcomes.

It is proposed that the LD Development Fund will move from the PCT to the Local Authority to be used for the priorities listed in the present consultative document.

The provision of good health care will focus on the needs of this population through robust information, health checks and the role of GPs in working more effectively with people with LD. Health facilitators will play a crucial part in ensuring that the Health Action Plans are in place and are being used; and staff in mainstream health services will know more about the needs of people with LD. The development of local Specialist LD services and enhanced integrated community LD teams are an essential component of this vision, ensuring individuals with the most complex needs receive the healthcare they require.

The overarching vision for health is that all people with LD, irrespective of where they live, will be able to access and receive appropriate mainstream and specialist services needed to maintain a healthy life. The principles shaping this vision are that:

- All service delivery will be person-centred
- The majority of people with a learning disability will have:
 - an identified health facilitator
 - a comprehensive health check led by primary care
 - a health action plan
- PCT's will be actively engaged as full partners in the local multi-agency planning and review of services for people with a learning disability.
- Within specialist services there will be a clear model of integration that provides support in the person's own environment where possible.
- Advocacy and choice will be enhanced through a wide range and variety of information.

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introduction

Learning Disabilities (LD) is not an identified separate workstream in the Darzi NHS Next Stage Review, and in the local review of Northamptonshire's Health Services, the service area was also originally part of the Mental health workstream.

The decision in Northamptonshire to have a specific LD group has reinforced the commitment to ensure that the NHS vision of services being Fair, Personalised, Effective and Safe is delivered. In LD services this vision is especially pertinent.

The demographic changes in Northamptonshire indicate that with an increase in population numbers there will be a concomitant rise in the numbers of people with complex needs, including those who have LD, and with medical and technological advances life expectancy will also increase. Unfortunately, robust epidemiological data are not available. The current strategy being developed for Older People will need to take into account how services will be delivered for vulnerable people with LD.

Despite having greater health needs than others, it is reported that people who have LD do not typically seek out health

care. A system organised on facilitation and health checks is needed to ensure care is provided when necessary.

Over the past few years there has been a greater focus on the needs and rights of people with LD. The first White Paper in 30 years addressing these issues, Valuing People (DH 2001) promotes good practice as part of the modernisation agenda in the NHS, stating that the main objective for the NHS is “.....to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary”.

Six years on from the original Valuing People paper, Valuing People NOW was published in December 2007, and is in the consultation phase until March 2008. This document has major implications for health services, the themes of which have already been raised in the workstreams, and need to be a critical part of this review.

The main priorities identified for the next 3 years (2008-2011) are:

- personalisation – so that people have real choice and control

over their lives and services;

- what people do during the day (and evenings and weekends) – helping people to be properly included in their communities, with a particular focus on paid work;
- better health – ensuring that the NHS provides full and equal access to good quality healthcare;
- access to housing – housing that people want and need with a particular emphasis on home ownership and tenancies; and
- making sure that change happens and the policy is delivered – including making partnership boards more effective.

Northamptonshire Local Authority and the local NHS are committed to these priorities which they are taking forward through the In Control project. Progress to date shows that by 2010, 258 people will be in 'ordinary living' circumstances. Currently, 62 people have been placed with a further 50 in 2008/09 and 50 in 2009/10. A further 96 will be placed following the re-provision of health campus residential services by 2010. This change will have a direct impact on the way specialist services will need to be commissioned

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The Disability Rights Commission highlighted the inequality in services for people with LD who had physical health problems, and who had also undergone fewer health investigations and screening than others in the population.

In 1999 the NHS Executive produced a booklet *Once a Day* stressing the necessity for people with LD to have the same rights of access to health services as everyone else.

In order to ensure that the health care needs of this group are met, Specialist LD Services are essential to provide the specific and additional support, and to work in partnership with mainstream health services and other appropriate specialist services to ensure that access is fair, effective and safe.

The working group looked at good practice for adults with LD, noting that the children's issues would be addressed in a separate workstream. However, reference is made to children at the transitional stage to adult services where there are issues in provision of care.

This report summarises the main areas that were felt to be important in improving the level of health services for people with LD, and their carers, in Northamptonshire.

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review of the evidence base

A great deal of research has been carried out in the field of LD much with a focus on specific conditions eg autism, but also on generic issues such as access, health checks and plans, and information.

The Valuing People website provides materials to be used for good practice and highlights the importance of partnership working; integrated planning; care pathways promoting individual services closer to home ; swift access and the importance of the education and teaching role in service provision.

“Out of the box” ideas pack, on this website reinforces the belief that progress will be made when support is provided which prevents hospital admission; which enables access to specialist services; and which has dedicated local LD services

MENCAP’s *Treat me right!* and *Death by Indifference* highlight the importance of carers’ involvement and a lack of understanding and awareness of issues which results in death.

The National Institute for Health Research’s list of current work shows research being undertaken in Sheffield, the findings of which will be disseminated after completion

in December 2007. This project will aim to tie emergent research knowledge to policy and practice.

In 2003, the National Primary Care Research and Development Centre (University of Manchester) undertook a literature review of access to health care for people with LD. Alison Alborz who was the researcher, raised important issues around the meaning of access, the continuum of access and the differences between ‘having’ access and ‘gaining’ access.

A further study in 2005 by the same author on *The role of health check programmes in improving access to mainstream healthcare for people with Learning Disabilities* gave evidence on the benefits of providing regular health checks. She suggests that the service ought to be nurse-led, linked to resources from Quality Outcomes Framework (QOFs) to enable implementation to be started and that importance be given to rigorous recording of information.

The Primary Care Service Framework - Management of Health for people with Learning Disability in Primary Care specifies equality of access; regular individual checks; individual Health Action Plans; reduced need for hospital admission/length of stay;

promotion of better health outcomes and better involvement in health care; and an improvement in support, information sharing and understanding needs.

The role of commissioning is seen as crucial as evidenced by recent documentation from the DH Office of the National Director of Learning Disabilities, *Commissioning Specialist Adult Learning Disabilities Health Services. Good Practice Guidance*.

The publication of the toolkit *Green Light - Making it Happen (2004)*, supports local health and social care communities to improve mental health services for people with LD, and is important in planning future specialist services and should lead to improvements in service provision.

The second *Mansell Report* (reviewed in Nov 2007), looked at services for people with LD and challenging behaviour, or mental health needs and highlighted the need for better use of investment to develop and expand the capacity for local services to deal with the needs of this group of people, along with the need for specialist services locally to support good mainstream practice.

A combined report published by the Royal College of Psychiatrists, British Psychological

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Society and Royal College of Speech and Language Therapists, *Challenging Behaviour: A Unified Approach*, in June 2007, detailed good practice standards for services supporting people with LD who present behavioural challenges.

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regional findings

The regional workstream on Mental Health and Learning Disability focussed primarily on the mental health needs of people with LD, thus missing the opportunity to explore how the Darzi principles could be used to address all of the needs of this group of individuals.

The group felt that it was essential for the issues raised and highlighted in this report by the Northamptonshire LD workstream to be submitted as part of the Darzi review.

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public feedback

The Northamptonshire Partnership Board organised three deliberative events in December 2007, in different locations, to give users, carers, members of the public, staff and key stakeholders, an opportunity to put views forward on the future vision for health services. More than 300 people attended and the specific comments, questions and issues raised in relation to the 2 questions posed for LD discussions are as reported below. (The full report is available from the PCT) Some of the views as expressed have been categorised under various headings.

How would you like to see services for this group of people improved?

Flexible and personalised care

The groups discussing this area felt that flexibility and personalised care together with support and help to maintain independence of the individual was highly important.

Better levels of communication and care that is flexible

Some groups felt that people with severe learning disabilities get support but those with less severe learning disabilities often fall through the net and get little if any support

Treated as other citizens

There should be an active reduction in stigmatising people with learning disabilities and that the individual should be seen as a 'whole' by medical professions.

People with LD should be seen as individuals not as people with a disability.

People with learning disabilities should be asked their views on service development to ensure that services are not misdirected or developed which would result in people easily falling through the gaps.

Transition/Integration

Improvement can be made in developing services that have a focus on smooth transition between children and adult services.

Services need to match the individual, often high level needs.

There should be continuity of support and healthcare which would stop people with learning disabilities being passed from pillar to post with improved transition and early communication between health and social care. Consider equity of services

There needs to be better respite care with

specific identified need and increased interface between health and education. Transition period is extremely important. Is it appropriate to have a 20 yr old in paediatric services? What are the individuals needs?

Education and Training

There needs to be better training of front line staff –not just from health i.e. police. Multidisciplinary training would be beneficial and give rise to increased understanding of need. Better links with education from health services and health and social care.

Education of public and health staff essential on learning disabilities i.e. often dealing with a myriad of issues e.g. a person with learning disabilities with diabetes, issue of patient/ family education and compliance with medication together with safety.

Information

Information on specific conditions for people who provide care for children with learning disability should be more easily available

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What areas of service provision for people with a learning disability would benefit most from an integrated approach between health and social services?

Funding/budgetary issues

A variety of discussions took place on this issue with funding/budgets and better levels of communication and outreach services being mentioned specifically. Pooled formalised budgets and one decision making body played a major role in the discussions.

Respite care

Among other areas, specialist multidisciplinary teams, a champion in each of the stakeholders and trusts which would push forward the learning disabilities issues and agenda, better outreach and improved respite care all featured highly.

Hospital admission can lead to respite care by default.

Currently a slow response to assessment and provision of equipment this needs to become a top priority together with support for carers including respite care

Transition

Area of transition needs to be specifically focussed on.

Choice

Specialist units are being closed down as move to community is deemed essential, however where is the choice in this? – Inclusion as a ‘fad’ rather than looking at the needs of the individual who may not be able to cope or want to live in the community. People with learning disabilities in the community need support from both health and social care

Integration

The groups felt strongly that separation of health and social care needs puts up unnecessary barriers.

Facilities need further development as children with learning disabilities can’t integrate and come up against cultural barriers. Need to plan now for growth agenda i.e. facilities for people with LD need to be planned .

In determining the vision for the future and determining the model of care the workstream was mindful of these views and felt they accorded with the vision expressed by the members of the workstream.

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model of care (adults)

The model of care to ensure good quality care was based on a series of integrated care pathways which enable people with LD to receive a gold standard health service. This model will also support the Putting People First: social care concordat, by joint and collaborative working to provide personalised services, and based on the vision of all people with a learning disability in Northamptonshire being able to live in ordinary living circumstances.

The components of the model, with some service examples, which were addressed, include:

Healthy Living

Health assessments carried out in accordance with Primary Care framework; training available for providers of primary care. Health promotion activities are accessible to all people with LD
Health facilitators in place.

Primary Care and Access to Services

Joined up working and commissioning with a reliable LD register
GPs as first point of contact with a knowledge base of services for appropriate referral and guidance
An identifiable primary care clinical lead for LD

GPs resourced to offer an enhanced service to meet needs of people with LD.

Specialist Services

Small in-patient facility
Intensive community support and crisis response
Enhanced Integrated community teams for people with LD
Potential to reduce out of county placements and to repatriate those placed away from Northamptonshire

Support to Carers

Expertise of carers used fully and expectations understood
Information and support more easily available.
Family carers have support through a 'named' worker
Single point of access to services through a knowledgeable person

Partnership Working

Evidence of parent partnership and participation, in line with Valuing People, Northamptonshire County Council's 'Children's Services Guidance', and "Contact a Family" model and literature
Joint approach to care, funding and respite
Improved liaison at transition
Carers' views taken into account at beginning

of planning process through to development and review of services

Seamless children and adult services for health and social services, with clear roles, lines of accountability and responsibility, including voluntary agencies in service provision through links with Partnership Boards.

Each of these areas is inter-linked and aims to follow the policy guidance with a service designed around the needs of the individual.

Each of the components of the model will have measurable outcomes for example; number of health action plans, number of annual health checks and number of GPs providing an enhanced service as part of Healthy Living and Primary Care/ Access to Services; number of out of county placements, length of stay in Assessment and Treatment Unit and number of individuals with LD accessing mainstream services within Specialist Services.

Partnership working is a major factor in planning through LD Partnership Boards and in joint strategic needs assessment with the Local Authority, and is essential to ensure effective implementation of policies.

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existing good practice

The re-provision of NHS residential services through the individualised budgets methodology is paramount in enabling the vision of ‘ordinary living’ for all to be achieved. This good practice conforms to all that is in the guidance and Northamptonshire is the only County in the East Midlands which has adopted this approach.

Within Northamptonshire there are many examples of care being provided which is person-centred and based on evidence which is available. Examples given reflect the elements highlighted in the model of care. Some of the services provided by Northamptonshire Healthcare Trust (NHT) have been recognised through awards for good practice, inclusion, leadership and innovation, and invitations to present papers and share knowledge. Services in this category are:

- Access to breast screening services for women with LD where, through partnership working, a service is now in place and effectiveness shown by the evidence of early diagnosis and treatment of breast cancer .
- Development of a Health Action Plan (HAP) Toolkit which involved service users in the production of the toolkit.
- The Learning Disability Journal Club which provides a forum for staff from a variety of disciplines to have time, and gain confidence, in appraising research to determine best available evidence and relating to practice.
- Awareness training for staff on the topics of relationships, sexuality and abuse in relation to people with LD
- Provision of day opportunities through the development of a peripatetic support team.
- Within NHT, there are also examples of a whole family approach in behaviour therapy; of user and carer involvement in Health Promotion; specific training for staff in assessments (Changing Skills) and in partnership working (Personality Disorder Team and Community Forensic team).
- The Trust’s use of a Clinical Competency Folder is an effective way of evaluating services through audit, and identifying staff training needs.
- A Carers’ policy is in operation between NHT, Kettering General Hospital and Northamptonshire County Council. Carers’ registers are being developed in GP practices.
- A joint epilepsy clinic with paediatrics takes place in Northampton ; the community dental service provides a targeted service for those with special needs, and in Diabetes care, DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) is applied appropriately to meet user’s needs.
- Strategic health facilitators are in post and provide a strategic overview of what services are required, provide leadership and promote health facilitation and planning for people with LD.
- Easy read communication tools “Helping me in Hospital” and an Accident and Emergency Grab sheet to provide hospital staff with information on emergency presentations of conditions associated with LD. Development of Easy Read leaflets on Rights for those detained under the Mental Health Act
- Established Carers’ Reference group run by the Associate Director of the Learning Disability Service within NHT
- The Learning Disabilities Partnership Board (LDPB) is established and provides a good foundation for partnership working.

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obstacles

Whilst there were many examples of good practice it was acknowledged that in many cases the service was not universal and it was important that the 'pockets' of excellence were replicated across the county where appropriate. Some of the obstacles identified in the workstream are similar to those raised in the deliberative events, and are also identified in Valuing People **NOW** documentation

Organisational

- Culture and attitude in different organisations prevent LD being given any priority in many service developments and provision.
- Working with mental health teams can be problematic either through a lack of understanding or willingness to work with LD.
- The LDPB is not allowed to function as effectively as it could do if it was given true delegated responsibility and power.
- Perception of NHS/Local Authority having a history of promises with no delivery.
- LD teams in Local Authority and NHT are not co-located

Service

- No protected time for the development of the register in Primary Care.
- Protocols are in place for the specialist

service but are not being put into practice.

- Lack of resources for a professional to take on the named worker role.
- Transition from child services to adult services can cause problems with continuing care.
- Care and professional tension caused by different priorities; trust; jargon and attitude can prevent full participation.

Information

- Poor data analysis. Lots of information collected in pockets but not used in planning.
- Care packages restricted by lack of information available to carers and professionals.
- There are deficits in the skills and knowledge base of some of the health and social care professionals in meeting the needs of people with LD

Commissioning

- Need and demand for services are not based on epidemiology.
- No clear planning forum in operation with the feeling that decisions are made before consultation begins.
- Local providers of care packages often do not have the necessary skill mix to meet the needs of people with LD;

commissioners need to ensure care organisations provide competency-based training for all carers.

Further work to be undertaken:

- Active involvement in the consultation phase of Valuing People **NOW**
- Work to take place between PCT and Local Authority Commissioners to determine the main issues in implementing change and come to an agreement how to resolve difficulties exposed.
- Use of individual budgets for social care purposes under Section 256 funding to be explored.
- More work to be done in raising profile of LD and engaging other services, particularly around the need for involvement in planning and delivering care.
- Development and maintenance of a unified LD Register (in addition to LD Registers held at GP practices) that offers facilities for sharing of information as necessary and appropriate.
- More work to be done on development of the workforce and provision of training.
- The other workstreams in the review must ensure that they have addressed issues of access, equality and flexibility

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in service provision to meet the needs of people with LD. In particular the work on End of Life Care and Long Term Conditions must ensure that there are processes in place to provide appropriate care for people who have LD.

- The possibilities around using a Carers' Forum to be involved in planning and designing services, and led by a Senior Manager to champion support for carers, should be explored.

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recommendations

Within the County there is a need for:

- robust epidemiological data.
- Development of specialist services locally
- Community LD services that are integrated with social care to support ordinary living and establish equity of access to provision of generic health services
- A GP with Special Interest in LD, should be appointed, to take the role of lead Clinician, expanding the knowledge of LD in primary care, giving advice on commissioning of services, on the provision of primary care, and linking into current work being undertaken by the Royal College of General Practitioners.
- An Enhanced service should be commissioned to provide annual health checks for people with learning disabilities as outlined in the Primary Care Service Framework - Management of Health for People with Learning Disabilities in Primary Care (NHS Primary Care Contracting - July 2007).
- LDPB should give clear direction and use its authority to deliver the partnership agenda.
- A review of all out-of-county care which is commissioned with consideration of repatriation of individuals in the future.
- The number of health facilitators needs to be increased across Northamptonshire
- A communication strategy between primary and secondary care to strengthen the overall planning of care, including additional support for admission or appointments and advance notification of discharge arrangements.
- An integrated pathway needs to be developed between primary care and the acute hospital to enable early identification of, and support planning for individuals with LD prior to admission and on discharge from acute hospital.
- The PCT will develop quality commissioning for people with LD by using information about their health , and engaging with users and carers to ensure that inclusive mainstream and specialist services are provided; and all services will use the Disability Equality Duty as the major framework to work towards more equal outcomes.