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**Manchester City Council  
Report for Resolution**

**Report to:** Health and Wellbeing Overview and Scrutiny Committee – 9  
September 2010

**Subject:** Learning Disability

**Report of:** Head of Manchester Learning Disability Partnership

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**Summary:**

This report focuses on two areas of disadvantage experienced by learning disabled people: 1) health and social care, and 2) transition to adulthood. It summarises the a variety of actions being taken by the Learning Disability Partnership and its partners to improve experiences and outcomes in both areas in the context of the recent Health Service Ombudsman report *Six Lives* and the *Getting a Life* initiative respectively.

**Recommendations:**

The committee is asked to note the work in progress, and to endorse the actions being taken.

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**Wards Affected:**

All

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**Contact Officers:**

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**Background documents (available for public inspection):**

None

## **1.0 Introduction**

- 1.1 Adult Learning Disability Services in Manchester are provided via partnership arrangements between the local authority and NHS, consisting of a pooled commissioning budget, joint commissioning team (JCT-ld) and an integrated provider, the Manchester Learning Disability Partnership (MLDP). There is also the Manchester Learning Disability (LD) Partnership Board which brings together major service stakeholders together with representative carers and users and having oversight of the delivery of learning disability services in the city.
- 1.2 This report covers work across sectors to
- a) improve health outcomes for learning disabled adults, and
  - b) improve the transition of young disabled people to adulthood.
- As such it focuses on two areas of particular disadvantage.

## **2.0 Background**

- 2.1 Learning disabled people have significantly poorer health than the rest of the population. There are several linked causes:

- Lifestyle factors – diet and exercise in particular.
- Health problems associated with some of the conditions that cause learning disability.
- Difficulty for many learning disabled people in identifying their own health needs.
- Unhelpful assumptions made by many health and social care staff about the value of health interventions and preventive work.
- Mainstream health services have until recently not prioritised equipping their staff with the knowledge and skills to work with this population.

MLDP has a number of initiatives in place to improve this situation, covering obesity and Coronary Heart Disease risk, Primary Care (support to GP practices to carry out annual health checks), joint work with the three main acute providers on staff training and patient passports.

- 2.2 The experience of reaching adulthood (transition) is challenging for all young people and their families. It is particularly difficult where youngsters have significant health and social needs and rely on well coordinated, responsive and effective services. Too often the experience of transition has been unsettling and stressful while the outcomes have been poor.
- 2.3 Manchester is a demonstration site for the National Getting a Life initiative for young people who are learning disabled, sponsored by four government departments and focusing on partnership working to achieve better life chances including, where possible, paid employment.

### 3.0 Health

3.1 An independent inquiry into health services for people with learning disabilities *Healthcare for All* reported in July 2008. The report was commissioned by the Secretary of State for Health and followed a publication by Mencap called *Death by Indifference* that highlighted cases of poor treatment and neglect experienced by a number of learning disabled people by general health services. The report, whilst highlighting some examples of good practice, confirmed that there was widespread discrimination against learning disabled people in the health service. This is despite the legislative framework designed to prevent such discrimination.

3.2 In the report 'Six Lives: the provision of public services to people with learning disabilities' (HMSO 2009) the Parliamentary and Health Service Ombudsman reported back on its own investigation into the deaths which triggered the Michael inquiry. In its conclusions, it recommended that all NHS and social care organisations in England should review urgently:

- *“the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;*
- *the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities; and should report accordingly to those responsible for the governance of those organisations.*
- *that both the PCT’s and Local Authorities should report accordingly to those responsible for the governance of those organisations by March 2010.”*

The issue of support while in hospital has been a matter of concern in Manchester following recent deaths in hospital where there were significant concerns about the care received.

3.3 In April, 2010 a report on ***The current status of health and social care services in Manchester in meeting the needs of learning disabled people*** was considered by the NHS Manchester Board (Appendix 1). It provides detailed information that is not necessary to repeat here. However, key headline messages from the report are:-

- i. A year-on-year growth in the population of learning disabled adults known to the specialist learning disability service due to increased survival and fairer application of eligibility rules (the average of the last three years is 6.3% per year). The proportion from BME communities will rise to 22%.
- ii. A pattern of concerns about the quality of stays in hospital, including poor communication and liaison with learning disability specialists, poor discharge planning, lack of knowledge of how to support a learning disabled person (practically and legally), delays in identification of clinical problems and in care processes.
- iii. Unsafe level of learning disability psychiatry provision.

- iv. The need to engage commissioners of general health services.
- v. Increased expectations from government for the role of Learning Disability Partnership Boards in leading and monitoring strategy.
- vi. A variety of initiatives already are in hand in the city to improve both health status and health care of learning disabled people. Further priorities were also identified.

Among these initiatives are the following:-

### 3.4 **Fighting Fit**

This is a group of initiatives led by the MLDP, aimed at reducing obesity and consequent health problems among the learning disabled population.

Learning disabled adults are the most inactive group of people in our society and the most obese (around twice the level of the general population).

Aspects include:

- i. Education and awareness raising.
- ii. Provision of information about activities.
- iii. Targetted sports and exercise activities in cooperation with a variety of partners
- iv. Individual interventions to reduce obesity through appropriate diet and exercise.
- v. Monitoring of Body Mass Index (B<l) in in-house 24 hour care, and use of this data to ensure local managers are made accountable for uncontrolled increases in obesity.
- vi. Audit and research to establish the effectiveness of interventions.

### 3.5 **Health Checks in Primary Care**

The *Learning Disability Direct Enhanced Service* is a pilot programme sponsored by the Department of Health that incentivises GP practices to carry out the health checks recommended in *Our health our care our say: a new direction for community services* (DH, 2006). In Manchester, 60% of GP practices signed up, and in the first year (2008-9) this resulted in 709 health checks (i.e. approx 59% of the known learning disabled population). Data is not fully verified for last year but some practices have dropped out of the scheme. The only convincing solution to this disappointing take-up is for the requirement to be made mandatory for practices. Training, and verification of registers and checks was conducted by the community learning disability nurses from MLDP.

### 3.6 **Work with hospitals**

Formal projects are in place at each of the District General Hospitals in the city in partnership with the MLDP service. A variety of training events and resources have been arranged. A hospital passport (the 'Traffic Light') has been devised providing basic information on how to support the person effectively and with respect. In each hospital Trust there is clear ownership of this work at senior management level. Progress has been made on embedding these arrangements in routine care and the publicity surrounding one coroner's report has helped highlight the importance of this work. Following the issues identified in the case series of deaths in hospital collated by the Head of MLDP, all deaths of learning disabled people are reviewed so that reviews or investigations can be commissioned where concerns are identified.

### 3.7 Forward plan

The NHS Manchester Board was asked to formally support and approve the following actions:

- To Develop a Tier 4 **Assessment and Treatment resource** in Manchester
- To **review level of learning disability psychiatry** available in Manchester.
- To ensure that an influential **PCT commissioning representative attends the LD Partnership Board**.
- A task and finish group to be set up to establish better **informatics** for learning disabled people
- To ensure that a '**Whole systems approach**' is adopted when Serious Untoward Incidents are being investigated.
- A group is set up to develop a **mainstream commissioning and provider health service strategy** for meeting the needs of learning disabled people in Manchester.

3.8 The report was accepted, and a follow up report has been requested. Work is underway on a number of the actions and we are seeking greater clarity on the extent to which they have been integrated into the PCT business plans.

### 4.0 Transition

4.1. The following initiatives have followed from the Getting a Life project.

4.2. A new **Transition Planning Team** was established in April 2010, focusing at this stage on young people aged between 16 and 21 who are physically or learning disabled. It includes workers from the Directorate for Adult and Children's Services and is managed from the MLDP and Directorate for Adults. There is a health worker from the directorate but not from children's at this stage. The team is still in the process of establishing itself and taking over responsibilities. It offers the ability to start to process of planning and making arrangements with young people and their families earlier than has been the practice to date, ensuring that there is proper continuity. Close liaison with

colleagues in Children's services takes place to ensure that practice is adequately supported.

4.3. Better planning for young people will have the following benefits:

- A less stressful and more understandable process.
- Information will not be repeated to multiple workers.
- At the point of reaching 18, although many things will change, the same team will retain responsibility for the person's care plan, allowing families a stable point of contact.
- Expectations and commitments about resources will be clearer and better joined up.
- Better and earlier planning will lead to more inclusive outcomes and a reduction in unnecessary care expenditure since there will be fewer decisions taken under pressure.

4.4. A **Young People's Parliament** is being trialled by Manchester People First. This will increase the ability of young disabled people to make their views known to services in the city.

4.5. **Person Centred Planning** has been developed in partnership with family carers, schools and Connexions, to help young people plan for their future. This initiative will also reduce the assessment demand on care managers and other professional staff in the planning process, freeing them for more focussed work with those most in need of highly specialist supports.

4.6. **Two Employment projects** have been established for young people who are learning disabled, piloting new ways of introducing them to the world of real employment. Both use models that have shown their effectiveness elsewhere.

The Youth Supported Employment Project provides access to Saturday and other part time jobs using a buddy system for support from non-disabled young people. The participants receive the rate for the job. This provides experience of working and helps young people try out work roles just as non-disabled youngsters do.

Project Search offers internships in an employer organisation linked to classes provided by a (the Manchester) college. The Manchester scheme, starting in September is based at the Manchester Royal Infirmary. Like the Youth Supported Employment Project, Project Search relies on a supported employment agency to ensure that job roles are appropriately designed or adapted and there is the adequate level of support in the workplace.

4.7. Other related developments include the transfer of responsibility for college funding from the Learning and Skills Council to the City Council. This will afford opportunities to integrate funding streams and what were separate planning processes. This will ultimately allow better and more strategic use of college provision as part of the overall work to help young people 'get a life'.

The PCT's Personal Health Budgets pilot is also set to improve the way young people, with the most complex and intense needs, are supported.

- 4.8. However, the sudden reduction in the availability of Independent Living Fund finance has created a shortfall in the resource previously available to supplement care packages, disrupting plans for a number of this year's school and college leavers and creating additional pressure on council resources.

## **5.0 Conclusion**

The Committee is asked to note the report and endorse the actions being taken.



**Appendix 1 - NHS Manchester Board Report: April 2010**

**Manchester**

**NHS Manchester Board Meeting – 7<sup>th</sup> April 2010**

Report of:	Debbie Nixon
Paper prepared by:	Garry Parvin, Health Service Commissioner – Learning Disability Joint Commissioning Team Mark Burton - Head of Manchester Learning Disability Partnership
Signed off by Director:	Deborah Goodman
Date of paper	April 2010
Subject:	The current status of health and social care services in Manchester in meeting the needs of learning disabled people.
Background papers and links to priorities/objectives	<ul style="list-style-type: none"> <li>• Report to Board in 2008 on Independent Inquiry into Health Services.</li> <li>• Operational Plan.</li> <li>• Direct link to proposals for the future organisational arrangements of Manchester Community Health and Securing Our Shared Future.</li> </ul>
Purpose of the paper	This report gives an overview on the current status of health and social care services in Manchester in meeting the needs of learning disabled people as recommended by the health ombudsman.
Relevance of the paper to delivery of Commissioning Strategic Plan	Recommendations are consistent with delivering the strategic goals of the CSP.
Implications of access and inclusion	[Equality Impact Assessment being undertaken week commencing 29 March 2010].
How does the proposal contribute to reducing health inequalities	The recommendations will require all NHS providers to ensure that their services are accessible to the learning disabled population in Manchester.
How does the paper evidence World Class commissioning competencies and governance:	All competencies are affected by these recommendations.
How does the paper evidence Use of Resources Key Lines of Enquiries	
Action/decision required:	To endorse the actions proposed in the paper and require a follow up report in 6 months.

## 1. Background

- 1.1 In 2008 the Board received a paper prepared by the Manchester Learning Disability Partnership about Healthcare for All, the Independent Inquiry into health services for people with learning disabilities chaired by Sir Jonathan Michael. The inquiry had made 10 recommendations about improvements the NHS needed to make.
- 1.2 In the report '*Six Lives: the provision of public services to people with learning disabilities*' (HMSO 2009) the Parliamentary and Health Service Ombudsman reported back on its own investigation into the deaths which triggered the Michael inquiry. In its conclusions it recommended that all NHS and social care organisations in England should review urgently:
- *the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;*
  - *the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities; and should report accordingly to those responsible for the governance of those organisations.*
  - *that both the PCT's and Local Authorities should report accordingly to those responsible for the governance of those organisations by March 2010.*
- 1.3 The issue of support while in NHS health services is very current for services in Manchester particularly as 4 learning disabled people have died in hospital care in particularly tragic circumstances in the last 12 months.

## 2. Context

- 2.1 A letter sent by David Behan (Director General – Social Care Local Government and Care Partnerships) and by Anne Williams (National Director for Learning Disabilities) in January 2010 suggested that reporting should use the SHA / Valuing People Support Team Health Self Assessment Framework to highlight improvements in health and healthcare for people with learning disabilities.

The health assessment and report will be undertaken with the Manchester Learning Disability Partnership Board. An easy read or plain words version will be made available.

The report will:

- Give an overview of the learning disabled population in Manchester.
- Provide an update in relation to the operational functions of Manchester Learning Disability Partnership Board.
- Highlight themes regarding recent deaths of learning disabled people in Manchester's hospitals
- Present the outcome of the health assessment undertaken as part of the Learning Disability Partnership Board assessment.

- Provide a narrative assessment of the progress made in improving healthcare for people with learning disabilities, and where further work is needed; and
  - Include a summary of ‘good things happening’ and key priorities for improvement.
- 2.2 It is expected that the health self assessment will be conducted annually. This year’s assessment is expected to be completed by late April.
3. Overview of the learning disabled population in Manchester:
- 3.1 Appendix 1 gives an overview of the commissioning and provider arrangements for specialist learning disability services in Manchester. The following demographic changes which have occurred in the learning disabled population in Manchester which reflects an increasing demand for services. Main population changes are:
- Currently there are 1732 learning disabled adults known to Learning Disability Services in Manchester.
  - Between March 2002 and March 2006 the numbers of learning disabled adults accessing services increased from 987 to 1410. This figure demonstrates a growth of 30% during these years.
  - Independent research conducted in 2007 predicted that the population of adult users of specialised adult health and social care services for people with learning disabilities in Manchester will show a top-rate year-on-year annual increase of approximately 4.5%. However, based on current population analysis there has been a population increase averaging 6.3% over 3 years. This is much higher than the nationally predicted 1% increase in prevalence. For younger people (age 18–29), the increase in need is predicted to lie somewhere between 70% and 129%.
  - For older people (age 60+), the estimate predicts a 36% increase in need.
  - The evidence also suggests that the percentage of adult people from minority ethnic communities will rise from 16% to 22%, of whom the two largest groups will continue to be people from South Asian minority ethnic communities (estimated to rise from 8% to 11%), and people from black minority ethnic communities (estimated to rise from 6% to 7%).
  - There is an increase in case complexity driven by the increase in numbers of learning disabled people with needs in terms of complex physical impairments (including technology dependence), behavioural support, forensic issues and mental health.
  - Evidence demonstrates that there will be a substantial increase in the need for continued health services for people with learning disabilities in Manchester in the foreseeable future.
  - There are 30 learning disabled people from Manchester (the highest in the North West Region) detained within secure hospital services.
4. Update on the Learning Disability Partnership board for specialist adult learning disability services in Manchester
- 4.1 Since the publication of *Valuing People* (DH 2001) there has been a Manchester Learning Disability (LD) Partnership Board which brings together

major service stakeholders together with representative carers and users. The LD Partnership Board meets bimonthly and has oversight of the delivery of learning disability services in Manchester.

*Valuing People Now* (DH 2009) makes a clear expectation that Partnership Boards will need to take a more assertive role in monitoring and coordinate delivery of the strategy.

**5. Thematic analysis of recent deaths of learning disabled people in Manchester's hospitals**

- 5.1 It is important to recognise that it was the tragic deaths of six learning disabled people in hospital care that triggered the Michael Review, followed by the Health Ombudsman investigation. MLDP has undertaken a brief review of the deaths of 13 people known to learning disability services who died in hospital in 2009 and this contained in appendix 2.
- 5.2 Of the 13 people, 4 received care that gave serious cause for concern, there were issues of varying degree for a further 3 and for the remaining 6 the care appears to have been at least satisfactory.
- 5.3 In the cases where cause for concern arose the following themes emerged:
- unsafe discharge and poor discharge planning,
  - poor communication,
  - poor understanding of Mental Capacity Act (including best interest decisions),
  - lack of understanding of how to support a learning disabled person,
  - failure to follow advice from LD specialists and carers,
  - failure of or late identification and investigation of clinical problems,
  - failure to use agreed hospital passport,
  - delays in care processes,
  - unavailability of equipment.
  - the time taken for investigations to report.
- 5.4 A recent Learning Disability Workshop attended by representatives of the three Acute Trusts, Commissioning, NHS Manchester Clinical Governance and MDLP made the following recommendations that a system which ensured the following needed to be put in place :
- Better communication,
  - Better transfer of care,
  - An emergency pathway,
  - Training,
  - Sustainability.

Appendix 3 contains a full list of the proposals on how to take this forward.

**6. Valuing People Support Team Health Self Assessment:**

- 6.1. The process of the self assessment involves completing two feedback forms. The first is a general feedback form highlighting areas of good practice and priorities for the coming year. The second form is a measures and evidence

form. It was completing this that highlighted that data held on Manchester's learning disabled population is very fragmented and action to address this issue is highlighted as a priority for 2010/11

6.2 Both forms assess progress across four broad 'health targets', they are:

- Plans are in place to meet the needs of people who are no longer receiving treatment which require in-patient care in an acute/long-stay residential facility or hospital.
- The PCT is working closely with the Partnership Board and other local partners. This means that people with a learning disability can use the same health services and get the same treatment as everybody else.
- People with a learning disability are safe in National Health Service services
  - Progress is being made in implementing the service reforms and developments described in '*Valuing People*'.

6.3 Sitting underneath each overarching theme there are a series of sub measurements. See appendix 4 for fuller explanation for rating.

Below is a summary in terms of the overarching themes. Below each theme is a summary of key progress, areas NHS Manchester needs to address and a key priority for 2010/11. Each theme is marked using a RAG scheme.

The current performance as of April 2010 for NHS Manchester is:

HEALTH TARGET	RATING	RECOMMENDATION
Plans are in place to meet the needs of people who are no longer receiving treatment which require in-patient care in an acute/long-stay residential facility or hospital.	GREEN	To develop a Tier 4 <b>assessment and Treatment resource</b> in Manchester.  To <b>review level of learning disability psychiatry</b> available in Manchester.
The PCT is working closely with the Partnership Board and other local partners. This means that people with a learning disability can use the same health services and get the same treatment as everybody else.	AMBER	To ensure that an influential <b>PCT commissioning representative attends the LD Partnership Board</b> .  A task and finish group to be set up to establish better <b>informatics</b> for learning disabled people.
People with learning disabilities who use services that the NHS commissions or provides, are safe.	AMBER	To ensure both a primary and secondary care <b>health facilitator post</b> are developed.  To ensure that a ' <b>Whole systems approach</b> ' is adopted when SUI are being investigated.
Progress is being made in implementing the service reforms and developments described in ' <i>Valuing People</i> '.	AMBER	A group is set up to develop a <b>mainstream commissioning and provider health service strategy</b> for meeting the needs of learning disabled people in Manchester.

## 7. Conclusions

Across NHS Manchester there are many examples of excellent progress in becoming more responsive to and providing better health outcomes for learning disabled people. However, clearly there is still more to do. The purpose of this paper is both to inform and also to ensure that meeting the health needs of learning people remains high on the Board's agenda.

To secure further progress NHS Manchester Board is asked to adopt the recommendations as highlighted in table in section 6.

## 8. Recommendations

8.1 The Board is asked to formally support and approve the actions in this paper as summarised below:

- **To Develop a Tier 4 Assessment and Treatment resource in Manchester**
- **To review level of learning disability psychiatry available in Manchester.**
- **To ensure that an influential PCT commissioning representative attends the LD Partnership Board.**
- **A task and finish group to be set up to establish better informatics for learning disabled people**
- **To ensure that a 'Whole systems approach' is adopted when SUI are being investigated.**
- **A group is set up to develop a mainstream commissioning and provider health service strategy for meeting the needs of learning disabled people in Manchester**

## **Appendix 1- Annex 1:**

### **The commissioning, provider and partnership arrangements for specialist adult learning disability services in Manchester**

Manchester's Learning Disability Services are available for adults (18+) whose learning disability is *significant*. This means they are sufficiently disabled to need active service provision by a service with specific training and skills in effective work with learning disabled people.

Learning Disability Services in Manchester are well regarded within social care and health services. They have successfully built on fourteen years of partnership arrangements between the health and social care sectors which have proved robust and have pre-figured government policy and guidance. Arrangements are currently consolidated in the form of three Section 75 (previously Section 31) Agreements.

- Joint Commissioning
- Integrated Joint Provider
- Pooled budget

Joined up working between health and social care remains on the government agenda. The establishment of joint services from 1994 itself allowed a rationalisation of management, producing management savings at the time and reducing managers' need to manage the boundaries between health and social care.

Manchester's Learning Disability services perform well in terms of key performance indicators and targets, have high levels of user and carer involvement, work in partnership with other providers and agencies from both public and independent sectors, and can demonstrate the efficient use of public money. The ability to share experience, information and intelligence, develop common strategies and use resources cooperatively has helped MLDP and the JCT to overcome significant financial and service delivery challenges. Finally, person centred arrangements are the norm rather than the exception, although there is still more to do.

## Appendix 1 – Annex 2:

### Information on deaths of people with Learning Disabilities in Secondary Healthcare in Manchester (2009)

1. **G** admitted to Hospital on 22/01/09 as a result of a fall, sent home with paralysis and taken to his first floor bedroom. G called out which saw G re-admitted 23/01/09.

A catheter was placed in situ, which went wrong causing him to develop gangrene in his penis. A very thorough Serious Untoward Incident investigation was conducted (December 2010) by the hospital. A number of areas of concern were identified including:

- Unsafe discharge (of non-weight bearing patient).
- Delay in identifying injury from catheter and delay in seeking medical assessment.
- Poor communication and poor multidisciplinary working: poor understanding of roles and responsibilities between hospital and Id service.
- Uneven understanding of mental Capacity Act in both hospital and Id service.
- An action plan is being finalised (January 2010).

**Cause of Death:** Sepsis, Bronchopneumonia, Cervical Cord Compression.  
Gangrene of the penis due to problems with catheter.

**Date of Death:** 20/03/2009

**Serious  
concern**

2. **R** was admitted to hospital on 24/05/09 due to having collapsed – subsequently fell out of bed whilst an in-patient no neurological observation were put in place have sustained a head injury, no treatment to wound, was being dressed for discharge when he was in a coma. Had CT scan found to have subdural haemorrhaging, transferred to Hope Hospital had brain operation died later that day, 29/05/09.

Subsequent investigation looked into care issues, bed rails, MLDP healthcare / Traffic light document info not being utilised. Narrative verdict pointed to inadequacies in hospital care, including lack of understanding how to support a person who is learning disabled, failure to follow carer's advice based on knowledge of RE, failure to use hospital traffic light passport, failure to monitor head injury, failure to recognise coma, failure to organise timely scan.

Action plan agreed with hospital to remedy shortcomings.

**Cause of Death:** Pneumonia and Acute Subdural haemorrhage

**Date of Death:** 29/05/2009

**Serious  
concern**

**3. S** admitted to hospital on 13/10/09 with a chest Infection/pneumonia

Concerns raised over administration of IV Antibiotics, inconsistency in what dose had actually been administered – Doctors on ward did not have any concerns over infection but wished to insert PEG due to not eating or drinking and did not acknowledge original diagnosis of Pneumonia by Dr.P, x-ray result was not seen as a concern – advice given by Community Learning Disability Nurse on hydration and taking bloods was disregarded. As a result S became more dehydrated and the infection was not being addressed. On 19/10/09 due to distress and severe dehydration and weakness IV fluids were prescribed, deteriorated on 20/10/09 suffering and acute stroke passing away on 23/10/09.

Community Nurses (RNLD) have been in contact with PALS and Complaints Officer –arranging a meeting with the Matron to discuss the issues.

Referred to PCT with request for an investigation.

**Cause of Death:** Acute Stroke

**Date of Death:** 23/10/2009

**Serious concern**

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**4. C** admitted to hospital on 10/08/2009 with a chest infection and breathing difficulties.

Concerns were raised by support team that C was severely distressed because the hospital were not able to provide appropriate equipment for C due to her size. E.g. trying to transfer onto a bed because she was morbidly obese.

**Cause of Death:** Pulmonary embolism

**Date of Death:** 17/09/2009

**Some concern**

**5. G** admitted to hospital 05/09/2008 as a result of his HIV and Weight loss

No concerns have been raised as to this gentleman's stay in hospital

**Cause of Death:** HIV

**Date of Death:** 12/01/2009

**No concerns**

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**6. J** admitted to hospital on 08/04/2009 with Pneumonia. J had advanced dementia.

7 hour delay between admission and allocation of bed. On admission an MRSA swab had been taken however, before the results came back J was sent to theatre to have a PEG fitted. Subsequently, she died of sepsis.

A best interest decision was made by medical staff for the PEG to go ahead without the IMCA or the MDT being involved. Concerns identified about undue

use of restraint. The IMCA's report suggests that the appropriate after-care was not in place due to lack of planning as MDT would have raised issues such as pulling tubes out etc. Incident investigation carried out by hospital clinical governance..

**Cause of Death:** Pneumonia/ sepsis

**Date of Death:** 30/05/2009

**Serious concern**

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7. **C** admitted to hospital on 05/11/2009 with Septicaemia, discharged on 09/11/2009 and then re-admitted to MRI A+E Unit and then the Resus Unit on 10/11/2009 with Pnuemaccocal Septicaemia

Parents criticised the hospital because he did not have easy access to a toilet because his bed was positioned some distance from the toilet. E.g. he had defecated whilst on the way to toilet. Poor communication with father over DNR decision.

Wider concern over management of diet as he was morbidly obese.

**Cause of Death:** Septicaemia and Cholostrium Difficile

**Date of Death:** 10/11/2009

**Some concern**

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8. **J** admitted on 7 separate occasions between May 2008 and January 2009 mainly due to seizure activity. Last admission was to A7 on 26/01/2009 with a chest infection.

No concerns were raised.

**Cause of Death:** Chest Infection

**Date of Death:** 21/02/2009

**No concerns**

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9. **A** admitted with seizure activity and swallowing problems on 11/06/2009, having a history of cancer.

He had terminal cancer and lived longer than expected. No concerns identified.

**Cause of Death:** Awaiting official confirmation of Cause of Death

**Date of Death:** 04/07/2009

**No concerns**

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10. **M** admitted to hospital on 16/06/2009 with a chest infection

No known concerns mentioned.

**Cause of Death:** Awaiting official confirmation of Cause of Death

**Date of Death:** 01/07/2009

**No concerns**

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11. J was admitted to hospital on 12/11/2008 with Pneumonia and then transferred to Tameside Hospital because there wasn't an ICU bed available at the hospital. Transferred back to MRI where she died. No complaint made.

**Cause of Death:** Pneumonia

**Date of Death:** 07/01/2009

**No concerns**

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12. K admitted to hospital on 25/05/2008 with Cancer. Was placed in ICU where he died. Hospital staff were very good.

**Cause of Death:** Multiple organ failure, Acute Renal failure, Pelvis Tumour

**Date of Death:** 01/06/2008

**No concerns**

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13. J was admitted to hospital with distended abdomen. NWC staff were concerned when J did not appear to be investigated and a DNR note put on her notes. Hospital did not involve IMCA until Id care manager arranged this.

Joint investigation with hospital but this didn't cover GP element. D Mitchell (MLDP) to discuss with PCT clinical governance lead..

**Cause of Death:** natural causes: urinary tract infection, large intestinal obstruction, pyelonephritis with ischaemia, cardiac failure due to blocked arteries.

**Date of Death:** 9.5.2008

**Some concern**

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**Information quality**

It has proved difficult to obtain information. This has been reliant on staff in the community learning disability service. As a result an improved protocol is being adopted: all deaths will be reported to the Head of MLDP and a brief summary report of issues will be commissioned: on receipt this will be used as a basis for identifying the need for further investigation and commissioning it (with the PCT's clinical governance team and commissioners).

**Conclusions**

**Of the 13 people, 4 received care that gave serious cause for concern, there were issues of varying degree for a further 3 and for the remaining 6 the care appears to have been at least satisfactory.**

These conclusions may be subject to some revision since not all investigations have been completed. However, there is sufficient evidence here to indicate a systemic problem in ensuring acceptable care for learning disabled people during their hospital stays.

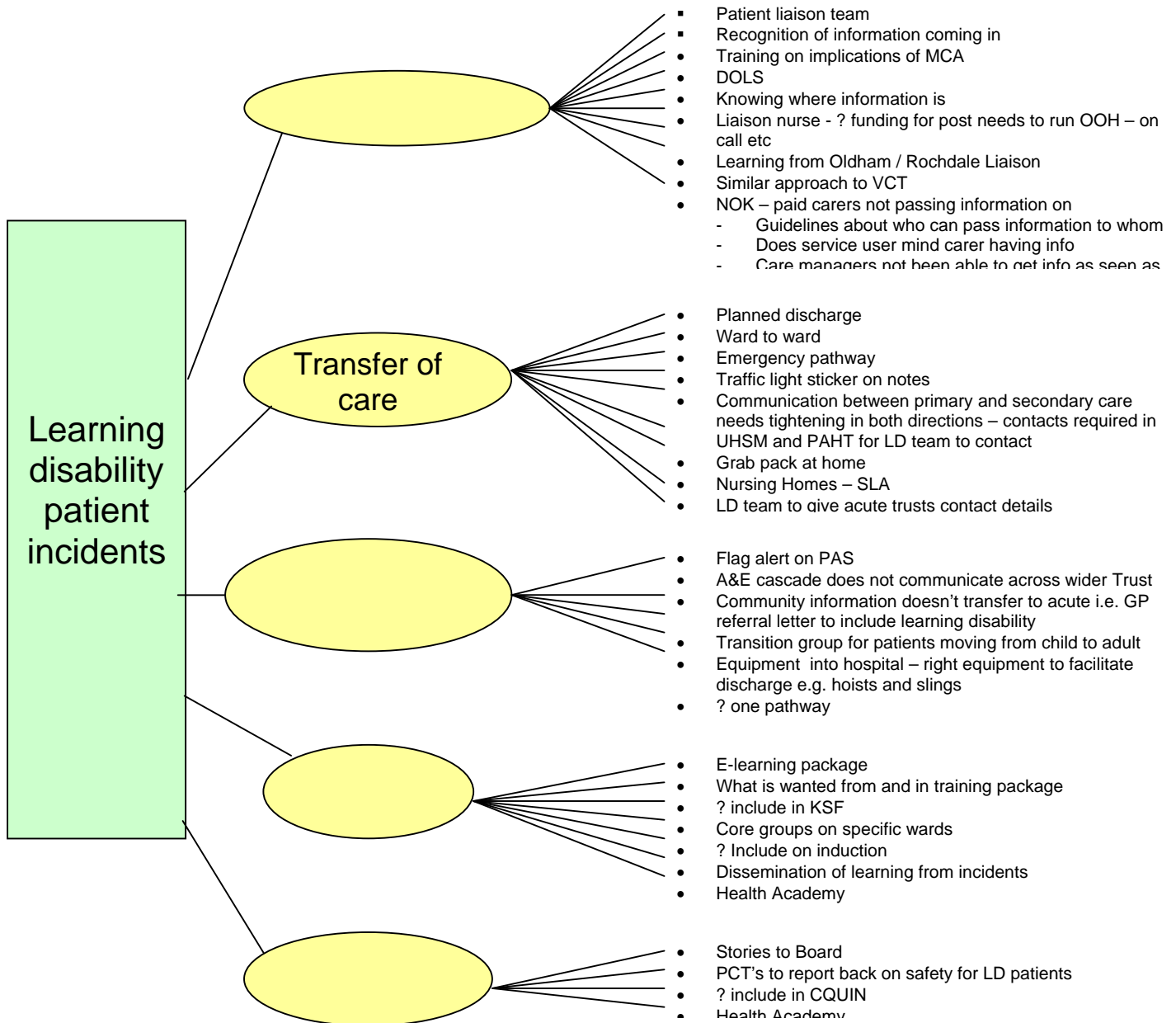
Issues identified (to date) were as follows:

- unsafe discharge and poor discharge planning,
- poor communication,
- poor understanding of Mental Capacity Act (including best interest decisions), lack of understanding of how to support a learning disabled person,
- failure to follow advice from Id specialists and carers,
- failure of or late identification and investigation of clinical problems,
- failure to use agreed hospital passport,
- delays in care processes,
- unavailability of equipment.

A further concern is the time it is taking for investigations to report.

**M Burton**  
**10 February, 2010**

**Appendix 1 – Annex 3: Recommendation to ensure Learning Disabled People are safe in Hospital.**



**Appendix 1 - Annex 4:**

<b>Top Health Target 1: Plans are in place to meet the needs of people who are no longer receiving treatment which require in-patient care in an acute/long-stay residential facility or hospital</b>			
<b>Good Things Happening</b>	<b>Where things need to get better</b>	<b>How did we score?</b>	<b>One thing we want to be better in 12 months (Key priority)</b>
<p>The resettlement of identified people from long stay hospitals, is complete</p> <p>Discharge planning is in place for people both in and out of district, and in both NHS and private sector hospital provision, whose treatment is either complete, or nearing completion</p>	<p>Manchester does not have a tier four assessment and treatment resource to prevent further escalation to regional hospital facilities.</p> <p>Manchester has a very low level of LD psychiatry cover.</p>	<b>LEVEL 3: GREEN</b>	<p>To have a Tier 4 resource in Manchester</p>
<b>Top Health Target 2: PCT's are working closely with local Partnership Boards and statutory and other partners, to address the health inequalities faced by people with learning disabilities</b>			
<b>Good Things Happening</b>	<b>Where things need to get better</b>	<b>How did we score?</b>	<b>One thing we want to be better in 12 months (Key priority)</b>
<p>60% of Manchester's GP practices have signed up to the DES</p> <p>Systems are in place to ensure the following are identified within GP Registers:</p> <ul style="list-style-type: none"> <li>• adults with a learning disability</li> </ul> <p>There is some anecdotal evidence that Primary Care Teams are tackling health inequalities and promoting the better health of those with learning disabilities registered with their Practice</p> <p>There have been a number of projects working with dentistry, physiotherapists and optometrists addressing and promoting the better health of people with learning disabilities</p>	<p>NHS Manchester, PCT's and partners need to promote further sign up to capture the other 40%</p> <p>Valuing People Now (DH 2009) states that <i>'all healthcare organisations should ensure that they collect data and information necessary to allow learning disabled people to be identified and their pathways tracked'</i></p> <p>Systems need to be in place to capture the following data:</p> <ul style="list-style-type: none"> <li>• Children</li> <li>• Older family carers</li> <li>• Those from minority ethnic groups</li> <li>• Carers of those from minority ethnic groups</li> <li>• Parents or carers with a Learning</li> </ul>	<b>LEVEL 2: AMBER</b>	<p><b>A task and finish group to be set up to look into ensuring better informatics for learning disabled people.</b></p>

	<p>Disability</p> <ul style="list-style-type: none"> <li>Deaths of learning disabled people</li> </ul> <p>There is a very low uptake to these invitations. Evidence is limited.</p> <p>There is a need to ensure that an influential PCT commissioning representative attend the Partnership Board and carers report difficulty accessing mental health services.</p>		
<b>Top Health Target 3: People with learning disabilities who use services that the NHS commissions or provides, are safe</b>			
<b>Good Things Happening</b>	<b>Where things need to get better</b>	<b>How did we score?</b>	<b>One thing we want to be better in 12 months (Key priority)</b>
<p>Specialist LD commissioners and providers are systematically addressing any areas of concern, relative to the learning points from recent Healthcare Commission investigations, national audit outcomes, and “Healthcare For All”</p> <p>NHS Manchester and the Manchester Adult Social Care has in place transparent and well understood policies and procedures relating to:</p> <ul style="list-style-type: none"> <li>Consent to treatment by people with learning disabilities</li> <li>Mental Capacity Act</li> <li>Disability Equality Duty</li> <li>DoLs provisions</li> </ul> <p>There is a review and analysis of complaints and adverse incidents affecting people with learning disabilities aimed at altering or improving practice in all organisations.</p> <p>There is a joint NHS and ASC Safeguarding Board to</p>	<p>There is a sufficient gap in terms of mainstream primary, secondary and mental health services addressing the care of learning disabled people when they go into hospital. See point 6.</p>	<p><b>LEVEL 2: AMBER</b></p>	<p>A strategic Primary care facilitator is required and Hospital based facilitators are required.</p>

<p>ensure a coherent approach to the protection of vulnerable adults from abuse.</p>			
<p><b>Top Health Target 3: Progress is being made in implementing the service reforms and developments described in 'Valuing People'</b></p>			
<p><b>Good Things Happening</b></p>	<p><b>Where things need to get better</b></p>	<p><b>How did we score?</b></p>	<p><b>One thing we want to be better in 12 months (Key priority)</b></p>
<p>Manchester has a comprehensive range of <i>community</i> specialist learning disabilities services available to sustain and support people in their local community.</p> <p>Manchester has thorough, well-functioning partnership agreements and protocols between organisations, guiding day to day commissioning and service provision.</p> <p>NHS Manchester and their partners are working with local and regional Offender Health teams to ensure that people with learning disabilities in prison have access to a full range of healthcare – in line with legislation, policy and best practice.</p>	<p>See health target 1 re assessment and treatment.</p> <p>People with learning disabilities and their families/supporters do not fully contribute to and participate in discussion, as well as in the planning, prioritisation and delivery of health services generally. There is no long term 'whole system' strategy to address the needs of people with autism spectrum disorder, which includes reference to adults with learning disabilities, and also to young people with learning disabilities approaching transition to adulthood.</p> <p>There is significant anecdotal evidence that the NSF for mental health is not equally and equitably applied to people with learning disabilities who require psychiatric services.</p> <p>There is NO coherent workforce Plan in each local area guiding the future training and development of people working in learning disability services, in both specialist and mainstream health care areas.</p>	<p><b>LEVEL 2 : AMBER</b></p>	<p>A strategic mainstream commissioning and provider health service framework for meeting the needs of learning disabled people is indicated.</p>