Department of Health, Social Services and Public Safety
www.dhsspsni.gov.uk

Subject: **Safeguarding of Service Users' Finances within Residential and Nursing Homes and Supported Living Settings.**	Circular Reference: **HSC(F) 08-2015** Date of Issue: **13 February 2015**
For Action by: Chief Executive and Director of Finance of each HSC Trust, HSCB, BSO **For Information to:** HSC Head of Internal Audit and RQIA. **Summary of Contents:** The purpose of this circular is to remind organisations to ensure that service users' finances are safeguarded in residential and nursing homes and supported living services within the statutory and independent sectors. **Enquiries**: Any enquiries about the contents of this Circular should be addressed to: Finance Policy, Accountability and Counter Fraud Unit DHSSPS Room D3 Castle Buildings Stormont BELFAST BT4 3SQ Tel: 028 9076 5696 fpau@dhsspsni.gov.uk	**Related documents:** Residential Care Homes – Minimum Standards Nursing Homes – Minimum Standards Domiciliary Care Agencies – Minimum Standards **Superseded Document:** HSS(F) 57/2009 Misappropriation of Residents' Monies – Implementation and Assurance of Controls in Statutory and Independent Homes **Expiry Date:** Not Applicable **Status of Contents:** Action **Implementation:** Immediate

BACKGROUND

1. The purpose of this guidance, which supersedes HSS (F) 57/2009 - Misappropriation of Residents' Monies – Implementation and Assurance of Controls, is to remind you of your responsibility to ensure that service users' finances are safeguarded within both the statutory and independent sectors. This follows a recent review by RQIA – 'Oversight of Services Users' Finances in Residential and Supported Living Settings'. In particular, this review highlighted the need to strengthen the level of assurances received from the Independent sector and to extend these assurances to supported living settings.

ACCOUNTABILITY ARRANGEMENTS/CONTROLS

2. Robust financial controls must be in place in all residential, nursing homes and supported living settings in both the statutory and independent sectors. This circular sets out the mandatory controls that must be in place within the statutory sector to ensure robust financial controls are in place and seeks assurances that similar controls (as appropriate) are in place within the Independent and Supported Living sector.

3. Within the Statutory sector, Accounting Officers must ensure that these controls are operating successfully, are in compliance with extant Departmental guidance and that they are reviewed on a regular basis.

4. Within the Independent and Supported Living sector, Accounting Officers must be able to demonstrate that they have taken reasonable steps to ensure that adequate financial controls are in place within Independent and Supported Living settings to ensure that Trusts' interests are protected.

5. Trusts have a statutory duty of care to its service users', regardless of the particular setting in which care is delivered, whilst it is accepted that Accounting Officers cannot be held **directly** accountable for the ongoing operation of controls in independent or supported living settings, Accounting Officers must ensure there is a proportionate level of oversight of service users' finances.

6. There are a number of existing controls within Trusts to ensure that robust arrangements are in place for handling service users' finances. These include entering into contractual arrangements with the independent care home/supported living service which provides recourse where the level of care is not as expected or where there are circumstances involving financial issues. This also includes liaison with service providers re: implementation of Internal Audit recommendations. It is further recognised that the care management review arrangements, together with the reporting procedures for complaints and untoward incidents reporting mechanisms provide additional control mechanisms for each Trust. Notwithstanding this, it is important that Accounting Officers can also demonstrate that they have taken appropriate steps to ensure that adequate financial controls are in place to safeguard service users' interests. Accounting Officers should also ensure that liaison between Trust finance and care colleagues is taking place and operating effectively.

FINANCIAL CONTROLS IN RESIDENTIAL AND NURSING HOMES AND SUPPORTED LIVING SETTINGS WITHIN BOTH THE STATUTORY AND INDEPENDENT SECTORS

7. To assist with this process, two pro forma templates have been developed to seek assurances that robust financial controls are in place within (i) residential and nursing homes and (ii) supported living settings. These have been developed in conjunction with HSC finance and care management colleagues. We have developed two templates to allow for the different levels of control within the different settings. These templates reflect the minimum controls for which assurance should be sought and Trusts can add additional controls to the templates if they wish. It should be noted that these templates reflect controls only and are not a list of procedures. Each service should have a detailed set of financial procedures which underpin these controls.

8. These templates are attached at Annex A & B and include controls in relation to authorisation, procedures, clients' agreements & accounts, deposits and income, withdrawals and expenditure, monitoring, authorising signatures and property security.

9. There are a few additional controls in respect of supported living settings and these include controls in relation to tenancy agreements and inventory listing.

ASSURANCES

10. Accounting Officers should ensure that there are effective processes in place to seek and obtain as a minimum, assurances in relation to financial controls for each setting (residential, nursing home and supported living in both statutory and independent sectors) within its geographical area. As the host Trust they should do this by:
    - Issuing the attached pro forma to each service within its geographical area by the end of February each year, relating to the current year;
    - Ensuring that these assurances are received by 31 March and reviewed for each service on a timely basis;
    - Where possible, use these assurances as part of the annual contract review process and consider failure to return the template as unsatisfactory performance and manage this in accordance with the terms of the regional contract/performance framework;
    - Sharing significant issues within the Trust and with other Trusts/ Internal audit and RQIA;
    - Providing copies of the assurances to other Trusts when requested, where service users' are placed outside their geographical area; and
    - Taking appropriate action for non-compliance.

INTERNAL AUDIT

11. Internal audit carry out an annual audit programme which includes residential and nursing homes within statutory and independent sectors. In line with the increasing use of supported living settings, internal audit have already extended their programme to include supported living settings. Trusts should use information from the assurance process (as at paragraph 10) to help inform their internal audit programme of any services which pose a greater level of risk.

CARE MANAGEMENT

12. An annual care review is carried out by a care manager with each service user to consider the standard / level of care that the service user is receiving and also seeks

assurances in relation to the service users' finances. Trusts must ensure there are adequate processes in place for sharing all information in relation to safeguarding service users' finances and ensuring there is regular liaison between finance and care management and others as necessary, such that the care manager has a complete picture and understanding of a service users finances in advance of the care review. To assist with this, Trusts should ensure that they have a standardised file structure to allow a complete picture of a service users finances. The Trust must ensure that care management staff are adequately trained to be able to carry out this annual review of service users' finances. Concerns about potential misappropriation of service users' monies identified via care management or other process, e.g. RQIA/Internal Audit inspections will trigger a referral to Trusts' adult protection services.

REGULATION AND QUALITY IMPROVEMENT AUTHORITY (RQIA)

13. RQIA is responsible for inspecting the availability of health and social care services and encouraging improvements in the quality of service provision. Its work provides assurance to the Department in respect of compliance with the regulations and minimum standards and the quality of service provision. RQIA's reports are published on its website at www.rqia.org.uk/inspections.

14. As a regulatory body, RQIA monitors compliance with the relevant regulations and minimum standards for residential and nursing home care through its programmes of inspections. RQIA takes action as necessary to ensure that the provider rectifies non-compliance. RQIA publishes all inspection reports on its website at www.rqia.org.uk/inspections and will alert Trusts immediately of any instances it may find of actual or potential abuse of vulnerable adults as well as actual or potential financial irregularity. It is the responsibility of Trusts to carry out such further investigations or audits as may be necessary; it is for Trusts to determine and take appropriate action on behalf of its service users'. However, RQIA will require reports from Trusts on the timescale and outcome of such enquiries when complete.

15. For practical purposes, responsibility for an investigation rests with the Trust in whose area the service is located and it will communicate and liaise closely with other Trusts which have placed their service users' in the facility.

RECOMMENDATIONS

16. Accounting Officers should ensure that existing controls operating in Trust services are reviewed to satisfy themselves that there are appropriate controls in place and that they are in compliance with extant Departmental guidance. Accounting Officers should also take steps to ensure that there are adequate financial controls in place in independent sector homes and supported living settings to ensure that Trusts' service users' interests are protected.

OTHER DEPARTMENTAL GUIDANCE

17. This circular should be read in conjunction with Care Management, Provision of services and charging guidance HSC (ECCU) 1/2010 or subsequent guidance.

18. In addition, your attention is drawn to the existing mandatory Departmental guidance which can be accessed through the following links:-

Residential Care Homes – Minimum Standards
http://www.dhsspsni.gov.uk/care_standards_-_residential_care_homes.pdf

Nursing Homes – Minimum Standards
http://www.dhsspsni.gov.uk/care_standards_-_nursing_homes-2.pdf

Domiciliary Care Agencies – Minimum Standards
http://www.dhsspsni.gov.uk/domiciliary_care_standards-4.pdf

HSS (F) 13/2007 – Financial Governance Model for New HSS Trusts
http://www.dhsspsni.gov.uk/hss_f_13-2007.pdf

Patients and Clients' Property can be found in section 28 of the Standing Financial Instructions within Circular HSS (F) 13/2007
http://www.dhsspsni.gov.uk/sos_res__del_of_p_sfis_mar_07.pdf

ACTION

19. Please ensure that this circular is brought to the attention of the appropriate staff within your organisation and that any relevant action points are noted.

This Circular supersedes HSS (F) 57/2009 Misappropriation of Patients' Monies – Implementation and Assurance of Controls.

Should you have any queries please contact Paula Shearer on [redacted]

Paula Shearer
Finance Policy, Accountability and Counter Fraud Unit

Annex A

Template for Residential Homes and Nursing Homes

Dear Provider,

Oversight of Service Users' Finances in Residential and Nursing Homes

The Department of Health, Social Services and Public Safety (DHSSPS) issues guidance for implementation by all Health and Social Care Trusts.

The guidance details the Trust's responsibility to take reasonable steps to ensure adequate financial controls are in place to safe guard residents' monies in all statutory and independent homes with which it places clients.

I would therefore be grateful if you would complete the attached declaration confirming the following controls are in operation within the above named facility, for which you are responsible.

Control/Process		**Response**
1. Authorisation	1.1. Where your facility is appointee/controller, do you hold written authorisation to support these arrangements for each client? If no applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No
2. Procedures	2.1. Do you hold up-to-date comprehensive financial procedures for managing clients' monies and clients' accounts? 2.2. Do all staff who are involved in the mgt of residents monies' receive adequate and regular training on these procedures?	Yes / No Yes / No

	If no applies to any of the above, please provide details/reasons below (or separately if necessary). _____ _____ _____	
3. Clients' Agreements	3.1. Do you have agreements in place, which clearly set out financial arrangements for each client? 3.2. Are these agreements reviewed, updated, agreed and signed annually to reflect changes in circumstances? (Note: RQIA guidance recognises that where a client does not have capacity to sign and no one else is willing/available, a facility should note this on the agreement) If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No
4. Clients' Accounts[1] & Reconciliations	4.1. Is there a separately identifiable bank account where clients' monies are held, separate from the facility's business bank account? 4.2. Are reconciliations between the bank account (as above) & clients' ledgers completed on a monthly basis? 4.3. Are all reconciliations prepared and reviewed by 2 separate Officers? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No

[1] Clients' Accounts are those accounts managed by the facility, which hold monies on behalf of clients.

5. Deposits & Income	5.1. Are all deposits to Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the facility?	Yes / No
	5.2. Is supporting documentation obtained and held on file for all deposits and income?	Yes / No
	5.3. Are receipts given for monies received (where appropriate e.g. relatives)?	Yes / No
	If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	
6. Withdrawals & Expenditure	6.1. Are all withdrawals from Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the home?	Yes / No
	6.2. Is supporting documentation obtained and held on file (receipts/invoices) for all withdrawals and expenditure?	Yes / No
	6.3. Are excessive withdrawals from Clients' Accounts reviewed by a Senior Officer of the facility on a regular basis?	Yes / No
	If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	
7. Monitoring Of Clients' Income & Expenditure	7.1. Is there regular detailed monitoring of clients' income & expenditure by a senior officer?	Yes / No
	7.2. Is consideration given to clients' spending patterns and appropriateness of spend and are changes in spending patterns reviewed?	Yes / No
	7.3. Are any irregularities reported to key worker?	Yes / No

	If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	
8. Client Records	8.1. Are ledger cards maintained for each client to record all income, deposits, withdrawals and expenditure? 8.2. Are these ledger cards appropriately completed, and authorised by a separate senior officer of the facility? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No
9. Authorising Signatures	9.1. Is there an up to date copy of specimen authorised signatures held on file? If no applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No
10. General Security of Property Held	10.1. Is clients' property (monies/valuables) held in a safe place within the facility and adequately secured? 10.2. Is the client or their representative aware of what is being held on their behalf and have authorised the safekeeping of these? 10.3. Are there robust controls around access to clients' property (including PIN numbers, passwords etc.) and restricted to minimal named staff?	Yes / No Yes / No Yes / No

	10.4. Are up to date and accurate records maintained of all items held for safekeeping? 10.5. Are up to date and accurate records maintained of all items of furniture and equipment brought into the service users' room? 10.6. Are there procedures to ensure that amounts kept for safekeeping are not excessive? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No
11. Internal Audit Recommendations	11.1. Have the internal audit recommendations circulated by the Trust to you during the year been considered? 11.2. If so, has an action plan been put in place to address any issues raised? If no applies above, please detail below any reasons why and the outstanding actions planned to be taken. _____ _____ _____	Yes / No Yes / No
12. RQIA Financial Inspection Recommendations	12.1. Have any RQIA requirements (under the relevant regulations) as well as recommendations issued to you during the year been considered? 12.2. If so, has an action plan been put in place to address any issues raised? If no applies above, please detail below any reasons why and the outstanding actions planned to be taken. _____ _____	Yes / No Yes / No

	_____	
13. Serious Adverse Incidents	13.1. Have there been any Serious Adverse Incidents in respect of management of clients' finances in the past 12 months? If YES applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No

Signed: _____ (**Registered Manager)**

Print Name: _____

Date: _____

Signed: _____ (**Registered Person)**

Print Name: _____

Date: _____

Completed forms should be returned to following address or scanned and emailed to …… by …… (Insert date)

Failure to complete this pro forma will be considered as unsatisfactory performance and be appropriately managed.

In addition, as part of a rolling internal audit programme, a number of facilities will be visited during the financial year to ensure that they have the necessary controls in place. This may include a review of the process and evidence used by the facility to conduct the self – assessment above.

The Trust may share Information provided in this return with other bodies responsible for auditing or administering public funds, in order to prevent and detect fraud.

This return will form part of the contract management review.

Your co-operation in this matter is greatly appreciated and if you wish to discuss this further please contact …… on

…….

Yours Sincerely

_____

Name and Designation

Annex B

Template for Supported Living Services

Dear Provider,

Oversight of Service Users' Finances in Supported Living Settings

The Department of Health, Social Services and Public Safety (DHSSPS) issues guidance for implementation by all Health and Social Care Trusts.

The guidance details the Trust's responsibility to take reasonable steps to ensure adequate financial controls are in place to safe guard residents' monies in supported living facilities with which it places clients.

I would therefore be grateful if you would complete the attached declaration confirming the following controls are in operation within the above named facility, for which you are responsible.

Control/Process		**Response**
1. Authorisation	1.2. Where your facility is appointee/controller, do you hold written authorisation to support these arrangements for each client? If no applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No
2. Procedures	2.1. Do you hold up-to-date comprehensive financial procedures for managing clients' monies and clients' accounts? 2.2. Do all staff who are involved in the mgt of residents monies' receive adequate and regular	Yes / No

	training on these procedures? If no applies to any of the above, please provide details/reasons below (or separately if necessary). _____ _____ _____	Yes / No
3. Financial Support Agreements	3.1. Do you have agreements in place, which clearly set out financial arrangements for each client? 3.2. Are these agreements reviewed, updated, agreed and signed annually to reflect changes in circumstances? (Note: RQIA guidance recognises that where a client does not have capacity to sign and no one else is willing/available, a facility should note this on the agreement) 3.3. Is income and expenditure clearly documented in FSA and updated annually? 3.4. Is there an up to date schedule of clients' benefits entitlements for each client? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No Yes / No
4. Tenancy Agreements	4.1. Are there Tenancy Agreements in place for all tenants and signed by both parties (or representatives)? (Note: RQIA guidance recognises that where a client does not have capacity to sign and no one else is willing/available, a facility should note this on the agreement) 4.2. Do you maintain an Inventory listing detailing tenants' ownership of additional items in the event of a tenant leaving the facility?	Yes / No Yes / No

	If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	
5. Clients' Accounts & Reconciliations	5.1. Is there a separately identifiable bank account where clients' monies are held, separate from the facility's business bank account?	Yes / No
	5.2. Are reconciliations between the bank account (as above) & clients' ledgers completed on a monthly basis?	Yes / No
	5.3. Do you operate common household accounts/shared kitties?	Yes / No
	5.4. Are these accounts/kitties reconciled monthly?	Yes / No
	5.5. Are all reconciliations prepared and reviewed by 2 separate Officers?	Yes / No
	5.6. Does the facility actively seek to minimise the use of cash by tenants through the use of standing orders for bills etc?	Yes / No
	If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	
6. Deposits & Income	6.1. Are all deposits to Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the facility?	Yes / No
	6.2. Is supporting documentation obtained and held on file for all deposits and income?	Yes / No

	6.3. Are receipts given for monies received (where appropriate e.g. relatives)? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No
7. Withdrawals & Expenditure	7.1. Are all withdrawals from Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the facility? 7.2. Is supporting documentation obtained and held on file (receipts/invoices) for all withdrawals and expenditure? 7.3. Are excessive withdrawals from Clients' Accounts reviewed by a Senior Officer of the facility on a regular basis? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No
8. Monitoring Of Clients' Income & Expenditure	8.1. Is there regular detailed monitoring of clients' income & expenditure by a senior officer? 8.2. Is consideration given to clients' spending patterns and appropriateness of spend and are changes in spending patterns reviewed? 8.3. Are any irregularities reported to key worker? If no applies to any of the above, please provide details below (or separately if necessary). _____	Yes / No Yes / No Yes / No

	_____ _____	
9. Client Records	9.1. Are ledger cards maintained for each client to record all income, deposits, withdrawals and expenditure? 9.2. Are these ledger cards appropriately completed, and authorised by a separate senior officer of the facility? If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No
10. Authorising Signatures	10.1. Is there an up to date copy of specimen authorised signatures held on file? If no applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No
11. General Security of Property Held	11.1. Is clients' property (monies/valuables) monies held in a safe place within the facility and adequately secured? 11.2. Is the client or their representative aware of what is being held on their behalf and have authorised the safekeeping of these? 11.3. Are there robust controls around access to clients' property (including PIN numbers, passwords etc.) and restricted to minimal named staff? 11.4. Are up to date and accurate records maintained of all items held for safekeeping? 11.5. Are there procedures to ensure that amounts kept for safekeeping are not excessive?	Yes / No Yes / No Yes / No Yes / No Yes / No

	If no applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	
12. Internal Audit Recommendations	12.1. Have the internal audit recommendations circulated by the Trust to you during the year been considered? 12.2. If so, has an action plan been put in place to address any issues raised? If no applies above, please detail below any reasons why and the outstanding actions planned to be taken. _____ _____ _____	Yes / No Yes / No
13. RQIA Financial Inspection Recommendations	13.1. Have any RQIA requirements (under the relevant regulations) as well as recommendations issued to you during the year been considered? 13.2. If so, has an action plan been put in place to address any issues raised? If no applies above, please detail below any reasons why and the outstanding actions planned to be taken. _____ _____ _____	Yes / No Yes / No
14. Serious Adverse Incidents	14.1. Have there been any Serious Adverse Incidents in respect of management of clients' finances in the past 12 months?	Yes / No

	If YES applies above, please provide details below (or separately if necessary). _____ _____ _____	

Signed: _____ (**Registered Manager)**

Print Name: _____

Date: _____

Signed: _____ (**Registered Person)**

Print Name: _____

Date: _____

Completed forms should be returned to following address or scanned and emailed to …… by …… (Insert date)

Failure to complete this pro forma will be considered as unsatisfactory performance and be appropriately managed.

In addition, as part of a rolling internal audit programme, a number of facilities will be visited during the financial year to ensure that they have the necessary controls in place. This process may include a review of the process and evidence used by the facility to conduct the self-assessment above.

The Trust may share Information provided in this return with other bodies responsible for auditing or administering public funds, in order to prevent and detect fraud.

This return will form part of the contract management review.

Your co-operation in this matter is greatly appreciated and if you wish to discuss this further please contact …… on

…….

Yours Sincerely

_____

Name and Designation

The Regulation and Quality Improvement Authority

Monitoring of Article 116 of The Mental Health (Northern Ireland) Order 1986

2014-2015

national preventive mechanism

Table of Contents

1.0 The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is a non-departmental public body established under the provision of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. RQIA is responsible for providing independent assurance concerning the quality, safety and availability of health and social care services in Northern Ireland. Moreover RQIA endeavours to encourage improvements in the quality of services and to safeguard the rights of service users. The Mental Health & Learning Disability Team (MHLD) undertakes a range of responsibilities for people with mental ill health and those with a learning disability, in accordance with the Mental Health (Northern Ireland) Order, 1986 (MHO).

1.1 Monitoring of Patient Finances by RQIA in accordance with the Mental Health (Northern Ireland) Order, 1986

Article 116 of the MHO outlines specific expectations in relation to the trusts' handling of patients' property as follows:

(1) Subjects to paragraphs (4) and (5), where it appears to a trust that any patient in any hospital or in any accommodation administered by it under the Health and Social Services (Northern Ireland) Order 1972 is incapable, by reason of mental disorder, of managing and administering his property and affairs, the trust may receive and hold money and valuables on behalf of that patient.

(2) A receipt or discharge given by a trust for any such money or valuables shall be treated as a valid receipt.

(3) Where a trust holds money or valuables on behalf of a person in pursuance of paragraph (1), it may expend that money or dispose of those valuables for the benefit of that person and in the exercise of the powers conferred by this paragraph, the trust shall have regard to the sentimental value that any article may have for the patient, or would have but for his mental disorder.

(4) A trust shall not receive or hold under paragraph (1) on behalf of any one patient without the consent of the RQIA money or valuables exceeding in the aggregate such sum as the Department may from time to time determine.

(5) Paragraph (1) shall not apply where a controller has been appointed in Northern Ireland in relation to the property and affairs of the patient.

The MHO also defines a role for RQIA in relation to oversight of patients' property at Article 86 (2) (c) (iv) in "preventing or redressing loss or damage to [patients] property";

RQIA is required to monitor the arrangements put in place by trusts to safeguard patients' monies. Specifically under Article 116(4) of the MHO,

trusts are not permitted to receive or hold balances in excess of an agreed sum without the consent of RQIA. This sum was set by the Department of Health, Social Services and Public Safety at no more than £20,000 for any single mental health or learning disability patient in September 2012.

1.2 Methodology used by RQIA to Monitor Compliance with Article 116 2013-14

In the 2013/2014 inspection year, RQIA monitored compliance with Article 116 through a focussed programme of financial inspections. Financial inspections were undertaken in 63 mental health and learning disability wards by an independent finance inspector. The finance inspector sought to obtain assurances that trusts apply best practice in the management of patients' property and monies through:

- Compliance with DHSSPS Circular 57/2009 - Misappropriation of Residents' Monies – Implementation and Assurance of Controls in Statutory and Independent Homes. This applies to all Trust facilities including hospitals;
- Application of accounting policies as detailed in their Standing Financial Instructions (SFIs);
- Implementation of comprehensive local procedures; and,
- Application of Standard 15 of the Nursing Homes Minimum Standards (in so far as this can be applied to hospital patients).

The inspections involved the review of:

- Availability of appropriate written procedures for the Handling of Patients' Private Property and Cash;
- Staff access to and awareness of the procedures;
- Staff training in the application of the procedures;
- Review of processes relating to withdrawal of patient's monies;
- Review of patient property books;
- Review of cash record books; and,
- Patients' income and expenditure records.

The inspector met with the ward manager, deputy ward manager or nurse in charge on each ward to discuss the processes in place to safeguard patients' monies and property. A report of inspection findings and a Quality

Improvement Plan (QIP) detailing recommendations was issued to each Trust in March 2014.

2.0 Follow up on Inspection Findings 2014-15

As part of its inspection to individual wards RQIA incorporated finance monitoring into its inspection programme for 2014-15. The Quality Improvement plans issued in March 2014 were reviewed by the MHLD inspector during unannounced visits to facilities and compliance assessed against recommendations.

2.1 Belfast Health and Social Care Trust

In 2013-14 the finance inspector visited 22 wards across three hospital sites in the BHSCT. A total of 39 recommendations were made. During the follow up inspections in 2014-15 inspectors noted that progress was fully met in 33 recommendations and not met in three recommendations. Two wards have closed since the last finance inspection.

See Appendix 2.

2.2 Northern Health and Social Care Trust

In 2013-14 the finance inspector visited 12 wards across two hospital sites in the NHSCT. A total of 41 recommendations were made for 10 wards. During the follow up inspections in 2014-15 inspectors noted that progress was fully met in 26 recommendations, not met in 12 recommendations and not applicable in 2 recommendations. Two wards have closed since the last finance inspection.

See Appendix 3

2.3 South Eastern Health and Social Care Trust

In 2013-14 the finance inspector visited seven wards across four hospital sites in the SEHSCT. A total of 15 recommendations were made for six wards. During the follow up inspections in 2014-15 inspectors noted that progress was fully met in 15 out of 15 recommendations (all six wards inspected).

2.4 Southern Health and Social Care Trust

In 2013-14 the finance inspector visited eight wards across three hospital sites in the SHSCT. A total of 18 recommendations were made for all wards. During the follow up inspections in 2014-15 inspectors noted that progress was fully met in 12 recommendations, partially met in two recommendations and not met in three recommendations. Three wards have closed since the financial inspection in 2013-14.

See Appendix 5

2.5 Western Health and Social Care Trust

In 2013-14 the finance inspector visited 14 wards across five hospital sites in the WHSCT. A total of 48 recommendations were made for 13 wards. During the follow up inspections in 2014-15 inspectors noted that progress was fully met in 30 recommendations and not met in 11 recommendations and one recommendation was assessed as no longer applicable. Two wards have closed since the last finance inspection in 2013-14.

See Appendix 6

3.0 Conclusions from Inspection Findings

Follow up inspection findings would indicate that patients' monies and property in the Mental Health and Learning Disability wards inspected had generally been managed appropriately and were being properly safeguarded. It was good to note that the majority of recommendations have been met since the last finance inspections in 2013-14. Some recommendations were assessed as no longer applicable and there were recommendations made for wards which have since closed.

However, in other wards inspected the lack of progress in relation to some recommendations has been restated for a second time. These recommendations are in relation to development and implementation of policies, recording of items,access to safe and weekly checks as well as individual statements from cash office. Training in relation to the management of patient finances was not available in some trusts. Trusts were advised that these recommendations should be implemented immediately to mitigate risks.

4.0 Next Steps

RQIA will evaluate the implementation of recommendations on individual wards as part of a planned programme of inspections in 2015/2016. This report will be shared with each Trust MHLD Director, and Director of Finance. A risk rating will be completed of wards in respect of further priority inspections in 2015/2016. RQIA will continue to monitor the management of patient finances as part of its statutory functions in accordance with the Mental Health (Northern Ireland) Order 1986. This will include reviewing Trusts' Standing Financial Instructions, policies and procedures, and management of Trust held funds for individual patients' monies and valuables with balances greater than £20,000.

Appendix 1 Wards Inspected

Belfast HSC Trust

No	Trust	Hospital	Ward	Date
1	BHSCT	Mater Hospital	Ward J - Mater	11/11/2014
2	BHSCT	Mater Hospital	Ward K - Mater	03/12/2014
3	BHSCT	Mater Hospital	Ward L - Mater	06/08/2014
4	BHSCT	Knockbracken	Shannon Clinic Ward 1	17/02/2015
5	BHSCT	Knockbracken	Shannon Clinic Ward 2	11/11/2014
6	BHSCT	Knockbracken	Shannon Clinic Ward 3	12/03/2015
7	BHSCT	Knockbracken	Valencia	29/01/2015
8	BHSCT	Knockbracken	Clare Ward	11/03/2015
9	BHSCT	Knockbracken	Avoca Ward	14/01/2015
10	BHSCT	Knockbracken	Innisfree	25/05/2015
11	BHSCT	Knockbracken	Dorothy Gardiner	26/03/2015
12	BHSCT	Knockbracken	Rathlin	04/02/2015
13	BHSCT	Muckamore Abbey	Cranfield Female	02/02/2015
14	BHSCT	Muckamore Abbey	Cranfield ICU	25/09/2014
15	BHSCT	Muckamore Abbey	Killead	24/11/2014
16	BHSCT	Muckamore Abbey	Cranfield Male	12/01/2015
17	BHSCT	Muckamore Abbey	Six Mile	14/01/2015
18	BHSCT	Muckamore Abbey	Erne	09/12/2014
19	BHSCT	Muckamore Abbey	Moylena	08/07/2014
20	BHSCT	Muckamore Abbey	Greenan	23/10/2014

Northern HSC Trust

No	Trust	Hospital	Ward	Date
1	NHSCT	Holywell Hospital	Tobernaveen Centre	29/01/2015
2	NHSCT	Holywell Hospital	Tobernaveen Lower	06/01/2015
3	NHSCT	Holywell Hospital	Tobernaveen Upper	15/01/2015
4	NHSCT	Holywell Hospital	Carrick 4	27/10/2014
5	NHSCT	Holywell Hospital	Lissan 1	02/09/2014
6	NHSCT	Holywell Hospital	Inver 1	11/03/2015
7	NHSCT	Holywell Hospital	Inver 4	21/01/2015
8	NHSCT	Causeway Hospital	Ross Thompson unit	15/12/2014

South Eastern HSC Trust

No	Trust	Hospital	Ward	Date
1	SEHSCT	Ulster Hospital	Ward 27 - Ulster	02/04/2014
2	SEHSCT	Downshire Hospital	Ward 27 - Downshire	05/11/2014
4	SEHSCT	Downe Hospital	Dementia Ward	22/01/2015
5	SEHSCT	Downe Hospital	Downe Acute	11/11/2014
6	SEHSCT	Lagan Valley Hospital	Ward 11	18/02/2015
7	SEHSCT	Lagan Valley Hospital	Ward 12	03/02/2015

Southern HSC Trust

No	Trust	Hospital	Ward	Date
1	SHSCT	Bluestone	Silverwood	09/02/2015
2	SHSCT	Bluestone	Bronte	05/11/2014
3	SHSCT	Bluestone	Cloughmore	07/04/2014
4	SHSCT	Bluestone	Willow	20/03/2015
5	SHSCT	Bluestone	Dorsey A & T	04/11/2014
6	SHSCT	Bluestone	Rosebrook	12/02/2015
7	SHSCT	St. Luke's Hospital	Gillis Memory Centre	06/01/2015

Western HSC Trust

No	Trust	Hospital	Ward	Date
1	WHSCT	T&F	Beech	25/02/2015
2	WHSCT	T&F	Oak B	11/11/2014
3	WHSCT	T&F	Lime	02/03/2015
4	WHSCT	Gransha Hospital	Cedar Ward	30/09/2014
5	WHSCT	Grangewood Hospital	Evish Female	11/08/2014
6	WHSCT	Grangewood Hospital	Carrick Male	25/02/2015
7	WHSCT	Lakeview Hospital	Strule Lodge	12/01/2015
8	WHSCT	Lakeview Hospital	Brooke Lodge	14/09/2014
9	WHSCT	Waterside Hospital	Ward 1	19/02/2015
10	WHSCT	Waterside Hospital	Ward 2	16/12/2014

Appendix 2 Belfast HSC Trust finance recommendations restated following 2014/15 inspection year

A total of 39 recommendations were made following the 2013/14 financial inspections. During the follow up inspections in 2014/15, inspectors noted that progress was fully met in 33 recommendations and not met in 3 recommendations. Two wards have closed since the last finance inspection.

The 3 recommendations that were not met have been restated following the 2014/15 inspection year and are listed below.

Inspection	Recommendation	Action Taken	Compliance
Innishfree, Knockbracken, 25 & 26 March 2015	It is recommended that the ward manager ensures that regular individual patient statements are received from the cash office at the ward to facilitate reconciliation of expenditure and receipts	Individual patient statements are not received from the cash office at the ward to facilitate reconciliation of expenditure and receipts. This recommendation will be restated for a second time	**Not met**
Moylena, Muckamore Abbey, 8 & 9 July 2014	It is recommended that the ward manager ensures that a record of staff who access the key to the Bisley drawer, and the reason for access, is maintained.	There was no record of staff who can access the Bisley drawer on the ward. This recommendation will be restated for a second time	**Not met**
Ward L, Mater Hospital, 06 August 2014	It is recommended that the Trust introduce a uniform policy for managing patients' finances across all wards.	A uniform policy for managing patients' finances across all wards was not available during the inspection. The Trust's finance department reported that the policy was not currently available.	**Not Met**

Appendix 3 Southern HSC Trust finance recommendations restated following 2014/15 inspection year

A total of 18 recommendations were made following the 2013/14 financial inspections. During the follow up inspections in 2014/15, inspectors noted that progress was fully met in 12 recommendations, partially met in 2 recommendations and not met in 3 recommendations. Three wards have closed since the last financial inspection in 2013/14.

The 3 recommendations that were not met and the 2 recommendations that were partially met, have been restated following the 2014/15 inspection year and are listed below.

Inspection	Recommendation	Action Taken	Compliance
Cloughmore, Craigavon Area Hospital, 7 April 2014	It is recommended that the ward manager ensures that all items brought into the ward on admission are listed appropriately, the area of their storage or transfer recorded, and appropriate receipting undertaken, particularly when relatives remove items from the ward.	The inspector reviewed the ward processes for ensuring the security of patient property and noted that patient valuables were listed on admission. The inspector did not find evidence of a process to record all items brought into the ward. This recommendation will be restated for a second time.	**Partially met**
	It is recommended that the Trust develops and implements a uniform policy for managing patients' finances within the Bluestone Unit, including managing and securing patients' property held in the ward safes.	The inspector was informed that a procedure for managing patient's money and property had been drafted and had been sent to the Trust's finance department for advice and guidance. However, at the time of the inspection this had not been implemented. This recommendation will be restated for a second time.	**Partially met**

Silverwood, Craigavon Area Hospital, 9 February 2015	It is recommended that the Trust develops and implements a uniform policy for managing patient's finances within the Bluestone Unit.	The inspector met with the ward manager and the Patient Flow and Bed Management Coordinator who stated that the uniform policy for the Bluestone Unit has not been implemented. The managers advised that the policy was currently under review by senior hospital management and is awaiting final approval. The inspector was not provided a copy of the draft policy.	**Not met**
Willow, Craigavon Area Hospital, 20 March 2015	It is recommended that the Trust develops and implements a uniform policy for managing patient's finances within the Bluestone Unit.	As stated above this was discussed at the conclusion of the inspection with the patient flow and bed management coordinator and the ward manager who advised that a uniform policy is being devised for the bluestone unit and should be available by May 2015.	**Not met**
	It is recommended that the ward manager ensures that all staff attend relevant training in policies and procedures for management of patients finances.	Staff have not received training in relation to the policies and procedures for management of patients' finances. However, the patient flow and bed management coordinator and the ward manager advised when the local policy is available to staff this will be implemented. However they were unable to give a date of when this training will be available to staff.	**Not met**

Appendix 4 Northern HSC Trust finance recommendations restated following 2014/15 inspection year

A total of 41 recommendations were made following the 2013/14 financial inspections. During the follow up inspections in 2014/15, inspectors noted that progress was fully met in 26 recommendations, not applicable in 2 recommendations and not met in 12 recommendations. Two wards have closed since the last finance inspection in 2013/14

The 12 recommendations that were not met, have been restated following the 2014/15 inspection year and are listed below.

Inspection	Recommendation	Action Taken	Compliance
Carrick 4, Holywell Hospital, 27 & 28 October 2014	It is recommended that the ward manager ensure that all staff attend up to date training in the management of patients' monies and valuables.	Inspectors were advised that training in the management of patients' monies and valuables is not currently available to staff working on the ward. Inspectors were advised that staff will liaise with colleagues in the finance department within the Trust in relation to making this training available. This recommendation will be restated for a second time.	**Not met**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct	Inspectors were informed that this process has not been implemented. This recommendation will be restated for a second time.	**Not met**
	It is recommended that the ward manager ensures that regular weekly checks of patients' money held against the cash ledger are undertaken and appropriately recorded.	There were no evidence on the days of the inspection which indicated that the ward manager was completing regular weekly checks of patients' money held against the cash ledger. This recommendation will be restated for a second time	**Not met**
Inver 4, Holywell Hospital, 21 & 22 January 2015	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	The ward manager stated that they do not routinely request patient statements from the hospital cash office. This recommendation will be restated a second time.	**Not met**

Lissan 1, Holywell Hospital, 2 & 3 September 2014	It is recommended that the ward manager ensure that all staff attend up to date training in the management of patients' monies and valuables.	Inspectors were advised that training in the management of patients' monies and valuables is not currently available to staff working on the ward. Inspectors were advised that the ward sister and senior management team for the ward are liaising with the colleagues in the finance department within the Trust in relation to making this training available.	**Not Met**
Ross Thompson Unit, Causeway Hospital 15 & 16 December 2014	It is recommended that the ward manager ensures that all items brought into the ward on admission that are removed by relatives are recorded. Record of receipt by the relative should be obtained.	Inspectors spoke with ward staff who advised that they do not document or record the removal of patient's items by relatives.	**Not met**
	It is recommended that the ward manager ensures that records of purchases made and change returned to patients are maintained along with appropriate receipting processes.	Staff on the Ross Thompson unit do not hold monies belonging to patients. Staff however informed inspectors that they may on occasions, at a patient's request, purchase items from the shop. Currently staff do not retain financial transaction records for when patients give money to staff, the reasons for this, item purchased and monies returned.	**Not met**
Tobernaveen Upper, Holywell Hospital, 15 January 2015	It is recommended that the ward manager ensures that all items brought into the ward on admission that are removed by relatives are recorded. Record of receipt by the relative should be obtained.	The ward manager advised that the following recommendation had not been achieved.	**Not met**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	The ward manager advised the inspector that at present they do not receive statements from the cash office. The ward manager has agreed to take this forward for immediate action.	**Not met**

Tobernaveen Centre, Holywell Hospital, 29 & 30 January 2015	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	Individual statements are not received from the cash office. The ward manager advised that if patients request a statement they can arrange this with the cash office. However to date this is not been implemented on the ward. This recommendation will be restated for a second time	**Not met**
Tobernaveen Lower, Holywell Hospital, 6 & 7 Jan 2015	It is recommended that the ward manager ensures that all items brought into the ward on admission that are removed by relatives are recorded. Record of receipt by the relative should be obtained.	The ward manager advised that the following recommendation had not been achieved. Following discussion with the inspector, the ward manager agreed steps to take in order to ensure the safeguarding of patients belongings in accordance with the recommendation.	**Not met**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	The ward manager advised the inspector that at present they do not receive statements from the cash office. The ward manager has agreed to take this forward for immediate action.	**Not met**

Appendix 5 Western Trust HSC finance recommendations restated following 2014/15 inspection year

A total of 48 recommendations were made following the 2013/14 financial inspections. During the follow up inspections in 2014/15, inspectors noted that progress was fully met in 30 recommendations, not met in 11 recommendations and 1 recommendation was no longer applicable. Two wards have closed since the last finance inspection in 2013/2014.

The 11 recommendations that were not met, have been restated following the 2014/15 inspection year and are listed below.

Inspection	Recommendation	Action Taken	Compliance
Beech, Tyrone and Fermanagh Hospital, 25 February 2015	It is recommended that the Trust reviews the current practice for authorisation of larger purchases, including eliminating the practice of the same staff authorising the purchase and verifying the receipt. A policy and procedure should be developed and implemented.	The purchase of larger items was signed by three different members of staff; however a policy and procedure had not been developed or implemented to reflect the current practice. The current policies and procedures pertaining to patients' property and finances had not been reviewed or updated since 2011/2012.	**Not met**
	It is recommended that the ward manager trust introduces a weekly audit of receipts against expenditure on this ward.	The inspector was advised by the ward manager that they do not complete a weekly audit of receipts.	**Not met**
	It is recommended that the Trust introduces a secondary check of expenditure records on this ward.	The inspector was provided with no evidence of secondary checks; there was also no evidence that expenditure was being audited or reviewed by the ward manager.	**Not met**
	It is recommended that the ward manager ensures that a record of all staff who obtain the key to the safe where patients' money is stored is maintained including the reason for access.	A review of ward records indicated that staff were not recording staff who obtain the key to the safe and/or a reason for access to the safe in relation to monies.	**Not met**
	It is recommended that the ward manager trust introduces a weekly audit of receipts against expenditure on this ward.	The inspector was advised by the ward manager that they do not complete a weekly audit of receipts.	**Not met**

Brooke Lodge, Lakeview Hospital, 14 September 2014	It is recommended that the ward manager ensures that regular statements are received from the cash office to facilitate verification of transactions and expenditure.	Inspectors were informed by the deputy ward manager that regular statements are not received from the cash office to facilitate verification of transactions and expenditure. This recommendation will be restated for a second time	**Not met**
	It is recommended that the Trust develops and implements a policy and procedure in relation to operating individual patient saving accounts.	Inspectors were informed by the deputy ward manager that a draft policy had been developed in relation to operating individual patient saving accounts. The draft policy was not available on the ward. This recommendation will be restated for a second time	**Not met**
	It is recommended that the ward manager ensures that updated training in the management of patients' finances is prioritised for all staff.	The inspectors were informed that training in the management of patients finances is not available to staff. This recommendation will restated for a second time.	**Not met**
Cedar, Gransha, 30 September & 1 October 2014	It is recommended that the ward manager ensures that regular statements are received from the cash office to facilitate verification of transactions and expenditure.	This process has not been implemented. This recommendation will be restated for a second time.	**Not met**
Lime, Tyrone and Fermanagh Hospital, 2 March 2015	It is recommended that the ward manager develops a system to ensure that where staff are making purchases on behalf of patients, a transparent record is maintained of the amount of money received, purchases made and change returned and verified by another staff member.	Ward staff do not record the purchases made by staff on a patients behalf. Instead when a member of staff obtains monies to spend on behalf of a patient, the money is recorded as signed out to the patient as opposed to the member of staff who has physically obtained the money.	**Not met**
	It is recommended that the ward manager ensures that a record is kept of the staff member who obtains the key to the patient's safe, and the reason for access is maintained.	The key to the safe is retained throughout the day by the nurse in charge who signs for receipt of the key from the previous shift. The ward does not currently record each occasion that the safe is opened, who opened it or why it was opened.	**Not met**

Department of
Health, Social Services and Public Safety
www.dhsspsni.gov.uk

Subject: **Safeguarding of Service Users' Finances within Residential and Nursing Homes and Supported Living Settings.**	**Circular Reference: HSC(F) 15-2016** **Date of Issue: 18 February 2016**
For Action by: Chief Executive and Director of Finance of each HSC Trust, and HSCB **For Information to:** HSC Head of Internal Audit and RQIA. **Summary of Contents:** This circular replaces HSC(F) 08-2015 and reminds organisations to ensure that service users' finances are safeguarded in residential and nursing homes and supported living services within the statutory and independent sectors. **Enquiries**: Any enquiries about the contents of this Circular should be addressed to: Finance Policy, Accountability and Counter Fraud Unit DHSSPS Room D3 Castle Buildings Stormont BELFAST BT4 3SQ Tel: 028 9076 5696 fpau@dhsspsni.gov.uk	**Related documents:** Residential Care Homes – Minimum Standards Nursing Homes – Minimum Standards Domiciliary Care Agencies – Minimum Standards **Superseded Documents:** HSC(F) 08-2015 **Expiry Date:** Not Applicable **Status of Contents:** Action **Implementation:** Immediate

BACKGROUND

1. The purpose of this guidance is to update HSC (F) 08-2015 to reflect additional assurances to be sought and further checks to be put in place to ensure that service users' finances are safeguarded within both the statutory and independent sectors. Circular HSC (F) 08-2015 was issued following a review by RQIA – 'Oversight of Services Users' Finances in Residential and Supported Living Settings' which highlighted the need to strengthen the level of assurances received from the Independent sector and to extend these assurances to supported living settings. Circular HSC(F) 08-2015 provided comprehensive guidance and included templates to be issued to facilities on an annual basis to gain satisfactory assurances.

2. A review of the process in 2014/15 identified areas where further clarification was needed to include minor amendments to the templates and additional guidance on the process for reviewing the returns. This circular reflects these changes and replaces Circular HSC (F) 08-2015 which is now superseded.

Changes to the templates

3. The templates have been amended to include 4 additional questions:

    - Do you have a transport scheme in place? (Question 2.3 on amended templates attached).
    - Is your transport scheme in line with RQIA guidelines? (Question 2.4 on amended templates attached).
    - Do you have a holiday policy if you facilitate staff to support residents/tenants to go on holiday? (Question 2.5 on amended templates attached).
    - Are RQIA aware of clients' monies in excess of £20,000 per client being managed by the facility? (Question 5.4 / 6.4 on amended templates attached).

4. Furthermore the templates are addressed to 'Dear Registered Manager' rather than 'Dear Service Provider'.

5. Amended templates can be found at Annex A and Annex B.

Other changes

6. A new section (section 16) has been added to the guidance below to incorporate the issues below.

- All returns should be checked to ensure that they have been signed by the registered manager / owner; otherwise they will need to be returned to the facility for re submission.
- Returns with 'N/A' or 'No' responses without explanations, where appropriate, should be followed up with the facility.
- Outstanding returns to be chased up.
- Trust Finance to share any issues identified in the returns with internal audit, contract management and care/case management.
- Trusts to carry out, where possible, rolling sample inspections particularly where issues have been identified or no explanations provided or no return received.
- Trust cover letter to highlight the issues above and emphasise that returns will be shared and compared with internal audit, RQIA and other bodies as appropriate

THE FOLLOWING SECTIONS FORM PART OF THE ORIGINAL GUIDANCE ISSUED IN CIRCULAR HSC(F) 08-2015 (ALONG WITH THE AMENDMENTS ABOVE) AND ARE STILL APPLICABLE

ACCOUNTABILITY ARRANGEMENTS/CONTROLS

7. Robust financial controls must be in place in all residential, nursing homes and supported living settings in both the statutory and independent sectors. This circular sets out the mandatory controls that must be in place within the statutory sector to ensure robust financial controls are in place and seeks assurances that similar controls (as appropriate) are in place within independent homes and supported living facilities.

8. Within the statutory sector, Accounting Officers must ensure that these controls are operating successfully, are in compliance with extant Departmental guidance and that they are reviewed on a regular basis.

9. Within independent homes and supported Living facilities, Accounting Officers must be able to demonstrate that they have taken reasonable steps to ensure that adequate financial controls are in place within independent homes and supported living settings to ensure that Trusts' interests are protected.

10. Trusts have a statutory duty of care to its service users', regardless of the particular setting in which care is delivered, whilst it is accepted that Accounting Officers cannot be held **directly** accountable for the ongoing operation of controls in independent homes or supported living settings, Accounting Officers must ensure there is a proportionate level of oversight of service users' finances.

11. There are a number of existing controls within Trusts to ensure that robust arrangements are in place for handling service users' finances. These include entering into contractual arrangements with the independent care home/supported living service which provides recourse where the level of care is not as expected or where there are circumstances involving financial issues. This also includes liaison with service providers re: implementation of Internal Audit recommendations. It is further recognised that the care/case management review arrangements, together with the reporting procedures for complaints and untoward incidents reporting mechanisms provide additional control mechanisms for each Trust. Notwithstanding this, it is important that Accounting Officers can also demonstrate that they have taken appropriate steps to ensure that adequate financial controls are in place to safeguard service users' interests. Accounting Officers should also ensure that liaison between Trust finance and care colleagues is taking place and operating effectively.

FINANCIAL CONTROLS IN RESIDENTIAL AND NURSING HOMES AND SUPPORTED LIVING SETTINGS WITHIN BOTH THE STATUTORY AND INDEPENDENT SECTORS

12. To assist with this process, two pro forma templates have been developed to seek assurances that robust financial controls are in place within (i) residential and nursing homes and (ii) supported living settings. These have been developed in conjunction with HSC finance and care/case management colleagues. We have developed two templates to allow for the different levels of control within the different settings. These templates reflect the minimum controls for which assurance should be sought and Trusts can add additional controls to the templates if they wish. It should be noted that these templates reflect controls only and are not a list of procedures. Each service should have a detailed set of financial procedures which underpin these controls.

13. These templates are attached at Annex A & B and include controls in relation to authorisation, procedures, clients' agreements & accounts, deposits and income, withdrawals and expenditure, monitoring, authorising signatures and property security.

14. There are a few additional controls in respect of supported living settings and these include controls in relation to tenancy agreements and inventory listing.

ASSURANCES

15. Accounting Officers should ensure that there are effective processes in place to seek and obtain as a minimum, assurances in relation to financial controls for each setting (residential, nursing home and supported living in both statutory and independent sectors) within its geographical area. As the host Trust they should do this by:
    - Issuing the attached pro forma to each service within its geographical area by the end of February each year, relating to the current year;
    - Ensuring that these assurances are received by 31 March and reviewed for each service on a timely basis;
    - Where possible, use these assurances as part of the annual contract review process and consider failure to return the template as unsatisfactory performance and manage this in accordance with the terms of the regional contract/performance framework;
    - Sharing significant issues within the Trust and with other Trusts/ Internal audit and RQIA;

- Providing copies of the assurances to other Trusts when requested, where service users' are placed outside their geographical area; and
- Taking appropriate action for non-compliance.

REVIEW OF COMPLETED TEMPLATES

16. Upon receipt of completed templates:
    - All returns should be checked to ensure that they have been signed by the registered manager and registered owner, otherwise they will need to be returned to the facility for re submission.
    - Returns with 'N/A' or 'No' responses without explanations, where appropriate, should be followed up with the facility.
    - Outstanding returns to be chased up.
    - Trust Finance to share any issues identified in the returns with internal audit, contract management and care/case management.
    - Trusts to carry out, where possible, sample inspections particularly where issues have been identified or no explanations provided or no return received.
    - Trust cover letter to highlight the issues above and emphasise that returns will be shared and compared with internal audit, RQIA and other bodies as appropriate

INTERNAL AUDIT

17. Internal audit carry out an annual audit programme which includes residential and nursing homes within statutory and independent sectors. In line with the increasing use of supported living settings, internal audit have already extended their programme to include supported living settings. Trusts should use information from the assurance process (as at paragraph 10) to help inform their internal audit programme of any services which pose a greater level of risk.

CARE/CASE MANAGEMENT

18. An annual care review is carried out by a care/case manager with each service user to consider the standard / level of care that the service user is receiving and also seeks assurances in relation to the service users' finances. Trusts must ensure there are adequate processes in place for sharing all information in relation to safeguarding service users' finances and ensuring there is regular liaison between finance and care/case management and others as necessary, such that the care/case manager has a complete picture and understanding of a service users finances in advance of the care review. To assist with this, Trusts should ensure that they have a standardised file structure to allow a complete picture of a service users finances. A useful template for the financial section of the care/case management review has been attached at Annex C. The Trust must ensure that care/case management staff are adequately trained to be able to carry out this annual review of service users' finances. Concerns about potential misappropriation of service users' monies identified via care/case management or other process, e.g. RQIA/Internal Audit inspections will trigger a referral to Trusts' adult protection services.

REGULATION AND QUALITY IMPROVEMENT AUTHORITY (RQIA)

19. RQIA is responsible for inspecting the availability of health and social care services and encouraging improvements in the quality of service provision. Its work provides assurance to the Department in respect of compliance with the regulations and minimum standards and the quality of service provision. RQIA's reports are published on its website at www.rqia.org.uk/inspections.

20. As a regulatory body, RQIA monitors compliance with the relevant regulations and minimum standards for residential and nursing home care through its programmes of inspections. RQIA takes action as necessary to ensure that the provider rectifies non-compliance. RQIA publishes all inspection reports on its website at www.rqia.org.uk/inspections and will alert Trusts immediately of any instances it may find of actual or potential abuse of vulnerable adults as well as actual or potential financial irregularity. It is the responsibility of Trusts to carry out such further investigations or audits as may be necessary; it is for Trusts to determine and take appropriate action on behalf of its service users'. However, RQIA will require reports from Trusts on the timescale and outcome of such enquiries when complete.

21. For practical purposes, responsibility for an investigation rests with the Trust in whose area the service is located and it will communicate and liaise closely with other Trusts which have placed their service users' in the facility.

RECOMMENDATIONS

22. Accounting Officers should ensure that existing controls operating in Trust services are reviewed to satisfy themselves that there are appropriate controls in place and that they are in compliance with extant Departmental guidance. Accounting Officers should also take steps to ensure that there are adequate financial controls in place in independent sector homes and supported living settings to ensure that Trusts' service users' interests are protected.

OTHER DEPARTMENTAL GUIDANCE

23. This circular should be read in conjunction with Care Management, Provision of services and charging guidance HSC (ECCU) 1/2010 or subsequent guidance.

24. In addition, your attention is drawn to the existing mandatory Departmental guidance which can be accessed through the following links:-

Residential Care Homes – Minimum Standards

https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/care-standards-residential-care-homes.pdf

Nursing Homes – Minimum Standards

https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/care-standards-nursing-agencies.pdf

Domiciliary Care Agencies – Minimum Standards

https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/care-standards-domiciliary-care.pdf

HSS (F) 13/2007 – Financial Governance Model for New HSS Trusts

https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/hssf-2007-13.pdf

Patients and Clients' Property can be found in section 28 of the Standing Financial Instructions within Circular HSS (F) 13/2007
https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/hssf-2007-13.pdf

ACTION

25. Please ensure that this circular is brought to the attention of the appropriate staff within your organisation and that any relevant action points are noted.

This Circular supersedes HSC(F) 08-2015 Safeguarding of Service Users' Finances within Residential and Nursing Homes and Supported Living Settings.

Should you have any queries please contact Paula Shearer on [redacted]

Paula Shearer
Finance Policy, Accountability and Counter Fraud Unit

Annex A

Template for Residential Homes and Nursing Homes

Dear Registered Manager,

Oversight of Service Users' Finances in Residential and Nursing Homes

The Department of Health, Social Services and Public Safety (DHSSPS) issues guidance for implementation by all Health and Social Care Trusts.

The guidance details the Trust's responsibility to take reasonable steps to ensure adequate financial controls are in place to safe guard residents' monies in all statutory and independent homes with which it places clients.

I would therefore be grateful if you would complete the attached declaration confirming the following controls are in operation within the above named facility, for which you are responsible.

Please ensure explanations are provided for all No and N/A responses.

Control/Process		**Response**
1. Authorisation	1.1. Where your facility is appointee/controller, do you hold written authorisation to support these arrangements for each client? If **No** applies above, please provide details below (or separately if necessary).	Yes / No
2. Procedures	2.1. Do you hold up-to-date comprehensive financial procedures for managing clients' monies and clients' accounts? 2.2. Do all staff who are involved in the mgt of residents monies' receive adequate and regular training on these procedures?	Yes / No Yes / No

	2.3. Do you have a transport scheme in place? 2.4. Is this transport scheme in line with RQIA guidelines? (If not applicable please state). 2.5. Do you have a holiday policy IF you facilitate staff to support residents to go on holiday? (If not applicable please state). If **No** applies to any of the above, please provide details/reasons below (or separately if necessary).	Yes / No Yes / No Yes / No
3. Clients' Agreements	3.1. Do you have agreements in place, which clearly set out financial arrangements for each client? 3.2. Are these agreements reviewed, updated, agreed and signed annually to reflect changes in circumstances? (Note: RQIA guidance recognises that where a client does not have capacity to sign and no one else is willing/available, a facility should note this on the agreement). If **No** applies to any of the above, please provide details below (or separately if necessary).	Yes / No Yes / No
4. Clients' Accounts[1] & Reconciliations	4.1. Is there a separately identifiable bank account where clients' monies are held, separate from the facility's business bank account? 4.2. Are reconciliations between the bank account (as above) & clients' ledgers completed on a monthly basis?	Yes / No Yes / No

[1] Clients' Accounts are those accounts managed by the facility, which hold monies on behalf of clients.

	4.3. Are all reconciliations prepared and reviewed by 2 separate Officers? If **No** applies to any of the above, please provide details below (or separately if necessary).	Yes / No
5. Deposits & Income	5.1. Are all deposits to Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the facility? 5.2. Is supporting documentation obtained and held on file for all deposits and income? 5.3. Are receipts given for monies received (where appropriate e.g. relatives)? 5.4. Are RQIA aware of clients' monies in excess of £20,000 per client being managed by the facility? If **No** applies to any of the above, please provide details below (or separately if necessary).	Yes / No Yes / No Yes / No Yes / No
6. Withdrawals & Expenditure	6.1. Are all withdrawals from Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the home? 6.2. Is supporting documentation obtained and held on file (receipts/invoices) for all withdrawals and expenditure? 6.3. Are excessive withdrawals from Clients' Accounts reviewed by a Senior Officer of the facility on a regular basis?	Yes / No Yes / No Yes / No

	If **No** applies to any of the above, please provide details below (or separately if necessary).	
7. Monitoring Of Clients' Income & Expenditure	7.1. Is there regular detailed monitoring of clients' income & expenditure by a senior officer? 7.2. Is consideration given to clients' spending patterns and appropriateness of spend and are changes in spending patterns reviewed? 7.3. Are any irregularities reported to key worker? If **No** applies to any of the above, please provide details below (or separately if necessary).	Yes / No Yes / No Yes / No
8. Client Records	8.1. Are ledger cards maintained for each client to record all income, deposits, withdrawals and expenditure? 8.2. Are these ledger cards appropriately completed, and authorised by a separate senior officer of the facility? If **No** applies to any of the above, please provide details below (or separately if necessary).	Yes / No Yes / No
9. Authorising Signatures	9.1. Is there an up to date copy of specimen authorised signatures held on file? If **No** applies above, please provide details below (or separately if necessary).	Yes / No
10. General Security of Property Held	10.1. Is clients' property (monies/valuables) held in a safe place within the facility and adequately secured? 10.2. Is the client or their representative aware of what is being held on their behalf and have authorised the safekeeping of these?	Yes / No Yes / No

	10.3. Are there robust controls around access to clients' property (including PIN numbers, passwords etc.) and restricted to minimal named staff?	Yes / No
	10.4. Are up to date and accurate records maintained of all items held for safekeeping?	Yes / No
	10.5. Are up to date and accurate records maintained of all items of furniture and equipment brought into the service users' room?	Yes / No
	10.6. Are there procedures to ensure that amounts kept for safekeeping are not excessive?	
	If **No** applies to any of the above, please provide details below (or separately if necessary).	
11. Internal Audit Recommendations	11.1. Have the internal audit recommendations circulated by the Trust to you during the year been considered?	Yes / No
	11.2. If so, has an action plan been put in place to address any issues raised?	Yes / No
	If **No** applies above, please detail below any reasons why and the outstanding actions planned to be taken.	
12. RQIA Financial Inspection Recommendations	12.1. Have any RQIA requirements (under the relevant regulations) as well as recommendations issued to you during the year been considered?	Yes / No
	12.2. If so, has an action plan been put in place to address any issues raised?	Yes / No

	If **No** applies above, please detail below any reasons why and the outstanding actions planned to be taken.	
13. Serious Adverse Incidents	13.1. Have there been any Serious Adverse Incidents in respect of management of clients' finances in the past 12 months? If **YES** applies above, please provide details below (or separately if necessary).	Yes / No

Signed: _____ (**Registered Manager)**

Print Name: _____

Date: _____

Signed: _____ (**Registered Person)**

Print Name: _____

Date: _____

Completed forms should be returned to following address or scanned and emailed to …… by …… (Insert date)

Failure to complete this pro forma will be considered as unsatisfactory performance and be appropriately managed.

In addition, as part of a rolling internal audit programme, a number of facilities will be visited during the financial year to ensure that they have the necessary controls in place. This may include a review of the process and evidence used by the facility to conduct the self – assessment above.

The Trust may share Information provided in this return with other bodies responsible for auditing or administering public funds, in order to prevent and detect fraud.

This return will form part of the contract management review.

Your co-operation in this matter is greatly appreciated and if you wish to discuss this further please contact …… on

…….

Yours Sincerely

Name and Designation

Annex B

Template for Supported Living Services

Dear Registered Manager,

Oversight of Service Users' Finances in Supported Living Settings

The Department of Health, Social Services and Public Safety (DHSSPS) issues guidance for implementation by all Health and Social Care Trusts.

The guidance details the Trust's responsibility to take reasonable steps to ensure adequate financial controls are in place to safe guard residents' monies in supported living facilities with which it places clients.

I would therefore be grateful if you would complete the attached declaration confirming the following controls are in operation within the above named facility, for which you are responsible.

Please ensure explanations are provided for all No and N/A responses.

Control/Process		**Response**
1. Authorisation	1.2. Where your facility is appointee/controller, do you hold written authorisation to support these arrangements for each client? If **No** applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No
2. Procedures	2.1. Do you hold up-to-date comprehensive financial procedures for managing clients' monies and	Yes / No

	clients' accounts? 2.2. Do all staff who are involved in the mgt of residents monies' receive adequate and regular training on these procedures? 2.3. Do you have a transport scheme in place? 2.4. Is this transport scheme in line with RQIA guidelines? (If not applicable please state). 2.5. Do you have a holiday policy IF you facilitate staff to support residents/tenants to go on holiday? (If not applicable please state). If **No** applies to any of the above, please provide details/reasons below (or separately if necessary). _____ _____ _____	 Yes / No Yes / No Yes / No Yes / No
3. Financial Support Agreements	3.1. Do you have agreements in place, which clearly set out financial arrangements for each client? 3.2. Are these agreements reviewed, updated, agreed and signed annually to reflect changes in circumstances? (Note: RQIA guidance recognises that where a client does not have capacity to sign and no one else is willing/available, a facility should note this on the agreement) 3.3. Is income and expenditure clearly documented in FSA and updated annually? 3.4. Is there an up to date schedule of clients' benefits entitlements for each client? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No Yes / No

4. Tenancy Agreements	4.1. Are there Tenancy Agreements in place for all tenants and signed by both parties (or representatives)? (Note: RQIA guidance recognises that where a client does not have capacity to sign and no one else is willing/available, a facility should note this on the agreement) 4.2. Do you maintain an Inventory listing detailing tenants' ownership of additional items in the event of a tenant leaving the facility? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No
5. Clients' Accounts & Reconciliations	5.1. Is there a separately identifiable bank account where clients' monies are held, separate from the facility's business bank account? 5.2. Are reconciliations between the bank account (as above) & clients' ledgers completed on a monthly basis? 5.3. Do you operate common household accounts/shared kitties? 5.4. Are these accounts/kitties reconciled monthly? 5.5. Are all reconciliations prepared and reviewed by 2 separate Officers? 5.6. Does the facility actively seek to minimise the use of cash by tenants through the use of standing orders for bills etc? If **No** applies to any of the above, please provide details below (or separately if necessary).	Yes / No Yes / No Yes / No Yes / No Yes / No Yes / No

	_____ _____ _____	
6. Deposits & Income	6.1. Are all deposits to Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the facility? 6.2. Is supporting documentation obtained and held on file for all deposits and income? 6.3. Are receipts given for monies received (where appropriate e.g. relatives)? 6.4. Are RQIA aware of clients' monies in excess of £20,000 per client being managed by the facility? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No Yes / No
7. Withdrawals & Expenditure	7.1. Are all withdrawals from Clients' Accounts authorised by the client (where possible) and signed by two appropriate officers of the facility? 7.2. Is supporting documentation obtained and held on file (receipts/invoices) for all withdrawals and expenditure? 7.3. Are excessive withdrawals from Clients' Accounts reviewed by a Senior Officer of the facility on a regular basis? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____	Yes / No Yes / No Yes / No

	_____	
8. Monitoring Of Clients' Income & Expenditure	8.1. Is there regular detailed monitoring of clients' income & expenditure by a senior officer? 8.2. Is consideration given to clients' spending patterns and appropriateness of spend and are changes in spending patterns reviewed? 8.3. Are any irregularities reported to key worker? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No
9. Client Records	9.1. Are ledger cards maintained for each client to record all income, deposits, withdrawals and expenditure? 9.2. Are these ledger cards appropriately completed, and authorised by a separate senior officer of the facility? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No
10. Authorising Signatures	10.1. Is there an up to date copy of specimen authorised signatures held on file? If **No** applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No

11. General Security of Property Held	11.1. Is clients' property (monies/valuables) monies held in a safe place within the facility and adequately secured? 11.2. Is the client or their representative aware of what is being held on their behalf and have authorised the safekeeping of these? 11.3. Are there robust controls around access to clients' property (including PIN numbers, passwords etc.) and restricted to minimal named staff? 11.4. Are up to date and accurate records maintained of all items held for safekeeping? 11.5. Are there procedures to ensure that amounts kept for safekeeping are not excessive? If **No** applies to any of the above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No Yes / No Yes / No Yes / No Yes / No
12. Internal Audit Recommendations	12.1. Have the internal audit recommendations circulated by the Trust to you during the year been considered? 12.2. If so, has an action plan been put in place to address any issues raised? If **No** applies above, please detail below any reasons why and the outstanding actions planned to be taken. _____ _____ _____	Yes / No Yes / No
13. RQIA Financial Inspection Recommendations	13.1. Have any RQIA requirements (under the relevant regulations) as well as recommendations issued to you during the year been considered?	Yes / No

	13.2. If so, has an action plan been put in place to address any issues raised? If **No** applies above, please detail below any reasons why and the outstanding actions planned to be taken. _____ _____ _____	Yes / No
14. Serious Adverse Incidents	14.1. Have there been any Serious Adverse Incidents in respect of management of clients' finances in the past 12 months? If **YES** applies above, please provide details below (or separately if necessary). _____ _____ _____	Yes / No

Signed: _____ (**Registered Manager)**

Print Name: _____

Date: _____

Signed: _____ (**Registered Person)**

Print Name: _____

Date: _____

Completed forms should be returned to following address or scanned and emailed to …… by …… (Insert date)

Failure to complete this pro forma will be considered as unsatisfactory performance and be appropriately managed.

In addition, as part of a rolling internal audit programme, a number of facilities will be visited during the financial year to ensure that they have the necessary controls in place. This process may include a review of the process and evidence used by the facility to conduct the self-assessment above.

The Trust may share Information provided in this return with other bodies responsible for auditing or administering public funds, in order to prevent and detect fraud.

This return will form part of the contract management review.

Your co-operation in this matter is greatly appreciated and if you wish to discuss this further please contact …… on

…….

Yours Sincerely

_____

Name and Designation

Annex C

Resident's/Tenant's Review Record

Finance Section (Final V. 17.6.15)

(Residential/Nursing/Supported Living)

Name of Client: _____

Placement Details: _____

Date of Placement: _____

Date of Review: _____

1. Is the resident placed at the appropriate regional tariff rate for their assessed Category of Care (as per RQIA classifications)? **(For Residential/ Nursing Home only)**
   Regional Rate ☐
   Rate paid by Trust ☐

2. Please outline reasons if the payment is above the appropriate regional tariff rate. **(For Residential/ Nursing Home only)**
   _____
   _____
   _____
   _____

3. Does the file contain the necessary assessment and subsequent specialist letter from contracts (if appropriate) corroborating the need for payment above the appropriate regional tariff rate? **(For Residential/ Nursing home only)**

   Yes ☐
   No ☐

If no specify what action you have taken:

_____

_____

4. Does the resident/tenant have capacity to manage finances, confirmed at multi-disciplinary review?
   Yes ☐

No ☐

5. Does the Tenant have a Financial Support Agreement (FSA) and is it up to date? **(Statutory Supported Living Only)**

Yes ☐
No ☐

6. Who is the Tenant/Resident's appointee (where applicable)?

---

7. Is there a Third party "Top Up" in place? **(For Residential/ Nursing Home only)**

Yes ☐
No ☐
Amount of Top up: - £_____

8. Has the Top Up changed this year? **(For Residential/ Nursing Home only)**

Yes ☐ Complete a NEW "Top-up Undertaking to pay form"
No ☐

9. Have there been any changes to arrangements for the management of finances since the last review?

Yes ☐
No ☐

10. List any changes to the services within the Care Plan/Individual Agreement since the previous review and record the reason or these.

_____

_____

_____

_____

11. Does the resident/tenant have available resources to fund those services which he/she privately funds? (this does not refer to top up)

Yes ☐

No ☐

If no, please highlight the issues

_____

_____

12. What are the additional resources/activities required above contract? Does the person have assessed need?

_____

---

13. What additional expenditure has been made from the resident's/tenant's personal account since the last review? For example; holidays, payments to other parties including family and transport costs.

_____

_____

14. Have these costs been agreed and recorded in the Care Plan?

Yes ☐
No ☐

If not, why? _____

_____

_____

15. Is the Home holding an accumulating balance in the Resident's Personal Allowance? If so please address how the Personal Allowance is being spent (refer to the resident's care plan).

_____

_____

_____

16. Please detail any changes to the weekly fees since the last review and the reason for this. This should include changes to any third party agreements in place.

_____

_____

_____

17. Are resident's/tenants contributions (Assessed charge) to weekly care fees up to date? (key worker checks with Finance Department in advance of review)
(For Residential/ Nursing home only)

Yes ☐
No ☐

If no, please outline why. _____

_____

_____

18. Has the Home confirmed that all financial transactions are properly receipted in accordance with RQIA Standards?

Yes ☐
No ☐

19 Keyworker to review a sample amount of receipts e.g. a month, during the last 12 months in the residents/ tenants personal cash books? Do they reconcile and are they reasonable?

_____

20. Record any other concerns in respect of the resident's/tenant's finances.

_____

21. State actions taken to address the above concerns

Signed by Keyworker: _____

Designation: _____

Date: _____

Signed by Home/Facility Manager or Representative: _____

Designation: _____

Date: _____

Signature of Resident or Relative/Representative (*delete as appropriate):

_____

Date: _____

The Regulation and Quality Improvement Authority

Monitoring of Patient Finances Under Article 116 of The Mental Health (Northern Ireland) Order 1986

2015-16

www.rqia.org.uk

Assurance, Challenge and Improvement in Health and Social Care

Table of Contents

1.0 The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is a non-departmental public body established under the provision of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. RQIA is responsible for providing independent assurance concerning the quality, safety and availability of health and social care services in Northern Ireland. Moreover RQIA endeavours to encourage improvements in the quality of services and to safeguard the rights of service users. The Mental Health and Learning Disability Team (MHLD) undertake a range of responsibilities for people with mental ill health and those with a learning disability, in accordance with the Mental Health (Northern Ireland) Order, 1986 (the Order).

1.1 Monitoring of Patient Finances by RQIA in accordance with the Mental Health (Northern Ireland) Order, 1986

Article 116 of the Order outlines specific expectations in relation to the trusts' handling of patients' property as follows:

(1) Subjects to paragraphs (4) and (5), where it appears to a trust that any patient in any hospital or in any accommodation administered by it under the Health and Social Services (Northern Ireland) Order 1972 is incapable, by reason of mental disorder, of managing and administering his property and affairs, the trust may receive and hold money and valuables on behalf of that patient.

(2) A receipt or discharge given by a trust for any such money or valuables shall be treated as a valid receipt.

(3) Where a trust holds money or valuables on behalf of a person in pursuance of paragraph (1), it may expend that money or dispose of those valuables for the benefit of that person and in the exercise of the powers conferred by this paragraph, the trust shall have regard to the sentimental value that any article may have for the patient, or would have but for his mental disorder.

(4) A trust shall not receive or hold under paragraph (1) on behalf of any one patient without the consent of the RQIA money or valuables exceeding in the aggregate such sum as the Department of Health may from time to time determine.

(5) Paragraph (1) shall not apply where a controller has been appointed in Northern Ireland in relation to the property and affairs of the patient.

The Order also defines a role for RQIA in relation to oversight of patients' property at Article 86 (2) (c) (iv) in preventing or redressing loss or damage to [patients] property;

RQIA is required to monitor the arrangements put in place by trusts to safeguard patients' monies. Specifically under Article 116(4) of the Order, trusts are not permitted to receive or hold balances in excess of an agreed sum without the consent of RQIA. This sum was set by the Department of Health, in September 2012, at no more than £20,000 for any single mental health or learning disability patient.

1.2 Methodology used by RQIA in 2015-16 to Monitor Compliance with Article 116

In the 2015-16 inspection year, RQIA monitored compliance with Article 116 by requesting and receiving quarterly returns from all five HSC trusts containing information regarding patients' finances. The MHLD team also requested and received up to date policies, procedures and Standing Financial Instructions (SFIs) from each trust. This information was reviewed by a designated MHLD inspector. Advice was sought from a finance inspector to obtain assurances that trusts apply best practice in the management of patients' property and monies through:

- Compliance with DHSSPS Circular 57/2009 - Misappropriation of Residents' Monies – Implementation and Assurance of Controls in Statutory and Independent Homes. This applies to all trust facilities including hospitals;

- Application of accounting policies as detailed in their SFIs; and;

- Implementation of comprehensive local procedures.

2.0 Follow up on Inspection Findings 2015-16

The MHLD team followed up on progress in relation to recommendations made during the financial inspections of 63 MHLD wards in 2013/14. During inspection visits each of the wards compliance was reviewed against recommendations that had been previously evidenced to be 'partially met' or 'not met'.

2.1 Belfast Health and Social Care Trust (BHSCT)

In 2013-14 financial inspections were undertaken on 22 wards across three hospital sites in the BHSCT. A total of 39 recommendations were made.

During follow up inspections in 2014-15 inspectors evidenced 33 recommendations to have been 'met' and three recommendations to have been 'not met'. Recommendations made for the two wards that had closed since the last finance inspection were not reviewed.

The three recommendations that were 'not met' were reviewed again during unannounced inspections in 2015-16; and were evidenced to been have 'met'. See Appendix 2.

The BHSCT reported holding finances over £20,000 on behalf of 24 patients in quarter 1 (01 April 15 – 30 June 15), 23 patients in quarter 2 (01 July 15 – 30 September 15) and quarter 3 (01 October 15 – 31 December 15) and 21 patients in quarter 4 (01 January 16 – 31 March 16). In all cases a controller was not appointed. RQIA will continue to monitor the BHSCT's quarterly returns in the 2016-17 inspection year, and were necessary give consent to the trust to hold pateints monies, or make recommendation that the trust make a referral to the Office of Care and Protection were these amounts continue to be over the agreed sum of £20,000.

2.2 Northern Health and Social Care Trust (NHSCT)

In 2013-14 financial inspections were undertaken on 12 wards across two hospital sites in the NHSCT. A total of 41 recommendations were made for 10 wards.

During follow up inspections in 2014-15 inspectors evidence 26 recommendations to have been 'met', 12 to have been 'not met' and two recommendations to be 'no longer applicable' (see Appendix 1). Recommendations made for the two wards that had closed since the last finance inspection in 2013-14 were not reviewed.

The 12 recommendations that were 'not met' were reviewed again during unannounced inspections in 2015-16, and were evidenced to have been 'met'. See Appendix 3.

The NHSCT reported holding finances over the agreed sum of £20,000 on behalf of five patients throughout the year. In quarter 1 (01 April 15 – 30 June 15) and quarter 2 (01 July 15 – 30 September 15) four patients had a controller appointed. In quarter 3 (01 October 15 – 31 December 15) and quarter 4 (01 January 16 - 31 March 16) all five patients had a controller appointed. In these cases consent was not required from RQIA. Monitoring of the NHSCT's quarterly returns will continue by RQIA in the 2016-17 inspection year.

2.3 South Eastern Health and Social Care Trust (SEHSCT)

In 2013-14 financial inspections were undertaken on seven wards across four hospital sites. A total of 15 recommendations were made for six wards.

During follow up inspections in 2014-15 inspectors evidenced all 15 recommendations to have been 'met'. As a result there were no recommendations requiring further follow up during unannounced inspections in the SEHSCT wards during the 2015-16 inspection year.

The SEHSCT reported holding finances over the agreed sum of £20,000 on behalf of five patients throughout the year. In all cases a controller was not appointed. RQIA will continue to monitor the SEHSCT's quarterly returns in the 2016-17 inspection year, and were necessary give consent to the trust to hold pateints monies, or make recommendation that the trust make a referral

to the Office of Care and Protection were these amounts continue to be over the agreed sum of £20,000.

2.4 Southern Health and Social Care Trust (SHSCT)

In 2013-14 financial inspections were undertaken on eight wards across three hospital sites in the Southern Trust. A total of 18 recommendations were made across all eight wards.

During follow up inspections in 2014-15 inspectors evidenced 12 recommendations to have been 'met', two recommendations to have been 'partially met' and three recommendations to have been 'not met'. Recommendations made for the three wards that had closed since the last finance inspection in 2013-14 were not reviewed.

The two recommendations that were 'partially met' and the three recommendations that were 'not met' where reviewed again during unannounced inspections in 2015-16 and were all evidenced to have been 'met'. See Appendix 4.

The SHSCT reported holding finances over £20,000 on behalf of two patients in quarter 1 (01 April 15 – 30 June 15), no patients in quarter 2 (01 July 15 – 31 September, one patient in quarter 3 (01 October 15 – 31 December 15) and 15) and no patients in quarter 4 (01 January 16 – 31 March 16). RQIA will continue to monitor the SHSCT's quarterly returns in the 2016-17 inspection year.

2.5 Western Health and Social Care Trust (WHSCT)

In 2013-14 financial inspections were undertaken on14 wards across five hospital sites in the WHSCT. A total of 48 recommendations were made for 13 wards.

During follow up inspections in 2014-15 inspectors evidenced 30 recommendations to have been 'met', 11 recommendations to have been 'not met' and one recommendation to be 'no longer applicable' (see Appendix 1). Recommendations made for the two wards that had closed since the last finance inspection in 2013-14 were not reviewed.

The 11 recommendations that were 'not met' were reviewed again during unannounced inspections in 2015-16. Inspectors evidenced 10 of the recommendations to have been 'met'. One recommendation relating to procedure for authorisation of larger purchases was evidenced to have been 'partially met' and will be followed up during an unannounced inspection in the 2016-17 inspection year. See Appendix 5.

The WHSCT reported that they held finances over £20,000 on behalf of two patients in quarters 1 – 3 (01 April – 31 December) and one patient in quarter 4 (01 January – 31 March). In all cases a controller was not appointed. RQIA will continue to monitor the WHSCT's quarterly returns in the 2016-17

inspection year, and were necessary give consent to the trust to hold pateints monies, or make recommendation that the trust make a referral to the Office of Care and Protection were these amounts continue to be over the agreed sum of £20,000.

3.0 Conclusions from Inspection Findings

Findings from the follow up inspections would indicate that patients' monies and property in the mental health and learning disability wards inspected by RQIA had been properly safeguarded. One recommendation remains 'partially met' and will be followed up again during the 2016-17 inspection year.

4.0 Next Steps

This report will be shared with the Director of Finance for each of the five HSC trusts.

RQIA will continue to monitor the management of patient finances as part of its statutory functions in accordance with the Mental Health (Northern Ireland) Order 1986. This will include continuing to review;

- trusts' SFI's, policies and procedures on an annual basis,
- the management of quarterly returns and action plans detailing the trust held funds for individual patients' monies and valuables with balances greater than £20,000,
- the arrangements put in place by trusts to safeguard patients' monies where a referral to the Office of Care and Protection has not been deemed appropriate, and;
- where a controller has not been appointed.

An annual report will be compiled by 30 June 2017. This will be published annually by the responsible MHLD inspector to include details of the total number of persons and amount of monies managed by each of the five HSC trusts. Details of any action taken by RQIA and the HSC trusts to safeguard patients' monies under Article 116(4) of the Order will be contained in this report.

Appendix 1 – Recommendations Evidenced to be 'No Longer Applicable' During the 2014-15 Inspection Year

Inspection	Recommendation	Action Taken	Compliance
Tobernaveen Centre, Holywell Hospital, 29 & 30 January 2015	It is recommended that the ward manager ensures that a system to verify clothes and other items purchased for patients are checked by ward staff against the receipt, confirmed as received by the patient and receipts retained.	This practice no longer takes place on the ward as the function of the ward has changed to patients being admitted who are over 65 and have a mental health problem. The ward manager informed the inspector that these patients predominantly ask their relatives/carers to purchase items for them. However the ward manager advised that if patients did want to purchase clothes or any other items they would set up a record book to check purchases against receipts and ask patients to sign that they have received the items and they would retained the receipt.	**No Longer Applicable**
Inver 4, Holywell Hospital, 22 June 2015	It is recommended that the ward manager ensures that a record of all staff who obtain the key to the safe where patients' money is temporarily stored including the reason for access.	The inspector was informed by the ward sister that patients' money is held in hospital accounts. There was no patient money held on the ward.	**No Longer Applicable**
Beech, Tyrone and Fermanagh Hospital, 25 February 2015	It is recommended that the Trust develops and implements a policy and procedure in relation to group purchases.	There was no evidence that the practice of group purchasing is ongoing and as a result the policy has not been developed.	**No Longer Applicable**

Appendix 2 Belfast HSC Trust Finance Recommendations Reviewed During the 2015-16 Inspection Year

Inspection	Recommendation	Action Taken	Compliance
Innishfree (NRU), Knockbracken, 07 July 2015	It is recommended that the ward manager ensures that regular individual patient statements are received from the cash office at the ward to facilitate reconciliation of expenditure and receipts	The inspector reviewed a sample of the cash statements received by the ward manager for all patients. These are crossed referenced with the ward records for any discrepancies.	**Met**
Moylena, Muckamore Abbey, 20 & 21 June 2015	It is recommended that the ward manager ensures that a record of staff who access the key to the Bisley drawer, and the reason for access, is maintained.	Inspectors reviewed the records in relation to patient finances and noted that a record of staff who had access to the key to the Bisley drawer and the reason for access was maintained	**Met**
Ward L, Mater Hospital, 06 August 2014	It is recommended that the Trust introduce a uniform policy for managing patients' finances across all wards.	The Trust's *'Patients' Finances and Private Property-Policy for Inpatients within Mental Health and Learning Disability Hospitals'* was up to date and had been implemented in September 2014. A copy of the policy was available in the ward's main office and on the Trust's intranet. A staff declaration sheet evidenced that staff had read and understood the procedures concerning the management of patient's private property.	**Met**

Appendix 3 Southern HSC Trust Finance Recommendations Reviewed During the 2015-16 Inspection Year

Inspection	Recommendation	Action Taken	Compliance
Cloughmore, Craigavon Area Hospital, 23 April 2015	It is recommended that the ward manager ensures that all items brought into the ward on admission are listed appropriately, the area of their storage or transfer recorded, and appropriate receipting undertaken, particularly when relatives remove items from the ward.	The inspector reviewed the patients property book. The patient signature indicated that the patient agreed and understood that 'items in their possession remain their responsibility'. On admission a record of the patient's property is recorded; records reviewed evidenced that this was signed by two staff and retained in the individual patient's file.	**Met**
	It is recommended that the Trust develops and implements a uniform policy for managing patients' finances within the Bluestone Unit, including managing and securing patients' property held in the ward safes.	The inspector was advised by the ward manager and patient flow and bed management coordinator that the uniform policy had not been created. The inspector was advised that this recommendation is currently being managed by the Trust's finance department. The inspector was advised that there was no draft policy available but that the policy will be made available from 31 May 2015.	**Not Met (See below for follow up)**
Cloughmore, Craigavon Area Hospital, 14 September 2015	It is recommended that the Trust develops and implements a uniform policy for managing patients' finances within the Bluestone Unit, including managing and securing patients' property held in the ward safes.	The inspectors reviewed the trust's policy and procedure for managing patients' private property which was issued in May 2015. This policy included the management of patients' finances within the Bluestone Unit, including managing and securing patients' property held in the ward safe.	**Met**

		Cloughmore does not currently have a safe on the ward.	
Silverwood, Craigavon Area Hospital, 27 August 2015	It is recommended that the Trust develops and implements a uniform policy for managing patient's finances within the Bluestone Unit.	The inspectors reviewed the policy and procedure for managing patients' private property this was issued in May 2015.	**Met**
Willow, Craigavon Area Hospital, 29 July 2015	It is recommended that the Trust develops and implements a uniform policy for managing patient's finances within the Bluestone Unit.	The ward manager stated that patients' money is not retained on the ward. A procedure was in place to direct staff on what to do when a patient is admitted with a large sum of money or valuable items. The inspectors reviewed the policy and procedure for managing patients' private property issued in May 2015.	**Met**
	It is recommended that the ward manager ensures that all staff attend relevant training in policies and procedures for management of patient's finances.	The ward manager stated that staff had not received formal training in the management of patients' finances. However, the policy was circulated to staff for comments before it was issued in May 2015. The policy and procedure for managing patients' private property was available for staff on the ward.	**Met**

Appendix 4 Northern HSC Trust Finance Recommendations Reviewed During the 2015-16 Inspection Year

Inspection	Recommendation	Action Taken	Compliance
Carrick 4, Holywell Hospital, 08 & 15 May 2015	It is recommended that the ward manager ensure that all staff attend up to date training in the management of patients' monies and valuables.	The inspector reviewed the training matrix for the ward and noted that 6 (23%) of the 26 staff currently working on the ward had no record of having attended this training. The inspector was informed that there were currently no further dates available for staff to attend.	**Not met (See inspection dated 19-25 November 15 for follow up)**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct	The Deputy Ward Manager advised the inspector that this practice was still not in place for any of the patients. A copy of the statements were obtained from the cash office by the Deputy Ward Manager by the end of the inspection, however these had not been cross referenced to the ward records of patients' finances.	**Not met (See inspection dated 19-25 November 15 for follow up)**
	It is recommended that the ward manager ensures that regular weekly checks of patients' money held against the cash ledger are undertaken and appropriately recorded.	The inspector reviewed the patients' account/safe register audit sheets for all patients and noted that weekly checks were not being completed. In the case of three of the 15 patients on the ward there had been no review of their records since February 2015. The deputy ward manager confirmed that these were the only checks currently undertaken. The ward manager confirmed that they had not been completing weekly checks of all patients' records.	**Not met (See inspection dated 19-25 November 15 for follow up)**

Carrick 4, Holywell Hospital, 19-23 November 2015	It is recommended that the ward manager ensure that all staff attend up to date training in the management of patients' monies and valuables.	Inspectors reviewed the training records and noted that all staff had attended up to date training on the management of patient's monies and valuables.	**Met**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct	Inspectors reviewed documentation in relation to patient's monies and noted that a copy of each patient's statement was received from the cash offices every month and retained in each patient's financial file. Inspectors also noted that the Ward Manager completes and documents a weekly safe audit and verifies that transactions were correct.	**Met**
	It is recommended that the ward manager ensures that regular weekly checks of patients' money held against the cash ledger are undertaken and appropriately recorded.	Inspectors reviewed documentation in relation to the patient's monies. An audit was completed every week of the amount of money held for each patient in the safe against the cash ledger.	**Met**
Inver 4, Holywell Hospital, 22 June 2015	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	The inspector reviewed a sample of the statements received from the cash office and could confirm that these are audited monthly by the ward manager. A receipt is returned to the cash office to confirm that the statements have been checked and are correct.	**Met**
Lissan 1, Holywell Hospital, 21 May 2015	It is recommended that the ward manager ensure that all staff attend up to date training in the management of patients' monies and valuables.	The inspector reviewed a copy of the staff training records and was pleased to note that 19 of the 20 staff currently working on the ward had completed this training.	**Met**
Ross Thompson Unit, Causeway Hospital 23 July 2015	It is recommended that the ward manager ensures that all items brought into the ward on admission that are removed by relatives are recorded.	The ward's patient property book evidenced that all valuable items brought into the ward by the patient were recorded. In circumstances where a relative removed	**Met**

	Record of receipt by the relative should be obtained.	items this was discussed with the patient, the relative and the multi-disciplinary team (as required). The removal of items registered in the patient property book was recorded. The inspector noted posters displayed on the wall opposite the ward's main entrance advising patients, relatives and visitors of their responsibility to inform staff should items of property be removed from the ward. This included clothing being removed for laundry.	
	It is recommended that the ward manager ensures that records of purchases made and change returned to patients are maintained along with appropriate receipting processes.	Purchases made by staff on behalf of a patient were recorded on a patient monies receipt form. The form was retained on the patient's file and included a record of the money spent and associated receipts. Entries onto the form were signed by two members of staff and the patient. Patient money receipt forms reviewed by the inspector had been completed in accordance to Trust policy and procedure.	**Met**
Tobernaveen Upper, Holywell Hospital, 08 June 2015	It is recommended that the ward manager ensures that all items brought into the ward on admission that are removed by relatives are recorded. Record of receipt by the relative should be obtained.	The inspectors noted posters displayed at ward level advising patients, relatives and visitors of their responsibility to inform staff should items of property be removed from the ward.	**Met**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	From May 2015 cash statements have been provided to the ward from the cash office. The inspectors reviewed a sample of the statements and could confirm that these are audited monthly by the ward manager. A	**Met**

		receipt is returned to the cash office to confirm that the statements have been checked and are correct.	
Tobernaveen Centre, Holywell Hospital, 25 June 2015	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	The inspector reviewed a sample of the statements received from the cash office which confirmed that these are audited monthly by the ward manager. A receipt is returned to the cash office to confirm that the statements have been checked and are correct.	**Met**
Tobernaveen Lower, Holywell Hospital, 14 May 2015	It is recommended that the ward manager ensures that all items brought into the ward on admission that are removed by relatives are recorded. Record of receipt by the relative should be obtained.	The inspector noted that ward management had displayed notices throughout the ward advising patients and visitors of their responsibilities regarding patient property. On the day of admission a record of patient property returned home is completed the inspector can confirm this is receipted accordingly.	**Met**
	It is recommended that the ward manager ensures that individual patient statements are received from the cash office in order to verify that transactions are correct.	The inspector met with the ward manager who advised that there were currently no patients on the ward deemed incapable of managing their finances. As a result the ward was not currently managing any patients' finances. The ward manager advised that any patient deemed incapable of managing their finances a statement would be obtained from the cash office. Ward management had displayed notices on the ward advising patients that a statement can be provided from the cash office on request.	**Met**

Appendix 5 Western Trust HSC Finance Recommendations Reviewed During the 2015-16 Inspection Year

Inspection	Recommendation	Action Taken	Compliance
Beech, Tyrone and Fermanagh Hospital, 20 July 2015	It is recommended that the Trust reviews the current practice for authorisation of larger purchases, including eliminating the practice of the same staff authorising the purchase and verifying the receipt. A policy and procedure should be developed and implemented.	Inspectors reviewed records regarding authorisation of larger purchases and there was evidence of 3 signatures to authorise the purchase, purchase the item and to verify receipts. However two policies in relation to this practice had not been reviewed and updated - the Cash Handling Policy Sept 2011 and the Patient Property Policy which had not been updated since March 2012 to reflect this new practice. A new recommendation will be made in relation to reviewing these two policies and procedures. This will be followed up during an unannounced inspection in the 2016-17 inspection year.	**Partially Met**
	It is recommended that the ward manager trust introduces a weekly audit of receipts against expenditure on this ward.	Inspectors reviewed financial records held on the ward. The acting ward manager had completed a weekly audit of receipts received and had checked this against expenditure.	**Met**
	It is recommended that the Trust introduces a secondary check of expenditure records on this ward.	There was evidence in the financial records that two staff members had checked receipts on the ward. The acting ward manager also completed a weekly check of records.	**Met**

	It is recommended that the ward manager ensures that a record of all staff who obtain the key to the safe where patients' money is stored is maintained including the reason for access.	Staff had recorded who obtained the key to the safe in the "Safe Key Register" book; this was signed by two members of staff. A book was also held to record the reason for access to the safe. This was audited each week by two members of staff	**Met**
Brooke Lodge, Lakeview Hospital, 6 & 7 May 2015 **(Now Known as Lakeview Hospital)**	It is recommended that the ward manager ensures that regular statements are received from the cash office to facilitate verification of transactions and expenditure.	Inspectors were informed that the patients admitted to the ward during the inspection did not have their money retained by the Trust's cash office. Patient's monies were held on the ward in the wards safe. Inspectors reviewed the safe records and noted that each patient had an individual cash record. Records had been completed in accordance to the Trust's cash handling procedures. Inspectors noted that the Trust's policy directed that staff ensure that only small amounts of patients' monies (under £50) should be retained in the safe. The Trust's policy detailed that patients presenting with more than £50 should have their money deposited within the Trust's cash office. However, inspectors evidenced that one patient had received a sum of £170 one week prior to the inspection. Inspectors were informed that the money had been provided by the patient's relative to purchase essential items. Inspectors were concerned that retaining this amount of money was contrary to section 1.4.10 of the Trust's patient	**Met**

		property procedures. Section 1.4.10 states that *'A maximum of £50.00 can be held at ward level for any patient'.* A new recommendation regarding this issue has been made. In circumstances where patients' money was retained by the Trust's finance department, statements of transactions and expenditure were provided to the patient on a monthly basis. It was good to note that the Trust's finance department conducted ongoing audits of the ward's petty cash, patient property, and the ward's safe and the safe records.	
	It is recommended that the Trust develops and implements a policy and procedure in relation to operating individual patient saving accounts.	The Trust's Cash Handling Procedures detailed the steps to be taken by ward staff regarding the management of patient property. Section 2.1.2 of the Trust's patient property procedures detailed that upon admission a patient's cash/valuable items must be sealed in the patient's property envelope and forwarded to the Trust's finance department. A finance officer informed inspectors that patients' monies (above the sum of £50) were deposited in a Trust account, under the patient's name, within a local branch of a national bank. A Trust finance officer	**Met**

		informed inspectors that the Trust's finance department reviewed each patient account and forwarded individual statements to the patient on a monthly basis.	
	It is recommended that the ward manager ensures that updated training in the management of patients' finances is prioritised for all staff.	Updated training for nursing staff in relation to the management of patients' finances had not taken place since the last inspection. This recommendation will be restated for a third time.	**Not met (Please see below for follow up)**
Brooke Lodge, Lakeview Hospital, 7-11 September 2015 **(Now known as Lakeview Hospital)**	It is recommended that the ward manager ensures that updated training in the management of patients' finances is prioritised for all staff.	Inspectors were informed a training package had been developed by the hospital manager. The training package was available and reviewed by inspectors and included the trust policy and procedure on the management of patient's property. Inspectors reviewed the record of attendees at the training. All staff were recorded as having attended the training. The training was delivered by the hospital manager and deputy ward manager.	**Met**
Cedar, Gransha, 9 June 2015 **(This ward has now closed)**	It is recommended that the ward manager ensures that regular statements are received from the cash office to facilitate verification of transactions and expenditure.	Eight of the patients admitted to the ward had accounts with the Trust's cash office. Inspectors reviewed the ward's patient cash balances book. The book evidenced that the ward manager received a patient balances update sheet from the cash office, for each patient, every two weeks. Cash office updates recorded the patient's name, hospital number, account balance, completed transactions and a subsequent	**Met**

		brought forward balance. Inspectors reviewed the records from the 4 November 2014. Records evidenced that patient monies retained by the cash office had been recorded in accordance to Trust policy and procedure.	
Lime, Tyrone and Fermanagh Hospital, 21 July 2015	It is recommended that the ward manager develops a system to ensure that where staff are making purchases on behalf of patients, a transparent record is maintained of the amount of money received, purchases made and change returned and verified by another staff member.	The inspectors reviewed the records for the management of patient finances. The inspectors observed that when staff where spending money on a patient's behalf, the money was signed out to the responsible member of staff. Records maintained evidenced the amount of money received, purchases made and change returned. Records were verified by a second member of member.	**Met**
	It is recommended that the ward manager ensures that a record is kept of the staff member who obtains the key to the patient's safe, and the reason for access is maintained.	The inspectors reviewed the finances records for the ward and noted that the safe key was signed by two nursing staff at the handover of each shift. In addition the contents of the safe were also checked daily by two nursing staff. Within each patient's finance records staff record the reason for removal of monies on each occasion. Individual patient's monies were also checked weekly and the records signed by two nursing staff.	**Met**

The Regulation and Quality Improvement Authority
9th Floor
Riverside Tower
5 Lanyon Place
BELFAST
BT1 3BT

Tel 028 9051 7500
Fax 028 9051 7501
Email info@rqia.org.uk
Web www.rqia.org.uk
@RQIANews

MAHI - STM - 118 - 2231

MMcG-266

Division of Clinical Psychology

Faculty for People with Learning Disabilities

The British Psychological Society

Commissioning Clinical Psychology services for adults with learning disabilities

Version 13.3.11

'Commissioning should be a powerful way of improving the quality of services experienced by people. By commissioning we mean the process of translating aspirations and need into timely and good services for users which meet their needs, promote their independence, provide choice, are cost effective and support the whole community.'

(Joint Review of Commissioning for People with Learning Disabilities and Complex Needs, 2009)

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.

ISBN: 978-1-85433-715-3

Printed and published by the British Psychological Society.

© The British Psychological Society 2011

The British Psychological Society
St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK
Telephone 0116 254 9568 Facsimile 0116 247 0787
E-mail mail@bps.org.uk Website www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

Foreword

This document has been produced by the Faculty for Learning Disabilities of the British Psychological Society. It is aimed primarily at commissioners of services, but we hope it will also be useful to Trusts, Social Services and service providers. We also hope it will be useful to families, carers and people with learning disabilities. It gives a description of what you can expect from us as clinical psychologists who work with adults with learning disabilities, and how you can judge whether or not our work has been effective. Our aim, as psychologists, is to promote valued, inclusive lives for people with learning disabilities; much of our work is with those with the most complex needs and this values base guides our clinical interventions.

We have not looked at the needs of children with learning disabilities, as we consider that to be the remit of those who work specifically with children.

The guide considers the nature of the work you might want from us, looks briefly at the extent of the need, the evidence base for what should be delivered, the outcomes that can be expected and some of the risks that might occur if services for people with specific needs are not commissioned effectively.

We have not specified 'ideal' budgets or grades of staff: we hope that there will be a dialogue between clinical psychologists, their employers and commissioners to determine the optimum skill mix required for the needs of the population served.

We realise that we are now working in times of severe economic constraint, and that service delivery will have to focus on priority areas of need. We hope that this document will assist in supporting more effective service delivery and closer scrutiny of outcomes.

This document is in electronic format, and our intention – as a Faculty – is to update it regularly in line with best practice guidance and developing service models. It has been produced in consultation with members of the Faculty, and we would like to acknowledge the work done by Debra Moore (of Debra Moore Associates) in assisting us in producing this guidance.

We hope you find it useful, and would be happy to receive any comments at: dcpldlead@bps.org.uk

Theresa Joyce, *Chair, Faculty for Learning Disabilities.*

Alick Bush, *Faculty Strategic Lead and Chief Editor.*

Main chapter authors: **Theresa Joyce**, **Alick Bush**, **Karen Dodd**, **Nigel Beail**, **Julian Morris**, **Gemma Gray** & **Zenobia Nadirshaw**.

MAHI - STM - 118 - 2234

MMcG-266

Contents

Executive summary

Commissioning Clinical Psychology services for adults with learning disabilities has been prepared by members of the Faculty for Learning Disabilities of the British Psychological Society's Division of Clinical Psychology. It has been developed to support the commissioning and provision of clinical psychology services and to consider how this fits with the wider landscape of support to adults with learning disabilities and their families. Although the focus of the document is on the unique contribution of clinical and other applied psychologists, it is emphasised that they usually work as part of a wider multi-disciplinary team.

The guide sets out to clarify the role of clinical psychologists and how this contributes to achieving the aims and objectives within current policy and guidance for people with learning disabilities. It describes how psychologists work within specialist health services and with colleagues in mainstream health and social care, in order to ensure that people with learning disabilities and their families receive support that is person-centred, effective, safe and dignified.

Clinical psychologists are key members of any modern specialist learning disability health service. This guide is designed to support the commissioners of these services by providing information, advice and evidence of the positive contribution psychologists can make to the lives of people with learning disabilities. At a time of unprecedented service change and financial restraint, it is essential that this scarce resource is used effectively to ensure the best possible outcomes within the available funding. The profession should take a lead role in redesigning and reconfiguring high quality services that are cost effective. The guide describes nine of the core areas where psychologists are likely to have a central role in promoting effective services for adults with learning disabilities. In each of these core areas the guide outlines the need for psychology provision, the evidence-base, and good practice that is required to deliver an excellent service. Each section outlines the outcomes that commissioners and service users should expect when such provision is in place. It describes the contribution that can be expected from a psychology service and the potential risks if the psychology service is not available or is ineffective.

The nine key areas include:

1. Assessment of capacity;
2. People who show behaviours that challenge services;
3. People with mental health problems;
4. People with autistic spectrum conditions;
5. People with dementia or who are at risk of developing dementia;
6. Offenders and those at risk of offending;
7. People with profound and multiple learning disabilities;
8. People with physical health needs including those who require support from mainstream NHS;
9. Supporting parents who have learning disabilities.

Other sections of the document outline the core role and skills of psychologists, the need for service provision to include everyone by planning for the needs of people from Black and Minority Ethnic Groups and newly-arrived communities, the leadership role in supporting the strategic direction of services and the organisation and delivery of psychology provision. In the current economic climate, clinical psychologists have a particularly important role to play in shaping services that are of high quality, are innovative, effective, provide value for money and promote approaches that prevent the breakdown of people's support in their communities.

In drafting the document, the Faculty has taken the decision to avoid making recommendations about the numbers and grades of psychologists who should be employed within a specified geographical area. Such decisions depend upon the needs of the local population, the range of local provision and other factors that will vary from area to area. However, we urge commissioners and service managers to consider the contribution that psychologists can make to achieving positive outcomes for people with learning disabilities in the different areas of service delivery.

Clinical psychologists work alongside the other members of the multi-disciplinary team in order to support mainstream practice and directly serve people with the most complex needs. They make use of a range of psychological models and areas of research to provide effective and person-centred support to people who are at the greatest risk of service breakdown. The core skills include assessment, formulation, intervention, evaluation and research, and developing the capacity and effectiveness of services.

Clinical psychologists have many positive contributions to make to specialist health services. For the purpose of this document nine specific areas of work are considered. Future revisions will add to these sections and consider the emerging evidence base in these and other areas.

Introduction

This guide has been developed to support the commissioning and provision of clinical psychology services and to consider how this fits with the wider landscape of support to adults with learning disabilities and their families. Although the focus of the document is about the unique contribution of clinical and other applied psychologists, it is emphasised that they work as part of a wider multi-disciplinary team.

Clinical psychologists are essential members of specialist adult learning disability health services working in inpatient and community teams and with a range of agencies and sectors to support the individual and their family.

This guide aims to:

- Support commissioners by clarifying the role and describing the work of clinical psychologists and how this contributes to achieving the aims and objectives within current policy and guidance for people with learning disabilities.
- Support partnership working within specialist health services and with colleagues in mainstream health and social care.
- Ensure that clinical psychology services are provided in a manner that meets the primary aim of supporting people and families with person-centred, effective, safe and dignified interventions.

Background

People with learning disabilities are a diverse group with a range of needs and wishes. People with learning disabilities are defined as having *a significant impairment both in intellectual functioning and in adaptive behaviour, with onset in childhood.* This group does not include people who may have more specific learning difficulties or conditions such as dyslexia or people who have acquired brain injury after the age of 18 years.

Figures suggest there are approximately 974,000 adults with learning disabilities in England and of these 145,000 will have a severe or profound learning disability. Within this population research suggests there will be higher than average number of younger English adults with more severe learning disabilities who belong to Bangladeshi and Pakistani South Asian minority ethnic communities.

In Northern Ireland, there are 16,366 adults and children with learning disabilities known to services – with 4468 of these having a severe or profound learning disability.

Whilst there are few population statistics about this group of people, evidence suggests that the numbers of people with more profound needs are rising due to a range of factors including advances in medical technology.

Overall, it is predicted that the number of people with learning disabilities in England will have risen by 15 per cent between 2001 and 2011, while the numbers of people aged 50 and over will have risen by 53 per cent between 2001 and 2021.

The first key objective in *World Class Commissioning* (DoH, 2007) is to understand the size and the needs of the population. Unfortunately, for many commissioners, the information available about local people with learning disabilities and particularly those with complex needs is often patchy and incomplete.

Initiatives such as the Public Health Observatory for Learning Disabilities (www.ihal.org.uk) will, in time, make a positive contribution to data and knowledge management. However, along with colleagues in social care, specialist health professionals such as clinical psychologists should be engaged with commissioners in helping to build up a robust picture of local current and future needs. This information can contribute to local mechanisms such as the Joint Strategic Needs Assessments (JSNA).

For commissioners, understanding the needs and wishes of people with learning disabilities will require increased listening to what people and families say they want and the key vehicle for this is person-centred planning.

Clinical psychologists are able to support a person-centred approach and work with commissioners and providers to ensure that supports are constructed in a person-centred way. They are also in a position to give advice about appropriate ways to engage people with learning disabilities actively in the commissioning process.

There has been increasing interest and concern about the commissioning and provision of health services for adults with learning disabilities. A number of high profile investigations and reports have raised important issues about the safety and effectiveness of both mainstream NHS and Specialist Adult Learning Disability Health Services.

This drive to improve the physical, mental and emotional health of people with learning disabilities has been reflected in Government policies across the UK and the initiatives which have been instigated such as NHS Campus Closure Programmes and provision of health checks.

World Class Commissioning (DoH, 2007) is about delivering better health and well-being for the local population, about improving health outcomes and reducing inequalities – *'adding years to life and life to years'*. Unfortunately, for people with learning disabilities, on the whole, it is a valued but distant ideal. The inequalities experienced by people with learning disabilities are well documented and widespread. They face prejudice and discrimination in many different areas but importantly, there is now significant evidence that they often experience problems accessing health care and equal treatment.

These poor experiences in health care not only impact on physical health but also mental health and well-being. The inability of local health services to support people appropriately has a distressing impact on the individual and their family and can often result in distant (and usually more expensive) placements. People with learning disabilities constitute one of the most vulnerable groups in society. Decades of institutional provision and poor investment have left a legacy in many areas where people are supported in restrictive and impoverished settings.

Commissioners need to ensure that the services they commission uphold the articles of the Human Rights Act 1995 and other related legislation and guidance such as Deprivation of Liberty Safeguards 2007 and the Mental Capacity Act 2005.

Clinical psychologists have a unique contribution to make in these areas using their skills and knowledge to assess and determine an individual's ability to make decisions and facilitate choice and control in day-to-day life as well as when contemplating major change or treatment.

World Class Commissioning (DoH, 2007) recognises that there needs to be a real partnership and relationship with local clinicians to improve health outcomes.

Clinical psychologists are well placed to support commissioners and providers to determine and deliver the types of services and supports that will support people with learning disabilities and their families in a safe, dignified and effective manner.

References

Bamford Review of mental health and learning disabilities (Northern Ireland)
www.rmhldni.gov.uk/

CeDR People with learning disabilities in England (2008).
www.lancs.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf

Commissioning Healthcare for People with Learning Disabilities (2009).
www.nhsconfed.org/Publications/briefings/2009-Briefings/Pages/Commissioning-healthcare-learning-disabilities.aspx

Department of Health. *Valuing People Now Resource Pack.*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097669

Department of Health (2007). *Commissioning Specialist Adult Learning Disability Health Services.*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

Department of Health (2007). *World Class Commissioning.*

Equal Lives Review of policy and services for people with learning disabilities in Northern Ireland.
www.rmhldni.gov.uk/equallivesreport.pdf

Fulfilling the promises (Wales).
www.healthchallengepembrokeshire.co.uk/objview.asp?object_id=13

Healthcare Commission (2006). *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnerships NHS Trust.*

Healthcare Commission (2007). *A life like any other – a national audit of specialist in-patient health care services for people with learning difficulties in England.*

Healthcare Commission (2007). *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust.*

Information about person-centred planning and approaches.
http://valuingpeople.gov.uk/dynamic/valuingpeople135.jsp

McConkey, R., Spollen, M. & Jamison, J. (2003). *Administrative Prevalence of Learning Disability in Northern Ireland.* Belfast: DHSSPS.

Sir Jonathon Michaels (2008). *Health care for ALL. The report of the Independent Inquiry into access to health care for people with learning disabilities.*

Statement on policy and practice for adults with learning disability (Wales).
http://wales.gov.uk/topics/health/publications/socialcare/guidance1/statementdisability?lang=en

Statistics Release: Adults with Learning Disabilities – Implementation of 'The same as you' Scotland (2008). www.scotland.gov.uk/Resource/Doc/217033/0058175.pdf

The Same As You? A review of services for people with learning disabilities. www.scotland.gov.uk/ldsr/docs/tsay-00.asp

Using the guide

Clinical psychologists are key members of any modern specialist learning disability health service. This guide is designed to support the commissioners of these services by providing information, advice and evidence of the positive contribution psychologists can make to the lives of people with learning disabilities.

This guide specifically describes the contribution made by clinical psychologists who are registered as such with the Health Professions Council. A number of services employ a range of other applied psychologists to provide specific psychological skills depending on the needs of the service – this can include *counselling psychologists* and *forensic psychologists*. By utilising the principles outlined by *New Ways of Working*, psychology services will also make use of a range of other people with psychological skills and competencies in order to meet the needs of local communities. These roles may include *assistant psychologists*, *behavioural assistants*, *counsellors*, *clinical assistants* and a variety of other job titles that have been developed to deliver specific tasks.

The document can be read from beginning to end or commissioners can 'dip in' to a specific section. Nine of the sections describe some of the key 'clinical areas' where psychologists are likely to have a central role within an authority. These areas include:

1. Assessment of capacity.
2. People who show behaviours that challenge services.
3. People with mental health problems.
4. People with autistic spectrum conditions.
5. People with dementia or who are at risk of developing dementia.
6. Offenders and those at risk of offending.
7. People with profound and multiple learning disabilities.
8. People with physical health needs including those who require support from mainstream NHS.
9. Supporting parents who have learning disabilities.

Each of these sections is organised in the same format:

- *Background* – demographics and the need for a psychological perspective.
- *Evidence-base* and good practice in this area.
- *Elements of an excellent service.*
- *Expected outcomes* when an excellent service (including psychology provision) is available.
- *Expected contribution* from a psychology service in order to deliver individualised outcomes.

- *Potential risks* to individuals and commissioners if the psychology service is not available and effective.

Other sections include guidance about meeting the needs of people from *Black and Minority Ethnic Groups*. In addition, there are sections on the *leadership role* of psychologists and the *organisation of psychology services* in order that they can best deliver the outcomes that are described in the guide.

The guide provides links to other resources that provide more in-depth information and materials on particular issues or subjects such as commissioning secure health services for people with learning disabilities.

The core role of clinical psychologists in specialist adult learning disability health services

Clinical psychologists provide a unique contribution to the aim of specialist learning disability services which is to support mainstream practice and directly serve those with the most complex needs (DH, 2007). Psychologists are trained to understand human behaviour within the context of the person and their environment. They are expected to synthesise information and to work proactively in complex organisational situations with some of the most complex service users. Psychologists work to achieve the following outcomes:

Person related:

- Better psychological services for those who are at greatest risk.
- Psychological services that are more responsive and person-centred.
- Improvement of local provision of support/care including health promotion and prevention.
- Prevention of inappropriate admissions to in-patient settings.
- Increased continuity of care for people who have long-term difficulties or special support needs.
- Supporting people to enjoy increased choice and control.
- Managing and reducing risk in complex situations.
- Reducing distress and improving quality of life for people with learning disability through planned psychological interventions.
- Ability to demonstrate effective outcomes.
- Supporting staff and family carers.
- Promoting social inclusion.
- Recognition and understanding of diversity.

Service related:

- Reduction in the inappropriate use of out of area placements.
- Improved understanding by all agencies of the psychological needs of people who use services.
- Enabling services to become more psychologically minded in their approach.
- Developing capacity of multi-disciplinary teams and services.
- Providing services that are delivered efficiently.
- Working with commissioners and services to bring about innovation and service improvements.
- Supporting continuous service improvement through an emphasis on outcomes and quality.
- Development of effective care pathways within services and in partnership with a range of care providers and mainstream services.

Core skills of clinical psychologists

Clinical psychologists draw on a number of different theories and areas of research to guide their work. The core skills of all psychologists are assessment, formulation, intervention, service development, evaluation and research.

Assessment

Psychologists will use a variety of different types of assessment to help to understand both the nature of an individual's learning disabilities and the reasons for their behaviour or their psychological difficulties/mental health problems. Assessments may be carried out with an individual (e.g. measures of cognitive ability, mood or beliefs; understanding the context within which a behaviour occurs); via a carer (e.g. to find out how far a carer thinks that someone's behaviour has changed); or at an organisational level (to find out what is preventing a particular service from supporting someone differently).

Formulation

The assessment information is then used to develop hypotheses about why a behaviour is occurring and what is maintaining it, or why people experience events as they do. Psychologists draw upon a range of different models to provide the best possible way of understanding the situation. This will usually lead to the psychologist developing a number of provisional hypotheses that will guide the intervention. Psychologists are particularly skilled at 'seeing the whole picture' and helping teams to manage a diverse, and often competing, set of issues (e.g. addressing short-term risks alongside Human Rights issues and the long-term need for change).

Intervention

An intervention should follow directly from the formulation. It is likely to include a number of different elements, each of which results from the hypotheses that were developed in the formulation. Psychologists will use the best available evidence-base to design an intervention. Interventions may be provided at an individual level (e.g. by helping someone to understand why they have offended and what steps they can take in the future to behave in different ways), or at a systems level (e.g. by building the capacity in a whole team through training workshops, or through interventions in groups and with families). Interventions may aim to respond to a particular set of problems or risk issues, but equally important is the development of 'preventative strategies'. Psychologists are experienced at working with staff in other agencies (e.g. social care providers, housing) to deliver interventions in places where the person lives or works

Evaluation and research

Evaluation is an important part of the psychologist's role. This will include evaluating whether an individual intervention is effective, and hence whether the formulation accurately reflects the reasons for the behaviour occurring. At a wider level, psychologists

are often asked to evaluate the effectiveness of a particular aspect of a service. In many services, psychologists are leading on the implementation of routine outcome measures in clinical practice. Psychologists also have an important role in using research knowledge to develop effective services, and generating new research knowledge by systematically evaluating different services and models.

Developing the capacity and effectiveness of services

Psychologists provide specific training on a number of issues, with the aim of enabling carers and others to understand the nature of the person's learning disability, challenging behaviour or other needs, as well as how to support them effectively in order to improve the capability of local providers. They provide supervision and support to colleagues, support staff and carers in relation to behavioural interventions and other therapeutic approaches. Psychologists have a significant part to play in bringing about innovation and change management at team and organisational levels; this is brought about through the breadth of clinical expertise and training, knowledge of the evidence-base and skills at influencing systems.

Resources

Department of Health (2007). *Commissioning Specialist Adult Learning Disability Health Services.* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

General information about clinical psychology and the work of the British Psychological Society can be found on the Society's website: www.bps.org.uk.

Most psychologists who work with adults who have a learning disability contribute to the British Psychological Society's Faculty for Learning Disabilities. Information about this faculty can be found at: www.bps.org.uk/dcp-ld/about/about_home.cfm

Assessment of capacity

Background

The Mental Capacity Act (MCA) 2005 placed in statute the process by which decisions are to be made on behalf of adults (over the age of 16) who lack the capacity to make them for themselves. It also provides a statutory definition of incapacity, and the steps that must be taken before incapacity is determined. Lack of capacity is decision-specific, but the first part of the two-stage test for it, is that the person must suffer from a mental disorder. Learning disability is clearly recognised as a mental disorder in this context, and people with learning disabilities may, therefore, fall under the jurisdiction of the Act. About 974,000 people in England have a learning disability (about two per cent of the population); 796,000 of them are aged 20 or over.

Trends

Since the implementation of the MCA 2005, there has been an increase in requests for specialist assessment of capacity. These have typically come from social services and also acute hospitals, with a focus on capacity to decide where to live, how to manage money and consent to treatment. Psychologists are frequently asked to carry out these assessments as part of their role in a community learning disabilities team, or to provide support to other people to enable them to establish whether the person they are supporting has the capacity to make a specific decision.

Evidence base and good practice

The British Psychological Society published guidelines relating to the assessment of capacity in 2006. These outlined good practice for psychologists when carrying out assessments of capacity, taking account of their competencies in psychometric assessment and interpretation as well the requirement to understand the legal framework. Capacity assessment consists of a two-stage test. The first part is that the person suffers from a mental disorder (in this case a learning disability), which may need to be determined through the use of psychometric assessment. The second is that it must be demonstrated that the person cannot:

- understand the information relevant to the decision;
- retain that information;
- use or weigh that information as part of the process of making the decision;
- communicate their decision (whether by talking, sign language or other means).

The person only needs to be unable to do one part of this test to be considered to lack capacity. Assessment of capacity requires that the local decision-maker is able to make relevant information accessible, use skilled interviewing techniques and then interpret the responses in order to make a judgement based on the balance of probability. Psychologists may be called upon to conduct detailed assessments in complex situations to assist the decision-maker.

Information about methods of assessment and relevant areas of questioning is included in the British Psychological Society's guidance, and also in the joint BMA/Law Society publication on the assessment of capacity.

Elements of an excellent service

- Clear pathway for referral for capacity assessments in complex situations.
- Clear pathway for advice and support to enable other decision-makers to undertake their responsibilities under the Act.
- Identified individuals who are skilled in undertaking assessments, and who can also advise others.
- Understanding of the relationship between mental capacity issues and safeguarding adults issues.
- Consent to treatment protocols in place and audited, with system for acting on findings.
- Good understanding of best interests decision-making.
- Expertise in adapting information in order to enable people with learning disabilities to make as many decisions for themselves as they can.
- Training on implementation of MCA 2005 is available and undertaken by staff.
- Trained Best Interests Assessors for the Deprivation of Liberty Safeguards.

Expected outcomes

- Increase in numbers of people with learning disabilities where consent to treatment has been formally assessed.
- Increase in numbers of referrals from acute hospitals for assistance with assessing and enhancing capacity.
- Documented decision-making process for those who lack capacity.
- Improved management of decisions such as managing money, residence.
- Increase in reporting and management of safeguarding adults issues.

Psychology contribution to delivering individualised outcomes and quality indicators

- Development of care pathway for capacity assessment.
- Specialised assessment of capacity in relation to a number of different decisions (e.g. treatment, where to live, managing money, getting married, consent to sexual relationship, making a will, etc.).
- Training frontline staff on capacity issues.
- Supervision and training of other staff who need to consider capacity issues.
- Chairing Best Interests meetings, particularly where there are complex issues and dilemmas.
- Auditing capacity and best interests processes.
- Carrying out Best Interests Assessments under the Deprivation of Liberty Safeguards.

Potential risks if services not available/not effective

- Breaches of law relating to capacity.
- Residential care services becoming unduly restrictive, such that it amounts to Deprivation of Liberty. People with challenging behaviour are likely to be especially susceptible to these responses.
- Breaches of Human Rights law.
- Consent issues not addressed in a way that meets the needs of people with learning disabilities.
- Challenges in Court of Protection.
- Claims of failure to meet professional standards.

Resources

For further information about Human Rights Act:
www.justice.gov.uk/about/human-rights.htm

For further information about the Mental Capacity Act including Deprivation of Liberty Safeguards:
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm

For further information about estimates of the number of people in England who have a learning disability: CeDR People with learning disabilities in England (2008).
www.lancs.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf

For resources on the assessment of capacity and determining best interests, please see the following:

British Psychological Society (2006). *Assessment of capacity in adults; interim guidance for psychologists.* www.bps.org.uk

British Psychological Society (2007). *Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves* (Edited by T. Joyce).
www.bps.org.uk

British Psychological Society (2010). *Audit tool for mental capacity assessments.* www.bps.org.uk

National End of Life Care Programme. *The route to success in end of life care – achieving quality for people with learning disabilities.* www.endoflifecareforadults.nhs.uk

People whose behaviours challenge services

Background

Demographic

Across the UK, it is likely that 24 per 100,000 of the general population present a serious challenge at any one time. A few of these people will present such a challenge continuously, but many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time. Research in the UK suggests that between 20 to 30 per cent of children with learning disabilities experience behavioural difficulties compared to four to 10 per cent of children without cognitive impairments. In the UK population 16 to 41 per cent of adults with learning disabilities may present challenging behaviours, depending on the assessment techniques used.

Trends

Transfer from institutional to community services has not reduced the incidence of challenging behaviours despite improvements in people's quality of life (DH, 2007).

The increased number of young people with autistic spectrum conditions is placing extra demand on services. Challenging behaviour is often implicated in the placement of children with learning disabilities in residential special schools. These placements are often disruptive of ties with families and local communities so that there are often additional problems obtaining appropriate local services once responsibility for the young person transfers from children's to adult services. The continued use of residential special schools away from people's homes presents significant problems for adult services.

Data

In 2006 over 11,000 people with learning disabilities in England were supported in out of area placements (SCIE, 2008). Having behaviours that challenge services was the most frequent characteristic of this group, with a lack of appropriate provision being cited as the most likely reason for such placements.

Challenging behaviours generally emerge in childhood and are highly persistent into adulthood. Those placed out of area are generally young and male, and often have a diagnosis of autism.

The SCIE review found that despite their claims to be specialist provision, out of area placements were often of poor quality – 37 per cent of people placed out of area had no behavioural support plan; over 50 per cent had no access to psychology; over 40 per cent had no access to psychiatry; and there were low numbers of person centred plans or health action plans.

Evidence base and good practice

The Mansell Report (DH, 2007) identifies the need to develop and expand the capacity of local services to understand and respond to challenging behaviours in order to support people locally and avoid the inappropriate use of expensive out of area placements that are of low quality. Mansell concludes that successful services require:

- Commitment of frontline staff and professionals to develop excellent local services, with sustained support from managers.
- A focus on individualisation – a thorough knowledge of the person and their experiences, leading to a personalised package of care.
- A well trained and supported workforce that provides evidence-based support to individuals.

Challenging Behaviour: a unified approach (RCPsych, BPS & RCS&LT, 2007) reviews the evidence for the need for individualised assessment and interventions within a framework of Positive Behavioural Support (PBS), based on the principles of Applied Behavioural Analysis. It highlights the features of 'capable environments' that will lead to better outcomes for people.

Despite the evidence of the effectiveness of PBS (BPS, 2004), studies show that the majority of interventions in services do not follow the available guidance and are not formally written down or evaluated. There is often an over-reliance on medications without an appropriate evidence-base.

The Health Care Commission has published a number of reports relating to maltreatment and abuse of people with learning disabilities in specialist inpatient settings. A key area of concern has been the inappropriate use of physical restraint.

Elements of an 'excellent service'

- Early intervention in childhood.
- Effective transition planning into adult services.
- Knowledge of the demographics of the local population, including those who are at risk of out of area placements.
- A range of local supports where people live and work.
- Capable workforce in all settings to ensure the suitability of local provision.
- Speedy response from skilled practitioners, with access to local supports when problems occur.
- Stepped care approach to assessment, formulation and intervention including appropriate use of Assessment and Treatment Units and access to general health provision.
- Locally-based individualised and specialised housing and support provision.
- Ability to demonstrate positive outcomes for individuals.
- Up-to-date information about the numbers and needs of people who are placed out of area.
- Appropriate use of assistive technology to enable people to be supported safely in the home and community.

Expected outcomes

- Increased use of evidence-based interventions.
- Reductions in the frequency and severity of challenging behaviour of individuals.
- Reduction in the use of medication, including polypharmacy.
- Reduction in the use of one-to-one support packages as the mechanism for managing risk.

- Reduction in the use of out of area placements.
- Reduction in harm to the person and to others.
- Better quality of life.
- Greater social inclusion.
- Increased carer support and satisfaction.
- Reduction in staff stress.
- A more skilled and knowledgeable workforce.

Psychology contribution to delivering individualised outcomes and quality indicators

- Lead on the development of care pathways for assessment, intervention and support.
- Lead on the development of protocols for the delivery of the care pathway.
- Lead on the development of individualised assessments including risk, behaviour, environment.
- Lead on the process of returning people from out of area placements.
- Lead on the development of multi-disciplinary formulations that help services to understand how to support the people they care for.
- Develop and train others to deliver specific evidence-based interventions for individuals, for example, anger management, behavioural support plan, risk management, adapted CBT, alternatives to physical and mechanical restraint.
- Develop specific evidence-based interventions for whole services, for example, systemic approaches with staff and carers, environmental adaptations, stress management, emotional support, supervision for managers, advice on training and capable workforce.
- Advising on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.

Potential risks if services not available/not effective

- Increased costs of one-to-one or out of area placements.
- More complaints.
- Potential safeguarding issues.
- Reliance on restrictive practices.
- Increase in abuse or harm to self and others.
- Carer breakdown.

Resources

British Institute for Learning Disabilities (BILD). www.bild.org.uk/behavioursupport.htm

Department of Health (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs (Revised).* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

Person-Centred Active Support. www.personcentredactivesupport.com/

RCPsych, BPS & RCS&LT (2007). *Challenging Behaviour: a unified approach.* www.bps.org.uk/sites/default/files/documents/challenging behaviour – a unified approach.pdf

SCIE Knowledge Review 20 – Commissioning person-centred, cost effective, local support for people with learning disabilities (2008). www.scie.org.uk/publications/knowledgereviews/kr20.asp

The Challenging Behaviour Foundation. www.thecbf.org.uk/

People with mental health problems

Background

Demographic

It is now recognised that people with learning disabilities experience the full range of mental health problems. Estimates on prevalence vary, but studies indicate that 25 to 40 per cent of people with learning disabilities also have additional mental health needs. People with borderline learning disabilities experience higher rates of mental ill health than the general population, but receive fewer treatments.

Trends

There is increasing evidence that people with learning disabilities are being more effectively diagnosed and treated for their mental health problems. This requires distinctive clinical skills to assess, treat and support people, through the use of both generic and specialist services including acute admission facilities, outreach services in the community, psychological therapy and long term support.

Data

Government policy has set a clear expectation that people who have learning disabilities and mental health problems should be able to access mainstream mental health services as appropriate. However, the reality for many people with learning disabilities is that their access to, and treatment from, mainstream mental health services is often poor. Unsurprisingly, all nine localities involved in a Joint Review of Commissioning for people with learning disabilities and complex needs reported problems with access and/or the treatment provided by local mental health services.

It is also acknowledged that for some people with learning disabilities, the use of mainstream mental health services such as an acute psychiatric ward will be inappropriate and they may be better served by the local specialist adult learning disability team.

The results of a review of 28 studies on adults (excluding children, adolescents, older adults and forensic populations) with learning disabilities using general adult services since beginning of 2003 reveals some interesting data. Evidence regarding referral to general community and inpatient mental health services indicates reduced access of people with learning disabilities. The mean length of stay for people with learning disabilities was found to be longer for people admitted to specialist learning disabilities beds than those admitted to general psychiatric beds. Studies using qualitative approaches to look at the inpatient environment found specialist inpatient units provided caring staff, positive environment, practical help and respite function, although was negatively rated by people with learning disabilities as causing isolation. People with learning disabilities rated general psychiatric wards more positively in terms of supportive peer relationships, but they were negatively rated in terms of staff being unfriendly or harmful, poor environment, lack of freedom, feeling upset by others' behaviour, and feeling vulnerable. Carers were more likely to rate specialist learning disabilities units more positively. Extra help and staff training are necessary to improve access to mainstream psychiatric services where these are the only alternative.

Evidence base and good practice

Clinical psychologists have been instrumental in developing local protocols for working with people with learning disabilities who have significant mental health problems. Depending upon the individual's particular circumstances, their needs may be best met by the Learning Disability service, the mainstream mental health service or by both of those services working together to offer the individual the most appropriate mix of skills and expertise available within both services. The Care Quality Commission includes standards from the Greenlight toolkit as quality standards for mental health and learning disability trusts – psychologists are involved in the process of ensuring that these standards are being met locally. Many Strategic Health Authorities and commissioners also use these standards as part of the CQUIN process. Department of Health guidance on *Commissioning Specialist Adult Learning Disability Health Services* gives more detail on this area and it is recommended this document be read in conjunction with this guidance.

There is an increasing evidence base for the use of psychological therapies with people with learning disabilities including of cognitive-behavioural, psychodynamic and systemic psychotherapies, as well as other approaches recommended by the National Institute for Health and Clinical Excellence (NICE) such as Eye Movement Desensitisation and Reprocessing, and Dialectical Behaviour Therapy. However, clinicians providing these treatments need a specialist understanding of how to adapt these to the needs of each individual person with learning disabilities because of their underlying cognitive deficits and different life experiences.

Meeting the mental health needs of people with learning disabilities requires a consideration of how new initiatives such as Improving Access to Psychological Therapies (IAPT) will be applied and what measures may need to be taken to ensure equal access.

IAPT focuses on 'common' mental health problems, i.e. depression and anxiety, which are addressed in primary care, or even prior to the involvement of primary care services. In January 2009 positive practice guidance was issued relating to people with learning disabilities and IAPT. The guidance identifies four key barriers to access:

- **Social restriction** including lack of support to access their GP or other services.
- **Challenging behaviour** may prevent people from being able to express feelings in words and underlying causes of behaviour is often not identified.
- **General practitioners** and other primary care professionals report lack of skills and knowledge to engage effectively with people with LD and experience time constraints which may present barriers.
- **Specialist mental health services** for a range of reasons (including lack of confidence) do not support effective access of people with learning disabilities to the service.

The Department of Health *New Horizons* programme is developing a shared national vision for health and well-being. Commissioners and providers will need to work together to ensure people with learning disabilities and mental health needs benefit from this new initiative.

Elements of an 'excellent service'

- Known demographics of people with learning disabilities with mental health problems in the local area.
- Multi-agency mental health strategy that reflects the principles and objectives of the Greenlight toolkit.
- Multi-agency care pathway for assessment, diagnosis, treatment and support of people with learning disabilities who have mental health problems.
- Multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services.
- Person-centred care using the Care Programme Approach.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions.
- Prompt access to appropriate in-patient and crisis resolution and home treatment services as required.
- Support is available to family carers and service providers.
- Capable workforce able to deliver excellence in mental health care for people with learning disabilities.
- Focus on recovery.

Expected outcomes

- Increase in prompt differential diagnosis of the person's difficulties.
- Appropriate access to mainstream mental health services.
- Increase in other conditions being treated promptly.
- Increase in accurate diagnosis of mental health problems.
- Reduction in behaviours which challenge.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

Psychology contribution to delivering individualised outcomes and quality indicators

- Work with other senior professionals on Greenlight toolkit, CQC standards and CQUIN targets.
- Lead on determination of appropriateness of IAPT services for people with learning disabilities and pathways across services.
- Lead on development of care pathways across MH and LD services.
- Lead on development of risk management frameworks.
- Support the development of protocols for joint working between services.
- Advise on developing and maintaining a service of excellence.

- Individualised assessment of the person across the range of mental health issues.
- Auditing and reviewing services.
- Adapting common psychological therapies to make them accessible to people with cognitive impairments. This applies to the main therapeutic modalities of cognitive-behavioural, psychodynamic and systemic psychotherapies, as well as other approaches recommended by NICE such as Eye Movement Desensitisation and Reprocessing, Cognitive Analytical Therapy and Dialectical Behaviour Therapy.
- To act as responsible clinician for offenders detained under the Mental Health Act and on Supervised Community Treatment Orders.
- Contribute to multidisciplinary approaches to relapse prevention.
- Developing and monitoring outcomes for individuals and services.
- Provide support, training and supervision to other professionals working with people with LD and mental health problems in the local health economy.

Potential risks if services not available/not effective

- Increased costs of one-to-one support packages.
- New 'in area' or out of area placements.
- Trusts do not comply with CQC standards around Greenlight toolkit.
- Trusts do not achieve CQUIN quality targets.
- Vulnerable service users fall between mainstream mental health and specialist learning disability services when they require mental health services.
- Less access to home-based assessment and intervention of mental health issues.
- Less access to appropriate psychological interventions.
- Increase in in-patient stays.
- More complaints.
- Potential safeguarding issues.
- Increase in Serious and Untoward Incidents such as abuse, harm or death to self and others.
- Carer breakdown.

Resources

Department of Health (2007). *Commissioning Specialist Adult Learning Disability Health Services*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

Department of Health (2009). *No Health without Mental Health.* www.dh.gov.uk/prod_consum–dh/groups/dh–digitalassets/documents/digitalasset/dh_124058.pdf

Green Light Toolkit. http://valuingpeople.gov.uk/dynamic/valuingpeople146.jsp

IAPT Positive Practice Guide – Learning disabilities. www.iapt.nhs.uk/silo/files/learning-disabilities-positive-practice-guide.pdf

Mental Health in Learning Disabilities Electronic Network. www.estiacentre.org/mhildnetwork.html

People with autistic spectrum conditions

Background

Demographic

The National Audit Office (2009) reports that there are an estimated 400,000 adults with an Autistic Spectrum Condition (ASC) in England, and that about half of people with an ASC have a learning disability. This suggests that there are at least 200,000 adults with a learning disability and an ASC in England (which is more than 20 per cent of the estimated population of 974,000 adults with a learning disability).

Valuing People Now (DH, 2009) highlights that adults with a learning disability and an ASC are one of the most excluded groups in society.

Trends

The number of people thought to have an ASC has increased hugely over the last 30 years. Baron-Cohen et al. (2009) report that in 1978 the consensus prevalence estimate of people with an ASC was four in 10,000 (0.04 per cent). Their research, however, resulted in a 2009 prevalence estimate of 157 per 10,000 (1.6 per cent). This suggests that there will be a big increase in demand for services for people with an ASC, and that all services, including those for adults with a learning disability, will need to develop and adapt accordingly.

Evidence base and good practice

Fulfilling and Rewarding Lives, the Department of Health strategy for adults with autism in England (2010), and the implementation guidance provide a focus for development of services in five key areas of services:

- increasing awareness and understanding of autism among frontline professionals;
- developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment;
- improving access for adults with autism to the services and support they need to live independently within the community;
- helping adults with autism into work;
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

As discussed elsewhere in this document, people with a learning disability placed 'out of area' are at an increased likelihood of poor outcomes. Although a small number of people with a learning disability and an ASC may need specialist services that cannot be provided in-area, most of this group's needs should be able to be met locally, often at lower cost than out-of area provision. However, approximately two-thirds of Local Authorities and NHS bodies who responded to a survey said that they found it fairly/very difficult to find appropriate local support and housing for people with autism (National Audit Office, 2009).

Elements of an excellent service

- Services provided 'in-area'.
- Data routinely collected on the number of people with a learning disability and an ASC, the number of people in this group placed 'out-of area' and the cost of these 'out of area' placements.
- A clear care pathway, including provision for diagnosis, assessment of strengths and needs and access to post-diagnosis services.
- Ability to support people with any difficulties they have resulting from their ASC, including any challenging behaviour or mental health problem.
- A strategy for developing the skills of the local workforce in recognising and working with people with a learning disability and an ASC.
- Links into a wider local strategy for supporting people with an ASC.
- Specialised local housing providers who are able to provide a range of appropriate supports in non-congregate settings

Expected outcomes

- Improved quality of life for adults with a learning disability and ASC
- Reduced use of 'out-of area' provision, leading to lower costs.
- Workforce skilled in identifying and supporting people with a learning disability and an ASC, resulting in more choice and opportunities for this group and fewer placement breakdowns.
- More people with a learning disability and an ASC accessing the services they need.

Expected contribution from a psychology service

The range of core skills of applied psychologists mean they can take lead roles throughout service provision for people with a learning disability and an ASC, in areas including:

- Diagnosis and post-diagnosis support, including education about ASCs.
- Assessment of individual strengths and needs.
- Providing assessment and evidence-based psychological interventions for any additional challenging behaviour or mental health problem.
- Providing assessment and intervention in other areas of need often associated with this group (e.g. understanding and use of social skills, understanding of relationships, etc.).
- Training social care staff and other professionals (e.g. GPs, CTPLD staff, CMHT staff, etc.) in the local area.
- Evaluating outcomes.
- Supporting commissioners to collect data on people with a learning disability and an ASC.
- Providing leadership in service development.
- Contributing to the development of wider local strategy and service provision for people with an ASC.

Potential risks if services not available/not effective

- Poorer individual outcomes for people with a learning disability and an ASC.
- Higher levels of unmet need, leading to more frequent placement breakdown and use of expensive 'out of area' or inpatient services to manage crises.
- Disjointed local services, contributing to poorer outcomes and higher costs.
- Limited availability of data for service planning and development.
- Limited skill in the local social care workforce, necessitating greater use of 'out of area' placements.
- Increase in complaints from families

Resources

Baron-Cohen, S., Scott, F.J., Allison, C., Williams, J., Bolton, P., Matthews, F.E. & Brayne, C. (2009). Autism Spectrum Prevalence: A school-based UK population study. *British Journal of Psychiatry*. http://bjp.rcpsych.org/cgi/reprint/194/6/500

Department of Health (2009). *Valuing People Now: A new three-year strategy for people with learning disabilities*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

Department of Health (2010). *Fulfilling and Rewarding Lives: The strategy for adults with autism in England*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

National Audit Office (2009). *Supporting people with autism through adulthood. Report by Comptroller and Auditor-General HC 556 Session 2008–2009*. www.nao.org.uk/publications/0809/autism.aspx

Dementia and people with learning disabilities

Background

Demographic

As with the general population, dementia is a growing issue in services for people with learning disabilities as a result of increased life expectancy. There is increasing evidence that people with learning disabilities in general are at increased risk of developing dementia, whilst the incidence is much higher for people with Down's syndrome. Within this group the rates of dementia in people are:

40 to 49 years	10 per cent to 25 per cent
50 to 59 years	20 per cent to 50 per cent
60+ years	30 per cent to 75 per cent.

Trends

It is estimated that by 2020 the proportion of people with learning disabilities over 65 years of age will have doubled and that over a third of all people with learning disabilities will be over 50 years of age. There is a much greater awareness of the risk of dementia by both staff and family carers, and the number of people being referred for concerns is increasing annually.

Data

Within one county in England there are 345 adults with Down's syndrome over the age of 30, and 25 per cent have suspected or diagnosed dementia.

Evidence base and good practice

In 2006 the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a joint clinical guideline on the management of dementia. This document recommended a co-ordinated and integrated approach to assessment, treatment and care, together with the development of appropriate assessment and support services for the person and carers.

The National Dementia Strategy (2009) identified key actions and activities for commissioners and providers to support the needs of this group of people. Psychologists have a key role in both the assessment and diagnostic process, but also in helping others to understand the issues presented by the dementia and adapt the care and the environment to ensure the best quality of life of the person with learning disabilities and dementia. The model assumes that carers who know and understand the person, understand what the dementia brings, and who can adapt the care accordingly, will enable the person to have a quality life, and reduce the impact on other people that they live with.

Guidance on assessment, diagnosis, treatment and support of people with learning disabilities and dementia has been written by the British Psychological Society and the Royal College of Psychiatry (2009). The guidance emphasises the need for effective and timely assessment, diagnosis, and treatment for people with learning disabilities suspected or confirmed as having dementia and to ensure quality support to them, their family and

other carers. Given the risk of early onset of dementia, it is advised that every adult with Down's syndrome is assessed to establish a baseline against which to compare future changes in functioning. The document recommends how environments can be adapted to ensure that people who develop dementia can be supported in ways that maximise their quality of life. A set of 'good practice standards' is provided, against which commissioners and service providers can audit their services.

Elements of an 'excellent service'

- Known demographics including a database of all adults with learning disabilities including identification of people with Down's syndrome and those in out of area placements.
- Multi-agency dementia strategy.
- Multi-agency care pathway for assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia.
- Multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services including baseline assessment for people with Down's syndrome by the age of 30.
- Person-centred dementia care.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions.
- All living and day service environments are dementia friendly.
- The person is supported to remain in their familiar home with additional supports provided in a timely manner.
- Support is available to family carers and service providers.
- There is a capable workforce able to deliver excellence in dementia care.
- End of Life care follows the requirements of the National End of Life Strategy.

Expected outcomes

- Increase in prompt differential diagnosis of the person's difficulties.
- Increase in other conditions being treated promptly.
- Increase in accurate diagnosis of dementia.
- Reduction in behavioural difficulties.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

Psychology contribution to delivering individualised outcomes and quality indicators

- Lead on development of dementia strategy.
- Lead on development of care pathway.
- Develop protocol for delivery of care pathway.
- Individualised assessment of the person.
- Formulation.
- Differential diagnosis.
- Specific evidence-based interventions for individuals, for example, reminiscence, anxiety management, behavioural support plan, risk management.
- Specific evidence-based interventions for services, for example, understanding model of dementia care, systemic approaches with staff and carers, environmental adaptations, stress management, emotional support, supervision for managers, advice on training and capable workforce.
- Advising on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.
- Delivery of training to staff and carers.

Potential risks if services not available/not effective

- Increased costs of one-to-one, new in area or out of area placements.
- More complaints.
- Potential safeguarding issues.
- Increase in behaviours leading to abuse or harm to self and others.
- Carer breakdown.

Resources

BPS/RCPsych (2009). *Dementia guidelines for people with learning disabilities.* www.dcp-ld.bps.org.uk/dcp-ld/publications/publications_home.cfm

National Dementia Strategy. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf

NICE/SCIE. *Guideline to improve care for people with dementia.* www.nice.org.uk/guidance/index.jsp?action=download&o=30323

Offenders and those at risk of offending

Background

Demographic

Offenders with learning disabilities generally fall in the mild range of intellectual disability. This is because a person requires *mens rea* before they can be considered culpable for an illegal act. Individuals of cognitive function lower than mild learning disabilities would not normally be considered to have *mens rea*. With that caveat in mind, a small percentage of people with learning disabilities are known to commit the full range of offences known to mainstream criminal services. Studies on the prevalence of offenders with learning disabilities in a range of criminal populations have found hugely diverse percentages from zero to around 30 per cent.

Data

The most common offences are associated with verbal and physical aggression, as is the case in mainstream criminal populations. Sexual offences and alcohol-related offences feature relatively frequently. Fire raising, theft and alcohol-related offences are recorded at low but consistent levels.

Evidence base and good practice

Specialist learning disability health services range from community-based teams to in-patient provision and many have a forensic service at low, medium or high levels of security. As part of the multi-disciplinary team, psychologists are delivering a range of programmes and treatments to this population including adapted sex offender treatment programmes, anger management, enhanced thinking skills and substance misuse. Psychologists play a key role in developing thorough risk assessments and risk management plans so that people can be supported in the least restrictive environment.

Psychologists can provide invaluable support at each stage of the criminal justice system to support people with learning disabilities to receive fair and equal treatment. The need to support offenders with learning disabilities has an increasing profile and the publication of the Prison Reform Trust *No One Knows* in 2008 has provided a clearer picture of the issues facing this group. The report estimates that up to 30 per cent of the prison population have learning disabilities or difficulties and provides evidence of the poor support and treatment experienced by many offenders with learning disabilities including bullying, harassment and discrimination.

Policy drivers to ensure people with learning disabilities are cared for as close to home as possible and in the least restrictive setting have a particular relevance for this group. Many people with learning disabilities and forensic needs are in high cost distant placements and at risk of getting 'stuck' in the system. By working in partnership with commissioners, psychologists are well placed to ensure that where appropriate, people are able to live closer to home and 'step down' to conditions of lesser security.

Clinical psychologists have been in the forefront of innovation using a range of techniques, such as exploring how far the *Good Lives* model used by forensic services can be adapted for people with mild disabilities.

Elements of an 'excellent service'

- Known demographics of people with learning disabilities who offend in the local area including in the Criminal Justice system.
- Multi-agency strategy for offenders with learning disabilities.
- Multi-agency care pathway for assessment, diagnosis, treatment and support of people with learning disabilities who offend or are at risk of offending.
- Court diversion processes that address the needs of people with learning disabilities.
- Multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services.
- Person-centred care.
- Effective risk management both within and across agencies including prison, probation, police, MAPPA, health and social services.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions within the community including offender treatment programmes.
- Prompt access to appropriate locked rehabilitation, low secure, medium secure and high secure services as required.
- Support is available to family carers and service providers.
- There is a capable workforce able to deliver excellence in for people with learning disabilities who offend or are at risk of offending.

Expected outcomes

- Increase in prompt differential diagnosis of the person's difficulties.
- Increase in the risk being managed promptly.
- Increase in accurate diagnosis of likelihood of offending.
- Reduction in offending.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

Psychology contribution to delivering individualised outcomes and quality indicators

- Work with other agencies on strategy for offenders with learning disabilities.
- Lead on development of care pathway across all forensic and learning disability services.
- Support the development of protocols for joint working between services.
- Work collaboratively with other professionals and agencies to protect the public.
- Individualised assessment of the person for offending behaviour and other co-morbid conditions; adapt assessment for people with all degrees of learning disabilities to identify treatability and treatment needs.
- Assessments as part of a low secure gate keeping role.

- Formulation.
- Differential diagnosis.
- Providing inreach to prisons.
- Adapting common psychological therapies and offender treatment programmes to make them accessible to people with cognitive impairments who offend. This applies to the main therapeutic modalities of cognitive-behavioural, psychodynamic and systemic psychotherapies.
- Deliver therapies (e.g. adapted sex offender treatment groups) in collaboration with other agency staff such as probation.
- To act as responsible clinician for offenders detained under the mental health act and on supervised community treatment orders.
- Relapse prevention.
- Risk management.
- Advising on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.
- Provide support, training and supervision to other professionals in the local health economy.

Potential risks if services not available/not effective

- Increased costs of one-to-one, low secure, medium secure and high secure placements.
- Increase in use of prison.
- Increase in behaviours leading to offending, abuse or harm to self and others.
- Potential safeguarding issues.
- More complaints.
- Carer breakdown.
- Increase in negative publicity about services.

Resources

G. Murphy (2006). *Breaking the Cycle – better help for people with learning disabilities at risk of offending – a framework for the north-west region*. www.nwtdt.com/

Department of Health (2009). *Lord Bradley's Review of people with mental health problems or learning disabilities in the criminal justice system.* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098694

Prison Reform Trust (2008). *No-One Knows – Learning Disabilities and Learning Difficulties in Prison*. www.prisonreformtrust.org.uk/uploads/documents/NOKNL.pdf

For Government guidance on the commissioning and standards for secure services. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_126177.pdf

People with profound and multiple learning disabilities

Background

Demographics

People with profound and multiple learning disabilities are among the most disabled individuals in our community. They have a profound intellectual disability and consequently severely limited understanding. In addition they have multiple disabilities which may include impairments of vision, hearing, and movement as well as other problems like epilepsy and autism. Some people have in addition problems of challenging behaviour such as self-injury (DH, 2010).

They are a relatively small, easily identifiable group with undeniable needs for support. It is estimated that there are just over 16,000 adults with profound and multiple disabilities in England now. This is about 0.03 per cent of the general population. It is likely that the incidence in Scotland, Wales and Northern Ireland is similar.

Trends

It is estimated that the number of adults with profound and multiple disabilities is likely to increase by an average of 1.8 per cent each year to 2026. In a 'district' with a population of 250,000, the number of adults with profound and multiple disabilities is expected to increase from about 78 in 2009 to 105 in 2026.

This rate will be higher in communities that have a younger demographic profile or a greater number of citizens from Pakistani and Bangladeshi communities, where the incidence of learning disabilities is greater.

Data

Research by Mencap shows that most parents of children and adults with profound and multiple disabilities spend more than 10 hours per day on essential physical care. A third of these parents said their caring role was continuous and meant they were caring for their son or daughter 24 hours a day, while more than half of parents were spending over eight hours per day on therapeutic and educational activities. Parents were woken up, on average, three times a night by the need to care for their son or daughter. Nearly half of families interviewed received no support from outside the family to help with care tasks and less than a quarter received more than two hours support a week to help them cope at home with care tasks. The study showed that 37 per cent of families were in contact with eight or more professionals and 80 per cent felt that professionals were poorly co-ordinated. People with profound and multiple disabilities experience a much higher mortality rate than the rest of the population, but many live well into adult life.

Evidence base and good practice

Raising our sights: services for adults with profound intellectual and multiple disabilities (DH, 2010) highlights examples of good practice to support adults with profound and multiple disabilities. Where families are supported to make the most of the 'personalisation' agenda, they are in general shown to be getting what they and their families needed and wanted. The report identifies a number of elements that make for a good service:

- All the examples of good practice involved designing and delivering arrangements tailored to the individual person's needs and preferences.
- Good services treat the family as the expert. In all the examples of good practice families had taken a leading role to get what they needed for their disabled family member.
- Good services focus on quality of staff relationships with the disabled person. Staff need to have a warm, respectful and caring relationship with the person.
- Good services sustain the package of care. If basic supplies like incontinence pads and other equipment are not readily available, the quality of life of the disabled person is undermined.
- Assistive technology such as microswitches, electric wheelchairs and communication aids can greatly enhance quality of life.

Elements of an 'excellent service'

- Use of information technology to increase the person's choice and control.
- Individualised support tailored to the person's needs and preferences.
- Families are seen as the experts by other services (e.g. GPs and acute hospital staff).
- 'Personalisation' includes adults with profound and multiple disabilities in a way that leads to improved quality of life.
- Development of independent advocacy arrangements to represent the interests of adults with profound and multiple disabilities.
- The development of more effective transition arrangements with the provision of proper planning and timely provision of appropriate services as people move into adulthood.
- Local agencies have up-to-date information about the number, needs and circumstances of people in their area currently and projected in the future to enable effective planning of services.
- Local workforce plans ensure that the social care workforce, including personal assistants, are trained in person-centred approaches to communication and support that meet the needs of adults with profound and multiple disabilities.
- Improved access to communication aids and assistive technology as a means of enhancing quality of life.
- Access to further education and other meaningful daytime activities outside the home.
- Access to a range of suitable short breaks.
- Co-ordinated inter-agency policies and practices to ensure people receive the support they need, when and where they need it.

Expected outcomes

- Increased availability of information technology to aid communication and choice making.
- Increased opportunities to indicate preferences and control their environment, through the development of developmentally appropriate communication.
- Increased use of self-directed services, including individualised budgets to control and direct the services they need.

- Improved quality of life.
- Lower costs on families (including non-monetary costs).
- Lower needs in other areas (e.g. health).
- Improved access to advice and support for families.
- Greater access to independent advocacy for individuals and their families.
- Improved quality of transition from children's to adult services.
- Reduced stress and burnout in families and paid staff.
- Increased opportunities to indicate preferences and control their environment.
- Reduced pain and distress.

Psychology contribution to delivering individualised outcomes and quality indicators

- Lead on development of care pathways.
- Carry out, and support others, to perform a range of assessments.
- Work with other professionals to develop and train staff and carers to deliver specific evidence-based interventions (e.g. Intensive Interaction) for individuals.
- Develop specific evidence-based interventions for whole services (e.g. person-centred active support).
- Advise on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.
- Assessment and interventions for individuals who self-injure.
- Development of alternatives to restraints.
- Lead on the promotion of decision-making within the MCA.

Potential risks if services not available/effective

- Increase in interventions involving physical restraint and possible safeguarding issues.
- Carer breakdown and the resultant dependence on alternative support packages.
- Increase in behaviours leading to abuse or harm to the person.
- Perpetuating the marginalisation and exclusion of one of the most neglected and needy groups of people in our society.

Resources

Commissioning services and support for people with learning disabilities and complex needs (2009). www.cqc.org.uk/_db/_documents/Report_for_commissioning_LD_joint_review.pdf

Department of Health (2010). *Raising our sights: Services for adults with profound intellectual and multiple disabilities. A report by Professor Jim Mansell.* www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117961.pdf

Mencap (2001). *No ordinary life: The support needs of families caring for children and adults with profound and multiple learning disabilities.* London: Royal Society for Mentally Handicapped Children and Adults. www.mencap.org.uk/document.asp?id=1671&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=pageType&pageType=112&pageno=&searchPhrase=

Mencap (2006). *Breaking point – families still need a break: A report on the continuing problem of caring without a break for children and adults with severe and profound learning disabilities.* London: Royal Society for Mentally Handicapped Children and Adults. www.mencap.org.uk/document.asp?id=297

People with physical health needs

Background

Demographic

People with learning disabilities have higher levels of ill health and much higher rates of premature death than the population as a whole. It is estimated that people with learning disabilities are 58 times more likely to die prematurely. People with learning disabilities have higher rates of obesity, coronary heart disease, respiratory disease, hearing impairment, dementia, osteoporosis and epilepsy. Some 26 per cent of people with learning disabilities are admitted to hospital each year compared with 14 per cent of the general population.

Trends

The evidence from a series of reports and inquiries shows that the National Health Service (NHS) is not yet commissioning or providing services in ways that adequately meet these health needs. This contributes to preventable ill health, poor quality of life and – at worst – premature deaths.

Sir Jonathan Michael's independent inquiry found that these inequalities arise in part because:

- people with learning disabilities find it harder to access assessment and treatment for general health care;
- health care providers make insufficient adjustments for communication problems, difficulty in understanding, or the individual preferences of people with learning disabilities;
- parents and carers struggle to be accepted as effective partners in care;
- health service staff have very limited knowledge about learning disabilities and are unfamiliar with the legislative framework;
- partnership working and communication are poor;
- although there are examples of good practice, witnesses have also described appalling examples of discrimination, abuse and neglect.

Data

People with learning disabilities tend to have markedly worse health than the population as a whole. The 2006 Disability Rights Commission report estimated that people with learning disabilities are two-and-a-half times more likely to have health problems.

There is widespread evidence of the burden of specific disease:

- around one person in three with learning disabilities is obese, compared with one person in five of the general population;
- coronary health disease (CHD) is the second most common cause of death in people with learning disabilities;
- the incidence of respiratory disease is three time higher in people with learning difficulties than in the general population;
- some 40 per cent of people with learning disabilities have a hearing impairment and many have common visual impairments;

- the rate of dementia is four times higher and the rate of schizophrenia three times higher than in the general population;
- people with learning disabilities tend to have substantially less bone density and experience higher levels of osteoporosis;
- epilepsy is over 20 times more common in people with learning disabilities than in the general population. Sudden unexplained death in epilepsy is five times more common in people with learning disabilities than in others with epilepsy.

Ill health has an obvious impact on quality of life for people with learning disabilities. Both adults and children with learning disabilities are at an increased risk of early death. Those under the age of 50 are 55 times more likely to die prematurely. For those over 50, the risk is 58 times more likely. The Government has agreed Sir Jonathan Michael's recommendation to establish a confidential inquiry to improve the evidence base on how to reduce the incidence of premature death (www.ihal.org.uk).

Evidence base and good practice

Securing the right services for people with learning disabilities is not just a matter of good commissioning practice. The Disability Discrimination Act 1995 places a duty on all health and social care organisations not to discriminate against disabled people or provide them with a poorer quality of service. It obliges organisations to make 'reasonable adjustments' to reflect the needs of disabled people.

Valuing People Now includes the Government's response to the independent inquiry chaired by Sir Jonathan Michael. The inquiry found that 'people with learning disabilities appear to receive less effective care than they are entitled to receive' and made ten recommendations to address these inequalities. The key recommendations for PCTs concern better leadership, better use of data to commission and monitor care, identifying and acting on health needs (through Joint Strategic Needs Assessments and Local Area Agreements) and securing general health services, including primary care, that make reasonable adjustments for people with learning disabilities.

The then Secretary of State for Health commissioned the independent inquiry following Mencap's report, *Death by Indifference,* which highlighted the cases of six people with learning disabilities who died while in the care of the NHS. The Parliamentary and Health Service Ombudsman and Local Government Ombudsman have recently reported on these individual cases. The Ombudsmen recommended that all NHS and social care organisations should urgently review the effectiveness of their systems – and their capacity/capability – for understanding and meeting the additional and often complex needs of people with learning disabilities. PCTs and other organisations were expected to report to their Boards by March 2010 on the action they had taken.

The Operating Framework for 2009/10 reinforced the importance of PCTs securing general health services that make reasonable adjustments for people with learning disabilities, monitoring uptake of annual health checks, and having systems in place to improve the overall quality of health care for people with learning disabilities.

These objectives align strongly with the emphasis in the NHS *Next Stage Review* and in the *World Class Commissioning* framework on more personalised services, a greater focus on health and well-being, and working in partnership with local authorities and other sectors.

Elements of an 'excellent' service

- Good data and information on people with learning disabilities and their journey through the general health care system.
- Good awareness in primary care of the health needs of people with learning disabilities.
- Priority given to people with learning disabilities.
- Good awareness of the additional needs of people with learning disabilities and their co-morbidities.
- Effective monitoring or performance management of providers' compliance with the legislative framework.
- Comprehensive training for health care staff about learning disabilities.

Expected outcomes

- Ensuring that health care providers make reasonable adjustments, as required by the Disability Discrimination Act.
- Increase in the number of person-centred care plans and health action plans.
- Increase in collaborative working with GP practices, PCTs, acute health providers, local authorities and local Learning Disability Partnership Boards.
- Increasing access to general health services that meet the individual needs identified in annual health checks.
- Increasing effective communication with service users and their families and carers to ensure that their needs, choices and preferences are understood and that services are available to reflect individual choices.
- Decreasing diagnostic overshadowing/overcoming the risk that people's reports of physical ill health or unusual behaviours are viewed as part of learning disabilities, and so are not investigated or treated.
- Increase in staff understanding and practice re issues of confidentiality, consent and mental capacity legislation for adults with learning disabilities.
- Improvement in training of those providing health care across primary care, community services and hospital care.
- Increased partnership working with patients, advocates, families and across professional boundaries.

Psychology contribution to delivering individualised outcomes and quality indicators

A key concern highlighted across these and other reports has been the lack of skills, knowledge and positive attitudes evident in the wider NHS in relation to people with learning disabilities. Psychologists have a valuable role to play in enabling people to access mainstream NHS services and in supporting their colleagues who work in these services to meet the needs of this group. For example, psychologists are well placed to provide training and specifically, to help mainstream professionals address complex issues such as capacity and consent.

Additional disabilities, particularly sensory impairments and their consequences may not always be fully understood by those caring for someone with learning disabilities. It is not uncommon for people to exhibit 'challenging behaviours' as a consequence of unmet physical need or pain. Psychologists can work with the individual and their carers to help them to detect patterns of behaviour that may signal an underlying health need and reduce the risk of 'diagnostic overshadowing'.

Supporting people to develop their own plans to address their health needs, including making use of tools such as health action plans is a key policy objective. Psychologists have a range of skills to support self-care and an individual and their families understanding of health needs.

Psychologists are able to use the evidence base to meet the physical health needs of people with learning disabilities, and to identify gaps in the evidence base to develop innovative approaches to meeting health needs.

Psychologists are also involved in helping to develop the health strategy for the local area in collaboration with other providers. They can also lead on audit, evaluation and research into health needs of people with learning disabilities.

Potential risks if services not available/not effective

- Poorer health care for people with learning disabilities.
- Non or late diagnosis of treatable or preventable health needs.
- Poor compliance with mental capacity legislation.
- Potential safeguarding issues.
- More complaints.
- Increase in behaviours that challenge.
- Greater and earlier mortality.

Resources

Directed Enhanced Scheme for annual health checks for people with learning disabilities.
www.pcc.nhs.uk/managemen-of-health-for-people-with-learning-disa

UK Heath and Learning Disability Network.
www.learningdisabilities.org.uk/information/have-your-say/the-uk-learning-disability-and-health-network/?locale=en

Valuing People Support Team website – health pages.
http://valuingpeople.gov.uk/dynamic/valuingpeople118.jsp

Supporting parents who have learning disabilities

Background

Demographic

There are large variations in estimates of the number of parents in the UK who have learning disabilities from 23,000 to 250,000 (DoH & DfES, 2007). In reality it is very difficult to obtain reliable estimates of numbers due to variations in the definition of learning disabilities over time and across services. Many parents with learning disabilities may well not be known to learning disability services. Some services work with people who would not be considered to have a learning disability as defined by international classification systems. The literature that is available tends to reflect those families who are known to social care services and focuses primarily on mothers.

Between 40 to 60 per cent of these parents will have their children removed from their care permanently. Children within these families are at risk of developmental delay, especially related to cognitive and language skill areas, doing less well at school and having greater behavioural difficulties, even when compared to other families of similar socio-economic backgrounds

Trends

There have been an increasing number of people with learning disabilities becoming parents during the last century, partly as a result of changing attitudes towards sexuality and people with learning disabilities. International research is beginning to show that the number of parents with learning disabilities is steadily growing. Anecdotally there appears to be more referrals to learning disability services for such parents than there were 10 to 15 years ago.

Data

Since 1988 the Special Parenting Service in Cornwall (total population 500,000) has worked with more than 850 families where one or both parents have had a learning disability.

Evidence base and good practice

There is evidence that parents with learning disabilities can learn and develop their parenting knowledge and skills as long as the interventions are tailored and adapted to take account of the parents' learning disabilities. The evidence is reviewed in the British Psychological Society's *Good Practice Guidance* (BPS, 2011, in press) and shows that parents with learning disabilities are capable of love and affection, they can learn and maintain with support a range of parenting skills involving both practical (e.g. child care and housekeeping) and relationship skills.

In recent years there have been a few specialised resources published to assist families with their parenting skills (e.g. CHANGE, BILD). Parents with learning disabilities are likely to require support with their parenting throughout the duration of a child's life, although the nature and extent of the support can vary. Services for parents vary across the UK and in all but a few areas there are no specific services developed for this very vulnerable group.

There have been three key reports published in the UK within the last 10 years that relate to parents with learning disabilities.

A Jigsaw of Services (Goodinge, 2000), inspected services across the country for all disabled parents (including those with learning disabilities) and found:

- A lack of co-ordination.
- Failure of professional collaboration.
- A gender bias towards women.
- Support services tended to be reactive and crisis-driven which immediately sets up problematic relationships with parents.

Tarleton, Ward and Howarth (2006) in their review of examples of good practice, *Finding the Right Support*, found an increase in positive practice in some services across the UK in relation to empowering parents with learning disabilities, raising awareness of their needs and the development of multi-agency support for these parents. They also emphasise that parents with learning disabilities often enter the child protection system due to concerns of perceived neglect by services, which are often due to the parents' cognitive impairments and the impact of social and economic deprivation rather than the result of abuse.

In 2007, the Department of Health published *Good Practice Guidance on Working with Parents with a Learning Disability* (DoH & DfES, 2007). It identified five key features of good practice in relation to working with parents with learning disabilities:

- Accessible information and communication.
- Clear and co-ordinated referral assessment procedures and processes.
- Support based on assessments of their needs and strengths.
- Long-term support.
- Access to independent advocacy.

Elements of an 'excellent service'

- Known demographics – how many parents with learning disabilities are there?
- Early identification of parents or potential parents.
- Agencies make referral into the learning disability services as early in pregnancy as is possible.
- Prompt assessments of whether or not the person has a learning disability – clear and efficient eligibility process.
- Multi-agency strategy for parents with learning disabilities.
- Multi-agency care pathway for how these parents are assessed in a co-ordinated way.
- Family-centred approach – rather than services that are focused solely upon either the parent or the child.
- The child's welfare remains of paramount importance across all agencies.
- Effective links between children's and learning disability services.
- Pooling of budgets in funding support for these families.
- Interventions/support available to parents on a long-term basis, and these are responsive to the changing needs of parents and children. 'The best predictor of future parental competency for parents with intellectual disabilities is the quality and frequency of social and practical support available to them on a daily basis' (McGaw, 1998, p.200).
- Interventions that are *preventative* rather than *crisis driven*.

- Facilitation to access local services.
- Interventions/groups specifically aimed at parents with learning disabilities.
- Access to advocacy for parents.

Expected outcomes

- Clear identification of parents who have a learning disability
- Interventions targeted at this group of vulnerable parents and children
- Thorough multi-agency assessments of parenting skills that highlight areas where interventions may be required.
- Ongoing support and interventions throughout the duration of the child's minority
- Services working together in a systematic and co-ordinated approach

Psychology contribution to delivering individualised outcomes and quality indicators

- Individualised assessment of the parent, for example, intellectual functioning, reading, numeracy skills, memory, and functional skills.
- Recommendations made as to how to optimise a parent's learning and skill acquisition.
- Work in partnership with other agencies in providing a comprehensive assessment of parenting skills.
- Provide guidance to other agencies in how to ensure that their interventions are tailored that take into account parents' learning disability.
- Provide advice, training, support and supervision to mainstream services, for example, family centres, health visitors who will also support these parents.
- Development of specialist groups for parents with learning disabilities (e.g. in Oxfordshire they have been piloting groups aimed at improving parenting competencies called 'Play Matters' and 'Keeping our Kids Safe').
- Evaluating efficacy of interventions.
- Developing and monitoring outcomes for individuals and their families.

Potential risks if services not available/not effective

- Individual risk factors and the consequences for the children, for example, developmental delay, behaviour difficulties, lower academic achievement.
- Over representation of these families within child protection services.
- Increasing numbers of children permanently removed from their parents care – costly both financially and in terms of outcomes for the children.
- Poor compliance with Human Rights Act.
- Risk of multiple pregnancies to replace 'lost' children.

Resources

Baum, S., Gray, G. & Stevens, S. (2011, in press). *Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities.* Leicester: British Psychological Society. www.bps.org.uk/dcp-ld/about/about_home.cfm

Department of Health & Department for Education and Skills (2007). *Good practice guidance on working with parents with a learning disability.* London: HMSO. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119

Department of Health (2008). *Joint Committee of Human Rights: A life like any other? Human rights of adults with learning disabilities.* London: The Stationery Office. www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf

McGaw, S. (2007). *Parent Assessment Manual* (3rd ed.). Truro: Pill Creek Publishing. www.pamsweb.co.uk

Including Everyone

Across UK Government policy documents there is an emphasis on ensuring that the needs of people with learning disabilities from Black and Minority Ethnic communities (BME) and newly-arrived communities are understood and met. It is well known that such groups often face 'double discrimination' and prejudice resulting in poor access to services and unmet need.

People with learning disabilities from BME communities are the focus of an annual census of people with learning disabilities in inpatient mental health and learning disability hospitals. The census 'Count Me In' is conducted by the Care Quality Commission and has highlighted higher admission rates for people with learning disabilities of Mixed White/ Black people, Black Caribbean and Other Black ethnic groups.

Psychologists are well placed to ensure that services take real and appropriate actions which result in positive outcomes for black and minority ethnic people with learning disabilities and for their carers.

Ways to improve access to services and improved outcomes include developing dedicated posts to support particular groups. For example, in Sheffield there is a high proportion of service users from South Asian communities. The Sheffield Learning Disability Case Register has identified the proportion of school leavers over the next number of years who will be from this community. In response to this, the Learning Disability Service has developed a new 'BME Clinical Assistant' post. The post-holder is a psychology graduate who is fluent in Punjabi and Urdu languages and acts as a bridge between the local community, families and the Learning Disability Service. She is trained in the 'Family Partnership Model' and supports both psychologists and speech and language therapists to ensure that the needs of people with profound and multiple disabilities and their family carers receive high quality care that is culturally sensitive.

Psychology contribution to delivering individualised outcomes and quality indicators

- Use evidence-based research to inform their practice.
- Be culturally competent in the assessment, formulation and intervention work with people from BME communities and their carers.
- Be trained to work with interpreters, voluntary sector and families and undertake race equality impact assessments.

Resources

Count Me In: National mental health and ethnicity census.
www.mhac.org.uk/census/census2009.php

Ethnicity Training Network. www.etn.leeds.ac.uk

National Advisory Group on Learning Disability and Ethnicity.
www.fpld.org.uk/our-work/community-and-inclusion/national-advisory-group-on-learning-disabilities-and-ethnicity/

National Learning Disability and Ethnicity Network. www.lden.org.uk/

Leadership and supporting the strategic direction

Clinical psychologists are in a key position to support commissioners and providers of learning disability services to achieve the aims and objectives set out in current policy and guidance of which there is an overarching theme of 'personalisation'. This is clearly articulated in *Putting People First* (DH, 2007) and in Lord Darzi's report *High Quality Health for All* (2008).

Key elements of this agenda are:

- maximising access to universal services;
- promoting independence;
- early intervention and prevention.

To achieve this will require significant changes in the way services are commissioned and shifts in patterns of provision, as increasing numbers of people are offered a personal budget.

This section contains examples of the type of work undertaken by psychologists to support people with learning disabilities and their families and to increase their choice and control.

Reducing out of area placements and providing services close to home

For a number of years there has been increasing concern about the numbers of people with learning disabilities in distant placements in health and social care. A recent SCIE Knowledge Review (20) identified the extremely high number of CSSR-funded placements by local authority borough and by region.

Supporting commissioners to develop good local services for their population and particularly those with the most complex needs requires skilled and competent specialist learning disability services including psychology. Psychologists have a range of skills to support commissioners with service design, delivery and evaluation as well as direct interventions with individuals themselves.

Psychology contribution to delivering individualised outcomes and quality indicators

- **Liaise with care commissioners** to identify people who could realistically return to their local community.
- **Provide leadership in multidisciplinary risk assessment and review**, assuring the highest standards of ethical, effective and evidence-based practice whilst considering cost issues
- **Conduct complex multi-theoretical assessments and clinical care plans**, integrated with other professional roles and putting the client at the centre of intervention, and calling on the carers and family context.
- **Develop a range of key pathways** that improve people's access to efficient and effective care systems.

- **Lead in the design of support packages** taking account of potential risks, and provide the necessary training to staff who will provide the support.
- **Evaluate the effect of returning home using a range of objective and subjective methods**; how well interventions were implemented, and their effectiveness.
- **Support other professionals and carers via consultation/supervision to create and maintain a culture of capability in meeting needs locally**. This could be on an ongoing basis, or the psychologist could help design and review local services, consistent with the Mansell report.

Leadership and innovation in teams

Clinical and other applied psychologists have important roles to play in achieving improved outcomes from team working. This includes helping to achieve the best design and operation for teams, effective individual service planning, peer consultation and support processes, and reflective practice. Psychologists have a breadth of skills in providing consultancy to organisations on organisational and systems improvements. In response to the challenges set out in *Equity and Excellence, Liberating the NHS*, psychologists in many services are taking a lead role in the redisgn of teams and whole systems as part of the local QIPP projects. They will often take a lead in supporting teams to:

- Work in multi- or inter-disciplinary ways, maximising the effectiveness of the individuals within the teams.
- Developing clear and achievable objectives.
- Developing innovative ways of working.
- Measuring outcomes and evaluating the effectiveness of the team.
- Driving up excellence.
- Decision making in complex situations.
- Developing evidence-based care pathways.

The BPS document *Working Psychologically in Teams* provides examples of ways in which psychologists can contribute to effective team working.

Outcome measures

With their training and experience in research methodologies, clinical psychologists are well placed to lead on the development and implementation of routine outcome measures in clinical practice (e.g. CORE-LD).

Clinical psychologists should provide a key element to leadership in services and teams. Leadership by psychologists is provided throughout the breadth of services. Clinical psychologists have a broad knowledge base and extensive training in psychological theory and practice, equipping them to operate effectively at an individual, team or service level, and take on transformational leadership roles.

They are trained to use the core skills of assessment, formulation, intervention and evaluation across the full range of the organisation. Depending on their level of experience, psychologists should be adopting leadership roles in:

- Delivering care to service users who have complex needs. This may include helping support staff to change their practices to deliver more appropriate or effective care

- Designing more effective and responsive services. In many areas, psychologists are members of Partnership Boards or senior management teams, and contribute to the development of new services. They are playing a central role in the development of effective Intensive Support Teams and organisational responses to those people who are inappropriately placed out of area.
- Clinical psychologists often have a formal leadership role beyond the psychology service. This includes such roles as multi disciplinary team leader, service manager and clinical director.
- Clinical psychologists can be expected to take a lead role in the development of routine outcome measures for pathways or whole services. They have expertise in the selection of appropriate measures, the design of evaluation processes, and analysis of the effectiveness of interventions.
- As *Payment by Results* approaches are developed in services for people with learning disabilities, clinical psychologists should play a lead role in setting up effective processes to implement and evaluate outcomes.
- Clinical psychologists are well placed to take a lead role in the CQUIN processes in specialist health trusts.

Supporting innovative treatment services

The Health care Commission has highlighted many limitations in the therapeutic services provided to vulnerable and challenging individuals. Psychologists have been in the forefront of innovation using a range of techniques, such as exploring how far the *Good Lives* model used by forensic services can be adapted for people with mild disabilities. Other psychologists have introduced a Dutch approach which utilises developmental psychology to enable staff and carers to comprehend the individual's personhood. This systemic approach goes beyond problem-solving concerning challenging behaviour. It assumes that carers who understand and know how to compensate for the person's 'vulnerable self' will enable the person to manage their emotional world more effectively, which in turn reduces challenges. The technique draws tacit knowledge into the therapeutic discussion by starting from staff and family experiences as they relate to the person, an approach which carers find extremely positive.

Future versions of this guidance will consider other emerging areas of innovative practice by clinical psychologists.

Organising the delivery of psychology services

Psychologists are a scarce and expensive resource. It is important that they are managed and organised in ways that maximise their effectiveness and ensure value for money. They are core members of multi-disciplinary teams and provide a strong leadership role in teams. One of the unique contributions of psychologists is their ability to 'formulate' in complex situations. This section addresses some of the factors that should be considered by the commissioners of psychology services.

Skill mix and New Ways of Working

In recent years there has been a rapid growth in demand from users and carers for psychological services. At the same time there has been a parallel growth in government policy making it clear that services should increase and improve the level of psychological care in services, and the availability of psychological interventions. The evidence base demonstrating the effectiveness of psychological interventions has grown in the last 20 years, and there is a need for the whole workforce to increase their level of psychological understanding and care. Applied psychologists make an important contribution to the training, supervision, mentoring and development of psychologically informed services.

Psychologists are at the forefront in the *New Ways of Working* (NWW) initiatives, aimed at improving the contribution and application of psychology to new and innovative practices. This has come out of the NIMHE National Workforce Programme in 2003 and looks at changing the practices of the current workforce. This has included developing extended roles beyond the scope of current professional practice, and bringing new people into the workforce in new roles at assistant and practitioner levels.

There is a long tradition of this type of approach within applied psychology. A variety of different roles have been developed which are aimed at ensuring people have easy access to psychological input from practitioners who have the most appropriate level of skill and training for the level of presenting problem. Psychology services across the UK have developed a variety of different posts including:

- **Assistant psychologists.** These are usually graduate psychologists who take on a range of assessments, interventions, research and evaluations under the supervision of a qualified clinical psychologist. They can provide a highly cost-effective support in situations that require psychological input that does not have to be from a qualified clinician. www.bps.org.uk/downloadfile.cfm?file_uuid=F33F19E3-1143-DFD0-7ED7-8CC2B5186D05&ext=pdf
- **Counsellors.** Many services that provide Talking Treatments employ counsellors to deliver one-to-one therapy, thus enabling qualified clinical psychologists to carry out a range of other tasks.
- **Approved Clinicians.** The new Mental Health Act has provided the opportunity for a number of clinical psychologists to take on the Approved Clinician role. This provides opportunities for a different skill-mix in teams. www.bps.org.uk/the-society/organisation-and-governance/professional-practice-board/ppb-activities/new_ways_of_working_for_applied_psychologists.cfm

- **BME clinical assistants and Family Partnership workers.** In several parts of the UK where there are high proportions of BME or newly-arrived communities, psychologists have been involved in the development of posts that are specifically aimed at improving the psychological care to this group of people.
- **Behavioural assistant.** Many services have developed 'behavioural assistant' posts that provide assessment and interventions for people who challenge services, by following protocols within a 'challenging behaviour care-pathway'.

Organising, Managing and Leading Psychology Services (BPS, 2007) provides examples of how psychologists can contribute to the development of effective services, and how they should be organised to ensure that this limited resource is managed as effectively as possible. The framework also outlines the leadership development tasks that are likely to be undertaken by psychologists at different levels of the organisation. It is important that an effective psychology service has the appropriate number of staff with the right skill mix to meet the needs of the local population. A variety of different Service Level Agreements are in place throughout the UK. Individual psychology service structures depend to a large extent on the needs of the population and design of local services.

The British Psychological Society publication *Clinical Psychology Leadership Development Framework* (BPS, 2011) sets out the core leadership competencies that can be expected of psychologists from pre-qualification to director levels of the profession.

Resources

British Psychological Society (2007). *New Ways of Working for Applied Psychologists in Health and Social Care: The end of the beginning*. www.bps.org.uk

MAHI - STM - 118 - 2284

MMcG-266

The British Psychological Society
St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK
Tel: 0116 254 9568 Fax 0116 247 0787 E-mail: mail@bps.org.uk
Website: www.bps.org.uk

ISBN 978-1-85433-715-3

Incorporated by Royal Charter Registered Charity No 229642

REP96/07.2011

MAHI - STM - 118 - 2285

Learning Disability
Professional Senate

Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers

A Briefing Paper on Service Specifications and Best Practice for Professionals, NHS Commissioners, CQC and Providers of Community Learning Disabilities Health Team

By the National LD Professional Senate

March 2015

' …the competence or capability of local 'mainstream services for people with learning disabilities will…influence the number of people defined as presenting a serious challenge. Well organised and managed services…will show fewer problems'

(Mansell Report, 1993)

'life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management'

(Mansell report, 2007)

'urgent need for systemic change within the NHS for people with learning disabilities' and outcomes were a 'shocking indictment of services which profess to value individuals and to personalise services according to individual need'

(Six Lives: The Provision of Public Services to People with LD, 2009)

'We should no more tolerate people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment. That is why I am asking councils and clinical commissioning groups to put this right as a matter of urgency.'

(Transforming care: A National response to Winterbourne View Hospital, 2012)

'The quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of 'reasonable adjustments' to avoid their serious disadvantage.'

(Confidential Inquiry into Premature Deaths of People with Learning Disabilities, 2013)

Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers

CONTENT

Introduction

It is clear that **life today is better for most individuals with learning disabilities and their families**. **However, there remain particular groups that remain at risk of unnecessarily restrictive lifestyles, poor access to services and opportunities, and serious health inequalities**.

Locally commissioned effective specialist Community Learning Disabilities Health Teams are critical to providing the essential support needed by people with learning disabilities and their families. And their **success can only be judged if this group of vulnerable people live full lives with more opportunities and less exposure to harm, as well as experience health outcomes in line with the wider general population**.

Good practice guidance such as *Services for People with Learning Disabilities and Challenging Behaviour*, first published in 1993, has been available for many years, and many argue that had this been fully implemented it is clearly arguable that Winterbourne View would not have happened. These concerns led to the previous *DH Good Practice Guidance: Commissioning Specialist Learning Disability Health Services* originally issued in 2007, which noted even then:

- *There is growing concern that some areas of the country have found it **difficult to develop commissioning strategies for specialist adult learning disability health services that reflect both current policy and best practice.***

- *This has **led in places to inappropriately funded services, outdated service models including ineffective integration arrangements, the poor development of a community infrastructure and an over-reliance on bed based services** (including NHS campuses and distant NHS & independent sector placements). Additionally, the **lack of appropriately funded and skilled specialist learning disability health services can be a major cause of failure by social care services** that are commissioned by local authorities.*

- *These, and associated problems, can mean that*
  - ***people with learning disabilities are getting 'stuck' in the NHS system or independent health placements often for many years and sometimes many miles from their home and/or,***
  - ***people placed in increasingly expensive and inappropriate social care services that are failing to meet their needs.***
  - ***People experience serious difficulty getting their healthcare needs met and are at risk of neglect and, at worst, abuse**.*

It is now clear that the NHS has not met the targets set out in *Transforming Care* and the *Concordat.* Clearly, the existing approaches have proved ineffective, and a different professional and commissioning approach to Community Learning Disabilities Health Teams and services is now needed in line with the challenges noted in for example '*Winterbourne View: Time for Change'* and *'Keys to Life'.*

In a similar vein, concerns regarding the effectiveness of existing community learning disability services were noted in Mencap's 2007 report *Death by Indifference* which described the circumstances surrounding the deaths of six people with learning disabilities who died while they were in the care of the NHS, exposed *'institutional discrimination'* by wider society and services.

In response, the resulting 2009 report of the Parliamentary and Health Service Ombudsman *Six Lives: The Provision of Public Services to People with Learning Disabilities* reinforced the urgent need for systemic change within the NHS for people with learning disabilities and considered the existing outcomes as a ***'shocking indictment of services which profess to value individuals and to personalise services according to individual need'**.*

The establishment of Learning Disabilities Public Health Observatories in England and Scotland, and the time-limited Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), recommended by the Independent Inquiry chaired by Sir Jonathan Michael, noted ***'We hoped to find that people with learning disabilities were living long and healthy lives to no lesser extent than those without learning disabilities. Our optimism has been quashed'***. The review of deaths that made people with learning disabilities particularly vulnerable to premature death was the relative inattention given to predicting potential problems, and then having to respond to those problems in a crisis.

The main areas highlighted were: firstly, addressing the knowledge that a person is fearful of contact with medical professionals, and secondly, predicting and planning for the future health and care needs of people who were likely to have changing support needs as their condition progresses, or their circumstances change. This involves effective support available from specialist community learning disability teams that enable mainstream health services to respond appropriately to individuals with complex support needs and their families.

The events at Winterbourne View and the CIPOLD inquiry highlight the importance of action to ***'rapidly expand and improve community provision for people with learning disabilities and/or autism who display - or are at risk of displaying behaviour that challenges'*** and ***'supporting people to access health services' through 'providing expert advice, support and training to health and social care providers; providing individual assessment, care coordination and therapeutic interventions for people with learning disabilities; offering advice and support for the provision of reasonable adjustments for people with learning disabilities, including the provision of easy read information.'***

There is now a collective recognition for ***'sufficient skilled support to people across all ages throughout (or at various times in their lives) and at times of crisis to minimise the admission to in-patient facilities'***.

This **requires joint action on the part of CCG and NHS England commissioners (working with their Local Authority colleagues, service providers and other stakeholders)** to ensure that a good local spectrum of responsive services are available to support people who challenge and present complex support needs and prevent expensive, restrictive and potentially risky out of area placements.

Critical to this are 5 essential elements that commissioners need to attend to for a good local service offer. That is:

- **Sufficient Specialist Learning Disabilities Clinical Capacity** as part of comprehensive and well-integrated community support services, with well-resourced Community Teams, that can readily access responsive specialist professionals

- **Adequate Skilled Community Support and Provider Capacity**, including a range of supported home, education and occupation options

- **Access to Expert** and learning disability informed **Care Management Capacity**

- **Joint Funding Capacity and Panels** to enable delivery of flexible support arrangements and on-going tracking of individual and wider services

- **Appropriate Models for the Integration of Health Care and Social Care Service Provision** so as to ensure a 'seamless service' for the user

To succeed, these components must be **accompanied by strong informed and effective local leadership, with well trained and committed staff** who have the competence, capacity and confidence to respond effectively to complex and challenging behaviour and work with people through all levels of difficulty.

This paper is mainly concerned with the adult health commissioning, health funds and healthcare element of this agenda. We do however recognise that the importance of integrating health care and social care means that this NHS approach must be complemented by specific action involving a review of the role of social workers and other care workers, as well as children's services. This therefore acknowledges that this responsibility of Local Authorities must be discharged in collaboration with NHS colleagues.

This work **applies to health services directly commissioned by CCGs or where these have been delegated through local Pooled Budgets with Local Authority lead commissioners**.

For such services **NHS commissioners retain ultimate responsibility to their regulators for the quality of outcomes achieved for individuals and the local community**. The accountability of Local Authorities to their regulatory bodies and to their electorate is a parallel and vital element in integrated services.

Real changes must take place in the ways Community Learning Disabilities Health Teams specialist health professionals, teams and services work for people with learning disabilities.

Overall, services must be more person-centred and act strategically across health and social care agencies deploying clinical skills, knowledge and time with a view to the long-term needs of individuals, families and communities, rather than continue adopting a reactive and solely individual case work bias.

The wider activities of Community Learning Disabilities Health Teams health professionals must also **be re-focused to give greater emphasis to providing high quality clinical expertise on both an individual and system-wide basis**.

Commissioned Community Learning Disabilities Health Teams must focus on delivering specialist clinical support for both registered patients (in local or out-of-area placements) and wider health promotion/ facilitation activities and service improvement programmes.

These recommendations are **in line with the defined responsibilities for CCGs and their equivalents in other nations in relation to NHS funding and commissioning responsibilities and for example the existing NHS England Business Plan** whereby NHS commissioners and regulators must ensure that there are local systems to ensure the needs of people with learning disabilities and their families are prioritised. They must be supported by effective evidence-based positive behaviour support work, at an individual and wider way that ensures people with complex support needs are safe and healthy.

This work has been reinforced by the *Transforming Care Concordat*, *National Audit Office* and *Keys to Life* reviews defining best practice for commissioning community services and innovative responses to effect change, as agreed across all stakeholders in responses to the Winterbourne View Update Review and CIPOLD inquiry findings.

Person-Centred Principles, Culture and Values

Person-Centred Practice and individual service design should be at the heart of the commissioned and provided specialist community learning disability health team practice. This agenda is supported by the DH *Ensuring Quality* Core Principles work that defined those essential capacity elements that must be considered and be place in a local effective functioning health and social care system. This approach has also been adopted by the Improving Lives Team Model, in the individual reviews arising from the *Transforming Care Concordat* as a model of good practice.

The principles are:

- Prevention and early intervention
- A whole systems life course approach
- Family carer and stakeholder partnerships
- Behaviour that challenges is reduced by better meeting needs and increasing quality of life support for communication
- Physical health support
- Mental health support
- Function based holistic assessment
- Support for additional needs
- Positive behavioural support
- Safeguarding and advocacy
- Specialist local services
- Workforce development
- Monitoring quality

Good quality learning disability services have an approach based on strong community support services, planned around people in the environment that they are in, focussing on person-centred care, and looking at each individual's needs. **This approach should be applied to all, including people with very complex support needs**. **Services must be committed to achieving the outcomes of 'rights, inclusion, independence and choice', and to ensuring that they 'stick with' individuals in spite of the difficulties experienced in meeting their needs**. These principles have long been re-affirmed in national policies such as *Valuing People Now, 'Rights, Independent Living, Control and Inclusion'* in England and *Keys to Life* in Scotland.

To do this, **all those supported by specialist community learning disability services should have in place good Person-Centred Plans and brief Personal Profiles describing their essential needs and positive active support plans** (not unread and unused lengthy inaccessible professional reports too often just filed away).

These plans and profiles therefore:

- Build on the best ways to listen to people and their behavior by getting to know each person and developing a picture directly through personal contacts, listening to what records do and do not say, face-to-face interviews/reviews, rather than listening to diagnostic labels and reputations

- Are specific, simple, clear and understood by all those involved, focusing on what works and does not work for individuals in reducing health disparities and restrictive practices

- Address the key areas of a person's life, health and well-being which are most concern and the people who care about them, recognizing individual needs, hopes, desires and capacities

- Have the backing of the person and people around them, with open clarification of constraints

- Do justice to the person in the way it describes individuals and support needs
- Accurately reflect what has been agreed
- Are unique to the individual and so do not package people or service specifications, or focus process and activity at the expense of outcomes
- See people with learning disabilities as valued human beings in need of opportunities
- Involve people getting together and building shared pictures of the way forward
- Check for consensus and disagreement without blame, surfacing and negotiating disagreements
- Record shared action plans with what, who, by when, how know if successful, and fall back positions to manage the inevitable reality when things do not go as planned
- Accept that the support solution today is not expected to last forever, as everyone grows and changes, so reviewing plans is a necessary continuous effort
- Value effective professional health expertise and personalised input

This positive approach towards supporting individuals must also be accompanied by equal attention to the needs of families through the initial adoption of key assumptions that support joint working. That is:

- The **emotional reactions** of families of individuals with disabilities are **normal, necessary and potentially productive** reactions
- Though the **family may need professional assistance in managing effective responses and education**, they are as capable as others in solving other problems without professional input. Their solutions may not be always be our solutions, and often that should be acceptable
- **Professionals must learn to work within the family's system**; this system should not always have to change to accommodate professional input
- Having a child with disabilities may not be the most important problem the family has at a given point in time. It is legitimate for other issues to be given priority, as family needs dictate
- **The family can often be the person's best, most committed, long- term advocate**
- Parents and professionals usually share a common concern for the long-term functioning of the individual with disabilities, although on occasion emotions can cloud appropriate judgements
- **Families usually want to do what is best for the individual and so want/should be actively and productively involved**
- All interventions, diagnostic and otherwise, should be based on clinical and empirical evidence, not on traditional unhelpful assumptions about parental/environmental pathology causes
- **Interventions should fully acknowledge the negative impact of the historical misconceptions of families of individuals with disabilities and common negative experiences families will have faced with services and so should seek to dilute this impact by positive service attitudes and actions**
- Professionals should be fully aware of their own interpersonal strengths and weaknesses. They should continuously strive to avoid inflicting their weaknesses and/or subjective values on the families with whom they work
- **The criterion of the '*least dangerous assumption*' should be applied to the selection of interventions or placement decisions. That is, in the absence of conclusive data, decisions should be based on the assumption that if incorrect, will have the least dangerous effect on the individual with disabilities and their family in terms considering out-of-area placements and restrictive clinical practices.**

- Even if very young, a full explanation regarding the possibility of specific disabilities is essential. Parents should be informed explicitly about the concrete features which support a diagnosis, those which do not, and the level of confidence, together with realistic but positive future options
- **Interventions should be sensitive to the unique emotional and practical problems faced by families, and accept their reactions as normal and legitimate reactions to an overwhelming situation**
- **Emotional and other types of support** (e.g. counselling, parent groups, circles of support, person-centred plans, parent advisors/link workers, training) **should be made easily available to the families who want them**. The assumption that all families need professional services should be avoided
- **Other types of support (e.g. respite breaks, leisure/ work activities, transport) which enable the individual to stay at home should be freely available to their families for as long as necessary**
- Interventions should be designed to meet the needs of the child in the broader context of the needs of the family
- **Parents should be recognised as an expert in many areas related to their child's unique history, behaviour and needs.**
- **Therefore, parents should usually have full membership of the multidisciplinary support teams, and should share equally in all team decisions providing a balance to professional expertise, and have the right to request re-evaluations of decisions at any time without receiving hostile responses.**
- **Of course not all families act in their children's best interests, both those of children with learning disabilities and without – and on these occasions formal 'best interest' challenges may be necessary and essential**
- Parents should usually have full access to all diagnostic and intervention information, facilitating individualised, flexible open partnerships
- **Under no circumstances should parents and families hear that 'nothing can be done'.** There may be times when local services run out of practical resources or expertise to resolve a problem, and at these times, **alternative options may need to be explored through open, transparent dialogue.**

Meeting the needs of families both as units in their own right, and as part of the communities in which they live, needs the input of social care services and of professional social work and thus requires effective models of integration.

Many of these assumptions equally apply for specialist learning disabilities community health teams when working with other paid carers and support services, where similar power differentials with professionals are apparent.

Implementing person-centred support on a broader scale is critical but only affordable if services really change fundamentally the way many Community Learning Disabilities Health Teams and services work today.

They must **become both more proactive and pragmatic in making strategic decisions about what they focus on doing within a positive values-based and individual service design framework**. Only then is it possible to achieve high quality, safe and compassionate care in the least restrictive settings and ensure fewer health disparities (i.e. access, quality and outcomes).

Key NHS Learning Disabilities Challenges

The core purpose of the NHS is to protect life and maintain health within the rubric of '***Adding life to years and years to life'***. This applies to people with learning disabilities and their families as much as the wider population and across the lifespan to two critical priorities for action. That is, '***Reducing Restrictive Practices and Reducing Health Disparities***'.

Learning disability health services have, in the past 25 years, moved from a predominantly bed-based to a community based model of care for most individuals. The intention accepted across society is a fundamental shift in the focus of care from a pathological (illness versus wellness) model, based in large institutions, to a more social (normalisation and inclusion) and person-centred model based in communities, thus improving the life chances of people with learning disabilities and their families.

The key principles adopted in designing, developing and delivering services have focused on the need to put the individual and their surrounding family or carers at the heart of a service, which should be personalised and designed to meet their needs. To enable this to happen, services have been guided to be organised so that they can support all people, including those individuals with the most complex support needs, as close to the person's community as possible.

Services have been directed to plan and intervene early, focussing on safely meeting the full range of needs and opportunities that improve a person's quality of life. At all times people using services should be treated with dignity and respect and should be included in planning and receiving care and treatment, with access to advocacy and independent representation when necessary, and supported by competent staff and professionals with access to continuous professional development or CPD opportunities that lead to better outcomes for all.

For most people with learning disabilities then, life is now better than decades ago and presents more opportunities for individuals and their families with more valued community options and experiences.

However, for one significant group of individuals this has not been so. Despite models of good practice being demonstrated for more than a generation, making this happen on a wider scale for all people with learning disabilities, especially those presenting with behaviours that challenge have continued to involve unnecessary restrictive options and less than an ordinary life experience.

Further, **people with learning disabilities generally experience poorer health than the general population**, with the significant differences in life chances and mortality to a large extent avoidable, and thus representing significant health inequalities that must be attended to.

In 2013, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) confirmed that: '***the substantial health care needs of people with learning disabilities too often go unmet as they can experience both avoidable illness and die prematurely, with symptoms not recognised by either the person or their family or carer leading to late diagnosis and treatment, too low expectations of the treatment they can expect and the therapeutic environment being too often unsuitable with a lack of reasonable adaptations***.'

Sir Jonathan Michael, in 2008, stressed that: ***'What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have learned that 'equal' does not mean 'the same' and that 'reasonable adjustments' that are needed to make services equally accessible to people with learning disabilities are not particularly difficult to make'***.
In December 2013, the DH published '*Winterbourne View: Transforming Care – One Year On*' with a Ministerial Forward that noted: ***'Winterbourne View was a scandal which shocked and appalled us all. The***

systemic failings there are as bad as those uncovered by Robert Francis in his report into Mid Staffordshire. We are not looking at one or two poorly-trained or malicious members of staff but at something much more insidious. That is why we need this full programme of work to address all the different aspects and underlying causes which allowed this to happen. We must take every step to be as sure as we possibly can be that this will not happen again.'

The NHS England Business Plan 'Putting Patients First' (2014/15 to 2016/17) has confirmed work to address this agenda as a priority action area noting ***'The purpose of this business area is to ensure that people with a learning disability or autism receive safe, appropriate care in a safe environment and they are protected from avoidable harm (in line with domain 5 of the NHS Outcomes Framework). A key aspect of this is ensuring that lessons are learned when things go wrong and action is taken to prevent a recurrence'.***

This means that specialist community learning disability services must be commissioned with sufficient capacity to help support these objectives with access to local specialist health and social care support for individuals across the life-course, and targeted at people with learning disabilities who have additional severe, complex or enduring support needs.

This calls for significant changes in the whole health and social care system to truly *Transform Care* across the lifespan provided through the on-going access to competent, credible, committed, capable Community Learning Disabilities Health Teams.

For this outcome, commissioners of and clinicians in Community Learning Disabilities Health Teams need to:

- secure better practical early support for children and families to tackle issues 'upstream' with staff encouraged to care, connect and deliver practical short full life plans and interventions
- promote good health care support and the well-being of individuals
- ensure that health care and social care services work effectively together
- undertake in-depth person-centred assessments of individuals and their clinical support needs
- flag up possible common co-morbidities and vulnerabilities (e.g. sensory impairments, respiratory conditions, epilepsy, dementia, autism and mental health difficulties), with accompanying education and awareness programmes for families and services
- develop, design and implement support packages using a range of therapeutic approaches
- ensure access to skilled and accessible core specialist professionally registered therapeutic support (e.g. nursing, OT, psychiatric, psychological, speech and language therapy, physiotherapy, dietetics, arts therapies), with support from effective clinical governance and supervision frameworks
- see 'behaviour that challenges and complex support needs in context', thereby responding to individuals by first removing stressors and building on capacity assets, rather than pathologising problems with individuals that require restrictive or 'removal' treatment responses
- support effective care management and resource allocation panel processes, and enable flexible use of health and social care monies and joint funding options
- provide effective skilled care coordination for small numbers of people presenting significant challenges in community and in-patient settings

- put in place positive behaviour and crisis response plans, including detailed challenging behaviour escalation response and emergency management plans that do not focus solely on moving the person elsewhere

- have clear credible on-going senior leadership and commitment to support action informed by a positive community vision and practice principles that avoid a reactive 'easy' placing people away approach

- support access when times get hard, and staying in the community setting is not possible, to short term flexible extra practical assistance and a wider spectrum of support resources (with step-up/step-down pathways that reduce the length of time people spend in in-patient settings and better manage crises)

- support on-going personal and professional leadership development and more robust longer-term work with skilled providers that are committed to demonstrating dignity/compassion/skills /endurance for supporting people with learning disabilities over the long run

- support access to competent local health and social care providers, encouraging multiagency training partnerships and collaborative service improvement programmes

It is important to remember that the DH's Winterbourne View Review found ***'there was a widespread failure to: design, commission and provide community-based services that meet the needs of children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges'***.

Although the past moves away from institutional and hospital models of care through the Valuing People agenda led to a clear need to initially prioritise social care and justice issues in the NHS commissioning agenda, in many cases this has been misunderstood. At times, this has inevitably meant that the valued and essential role of discrete specialist community learning disability teams and services has been inappropriately downplayed.

'Disability-blindness' to the often complex and additional support challenges of individuals presenting with high health and social care support needs is ineffective and will mean mistakes of the past will be repeated. This can be further threatened by the all-too common, but inappropriate, plans in many localities for locality-based integrated generic health and social care teams that limit access to necessary specialist learning disability professional input. Such undermining can be clearly seen as removing the essential 'reasonable adjustment' that specialist community learning disability teams and services provide.

This must be avoided so that **the focus of commissioned specialist Community Learning Disabilities Health Teams health staff is available to providing specialist clinical support (doing things that mainstream health and social care services cannot do) for CCG-registered patients (both in local or out-of-area placements), and wider health promotion/facilitation activities and service improvement programmes**.

Only then can the clear vision be realised, whereby:

'Everyone, with no exception, deserves a place to call home. Person by person, area by area, the number of people with learning disabilities and autism in secure hospitals or assessment and treatment settings will permanently reduce. At the same time local community-based support and early intervention will improve to the point it will become extremely rare for a person to be excluded from the right to live their life outside of a hospital setting.'

The Core Purpose of Community Learning Disabilities Health Teams

National policies have all wanted dedicated specialist NHS learning disability health services to **direct their efforts towards helping people enjoy better health and health care, in ways which opened up opportunities for independence and inclusion**. They have wanted services to **be person centred and show high quality expertise**.

It has also been expected that specialist learning disability health professionals **spend less time in direct work with people with learning disabilities in isolation, and more time on enabling people with learning disabilities use mainstream services and obtain opportunities for good health and life outcomes**.

The sorts of changes envisaged by *Valuing People* were in line with the challenges in **developing extended clinical and practitioner roles crossing professional and organisational boundaries**, and are even more pertinent today than when they were first defined more than 10 years ago.

It is clear that a **comprehensive community support model and infrastructure** requires at a minimum:

- An appropriately resourced Community Learning Disability Team
- Accessible specialist support both from health care and social care professionals
- A range of facilitated physical exercise, education, work and leisure opportunities
- Short breaks and 'respite' for carers (especially those of people with behaviour that challenges)
- Transition arrangements for children moving to adulthood, including addressing the critical loss of full-time education and over-arching medical oversight and annual reviews
- The capacity to access support and respond to crises 24 x 7
- Accessible resources to facilitate effective support for people with complex support needs and behaviour that challenges
- Policies and protocols for the design, monitoring and prevention of placement breakdown
- Effective integration of the components of the service.

For individuals with a wide range of support needs, such as many people with learning disabilities with complex support needs, adult services have too often been seen as confusing and fragmented due to the considerable overlap in professional and service roles. As a result, **Health teams and services should now be organised as fully inter-disciplinary team with sufficient critical mass in each locality to enable to deliver the identified 5 Essential Community LD Team functions required by commissioners** for inclusion in commissioning service specifications, operational policies and reviews. These being:

1. Support at a universal level for positive access to and effective responses from mainstream services
2. Targeted work with individuals and services enabling others to provide effective person-centred support to people with learning disabilities and their families/carers
3. Specialist direct clinical therapeutic support for people with complex behavioural and health support needs
4. Responding positively and effectively to crisis presentations and urgent demands
5. Quality assurance and strategic service development in support of commissioners

Integrated Health and Social Work Community Learning Disabilities Teams

Several factors are creating changes in the demand for both health and social care services for people with learning disabilities and their families:

- Significantly increased numbers of people with learning disabilities, partly caused by people living substantially longer as a result of medical and technological advances, with people needing additional support around illnesses and long-terms conditions linked to old age, in particular dementia for people with Downs Syndrome
- Significant changes in the demographic profile with increased numbers of people with complex needs requiring input from specialist health professionals. This particularly applies to young people with multiple disabilities transitioning into adulthood
- Increasing empowerment of people with learning disabilities and their families, resulting in higher expectations and demands for better quality services located nearer to local homes and communities.
- Increasing demand to support people with autistic spectrum disorders with or without learning disabilities to better diagnosis, early identification of need and post-diagnostic support.

Providing health interventions in a social context that fails to match an individual's essential support needs can be ineffective. Similarly, providing social support in a context devoid of effective health support can be ineffective. Both are two sides of the same coin and need attention to avoid support failure.

Historically, services for people with disabilities have been based on departmental or agency systems consisting of separate groups of professionals organised according to discipline. However, separate health and social care service responses are confusing, fragmented and expensive due to the considerable overlap in professional roles.

As a result, national policies have defined a vision for effective Community Learning Disability Teams supporting:

- fully-integrated professional work across disciplines and agencies, with all health and social professionals jointly accountable for the outcome of their work to local LD Partnership Boards or local Health and Social Care Partnerships arrangements
- social inclusion opportunities and outcomes
- organisational structures which encourage and promote inclusive working, through:
    - single points of access for health/social work referrals;
    - common contact assessment/core client databases;
    - integrated health/social work team management arrangements;
    - shared initial intake assessment allocations meetings;
    - shared common assessment process including essential current and historical information records;
    - common care plan/programme review systems;
    - re-focused multi-disciplinary and professional team meetings enabling reflective practice;
    - joint resource allocation panels supporting personalisation;
    - active team participation in regular multi-agency service development/contract reviews;
    - clear supportive professional leadership provided with a range of effective management, high quality supervision, training strategies and resources;
    - shared team bases and resource centres providing equipped meeting/training rooms and offices.

A clear care co-ordination framework is integral to making this work, with an underpinning principle being to adopt a single integrated health and social care process to deliver continuity of care for vulnerable people with complex needs requiring intensive intervention and/or long-term support. Service users should therefore be provided wherever possible with one integrated assessment process, one principal contact person, one care plan and one review process – including joint documentation, commonly agreed aligned eligibility criteria and integrated information systems. In principle, this is a vision that should be supported.

The 5 Essential Community Learning Disabilities Health Teams Functions

In essence, effectively commissioned specialist learning disability community health services:

- Promote safe, person-centred support and evidence-based practice
- Demonstrate positive outcomes, particularly in regard to reductions in restrictive practices and health inequalities
- Support mainstream practice and directly serve those with the most complex support needs
- Direct people away from institutional responses to crisis and put support around people in community settings
- Integrate planning and development work that promotes individualised local services close to home
- Include staff that offer advice and support to other professionals or services and those who provide day-to-day care, as well as direct interventions with people with learning disabilities and families
- Provide skills to provide specific and responsive care in all settings for people with learning disabilities and their families/carers
- Enable swift access, when needed, to medical, nursing and therapy professionals
- Invest in training and development for specialist professionals, families and front-line support staff
- Support a robust community infrastructure that takes a broad early intervention view on addressing health needs and the range of health and other factors associated with social exclusion and health inequalities to secure better and more inclusive service outcomes
- Fulfilling all legal/safeguarding requirements and ensure the voice of individuals and families is heard, including access to appropriate advocacy, representation and new ways of working to further enhance health care and reduce health inequalities.

1. Supporting Positive Access to and Responses from Mainstream Services - Health Promotion, Health Facilitation (through Individual Consultations, Supervision, Training and Policy/Practice Development)

Specialist health professionals in Community Learning Disabilities Health Teams must engage in strategic development work that supports better universal access to mainstream services and positive outcomes reducing known health inequalities.

This includes involvement in planned programmes of multi-agency training, education, mentoring, informing and consultancy to others about responding to the needs and concerns of people with learning disabilities. This should be seen as a non-negotiable component of a Community Learning Disabilities Health Teams service specification, especially in relation to supporting key target groups (Primary Care, Acute Hospitals, Mental Health Services, Social Care agencies, Police, Probation and Job Centre Plus) where their understanding of learning disabilities will be critical to achieving high quality health and social care outcomes.

Community Learning Disabilities Health Teams health professionals should work with mainstream providers, acute liaison, primary care liaison and prison liaison nurses about ways to support the specialist health and complex support needs of people with learning disabilities.

As such, some of the **core training competencies that Community Learning Disabilities Health Teams health staff should have and then also share through an organised local multi-agency training programme in line with best practice guidance** (and where appropriate including service users, families and paid carers as co-trainers) should include:

- Understanding Learning Disabilities
- Person-centred planning and Essential Lifestyle Planning approaches, including for example creative graphic facilitation strategies

- Health Action Planning
- Health Inequalities and Reasonable Adjustments
- General Communication and Listening strategies for people with speech, language and communication needs
- Effective Inclusive Communication strategies, including signs, symbols and accessible communication
- Enhancing Positive Interactions and Building Engagement
- Effective Skills Teaching, including where necessary Training in Systematic Instruction
- Understanding and Responding Positively to Behaviour that Challenges through Positive Behaviour Support
- Understanding and Responding Effectively to Mental Health/Dual Diagnoses Issues (including using PAS-ADD or other tools)
- Understanding and Responding to Autism Spectrum Conditions in Adults
- Applying Sensory Integration approaches positively
- Understanding and Responding to Loss and Bereavement
- Understanding Ageing & Learning Disabilities
- Understanding and Responding to Dementia
- Understanding and Responding to Epilepsy Supporting People with Profound and Multiple Disabilities
- Effective support with Eating, Drinking and Swallowing difficulties, including Dysphagia
- Understanding and responding to sensory impairments
- Special Parenting issues
- Effective Risk Management
- Managing Physical Aggression and Violence in Community Services for People with Learning Disabilities

Community Learning Disabilities Health Teams should provide on-going support, supervision and advice to services (especially primary, community and specialist acute/mental health and criminal justice services) to support them in:

- Establishing joint registers and flagging systems for all known local patients with learning disabilities, thereby enabling the provision of 'reasonable adjustments' and positive support plans that mitigate known health inequality and service access outcomes

- Ensuring regular dialogue and joint training meetings with mainstream health and social care services to discuss any particular general concerns and support plans

- Developing increasing confidence, skills and experience in supporting patients with complex health support needs through training and other service development interventions

- Implementing the Accessible Information standard specification once finalised

This work is necessary, although insufficient alone, in addressing all the barriers faced by people with learning disabilities accessing effective support from mainstream services and housing/support systems which matches an individual with complex needs.

2. Enabling Others to Provide Effective Person-Centred Support to People with Learning Disabilities (through targeted specialist assessments and formulations, liaison advice, person-focused training, short-term care coordination and clinical support) and including Joint 14+ Transition Work and Liaison Support

An effective Community Learning Disabilities Health Team should be able to:

- **Provide prompt and expert evidence-based practical focused assessments and formulations as to why any problems have or may arise, and interventions to mitigate concerns** that:
    - Address specific learning disability-related concerns
    - Reduce and shorten distress and suffering
    - Ensure that inappropriate or unnecessary interventions are avoided

- **Provide specialist advice, limited support and client-specific training** to people with learning disabilities, families, carers and service providers across the statutory, independent and voluntary sectors

- **Establish a detailed understanding of all local resources** relevant to support individuals with learning disabilities and their families/carers and promote effective integrated working maximising the health and well-being outcomes of individuals and the local community.

A key objective of effective targeted support from a Community Learning Disability Health Team should be to share and develop broader adoption of the 5 Good Communication Standards identified by the Royal College of Speech and Language Therapists. That is, raising awareness whereby:

1. There is a detailed description of how best to communicate with individuals.
2. Services demonstrate how they support individuals with disabilities and communication needs to be involved with decisions about their care and their services.
3. Staff value and use competently the best approaches to communication with each individual.
4. Services create opportunities, relationships and environments that make individuals want to communicate.
5. Individuals are supported to understand and express their needs in relation to their health and wellbeing.

Community Learning Disabilities Health Team health staff should provide targeted individual case-related teaching and accessible materials to people with learning disabilities and family carers about healthy living and specific health topics that enhance support for complex presentations, thereby working with them to develop their skills and confidence in speaking out about health matters, and making complaints or providing feedback to services where necessary to deliver better quality and more responsive services.

Community Learning Disabilities Health Teams support to wider local multi-agency and multi-professional training programmes should be encouraged as part of an agreed workforce development strategy.

The **local clarification of training that will be provided as core commissioned Community Learning Disabilities Health Teams as opposed to those elements that remain the responsibility of publically-funded services (in line with their contractual and disability equality duty obligations) should inform an agreed** plan. That is:

- Any mandatory health and safety elements as induction and foundation training
- Any core disability awareness training in line with the obligations to provide 'reasonable adaptations'
- Any non-person specific 'specialist disability' training noted as part of their specific care home or professional service offer (such as for example autism, dementia, mental health or sensory disabilities)

There may however be need to agree additional specific 'top-up' funding agreements to support local additional capacity where Community Learning Disabilities Health Teams training and other professional input is necessary to support agencies to meet their core CQC and other contracted responsibilities and obligations, for which they have already been funded as a 'specialist provider'.

Alternatively, there are some localities where there is an agreed top-slicing approach to remove some funding from the commissioned service contracts to enables additional local professional team capacity, training and cross-agency joint service-improvement development work.

In both these later cases, where this 'top-up' funding is necessary, these actions should be **supported in line with the obligation on Community Learning Disabilities Health Teams to support wider Learning Disability commissioning strategies and service-improvement programmes, and not be seen as additional income-generation opportunities.**

This type of joint working can be all the more important for Community Learning Disabilities Health Teams as this work can also **foster a culture of mutual local multi-agency support, sharing and joint investment in local practitioners as shared trainers to link local clinical interventions with training materials and services. This can also maximise the outcomes of other Team work, as well as providing additional information to inform quality assurance, monitoring and intervention compliance** and necessary service adjustments. As such, this type of training should be seen as more than 'train and hope', and instead essential scaffolding.

This function also includes the work of primary care, hospital, mental health and prison service liaison posts, (established as specific adjuncts to generic posts) because of the specific complex presenting disabilities or challenges that individuals can place on mainstream services. They can also assist the setting up and maintenance of 'flagging' registers.

Making equal access and outcomes a reality for people with complex disabilities and support needs often demands additional targeted and at times highly intensive specialist casework, as well as wider sensitive service planning and interventions. In terms of primary and secondary physical healthcare, this requires active roles rather than just signposting. Similarly in terms of mental health services (including forensic services) this requires active roles and breaking out of speciality silos. These types of development should be encouraged as they have been demonstrated to ensure equal access and outcomes in line with the same entitlements to independence, choice, inclusion and civil rights that people with learning disabilities and their families are entitled to.

3. Direct Specialist Clinical Therapeutic Support for People with Complex Behavioural and Health Support Needs (through specialist assessments and formulations, advice, training, longer-term care coordination and clinical support)

Community Learning Disabilities Health Teams must be able to support a substantial minority with complex support needs, who because of on-going complex support needs will remain in contact with the Community Learning Disabilities Health Teams for on-going interventions as the intensity of their support needs fluctuates over time.

This can necessitate **specialist care coordination and monitoring for periods of several years or even life-long in some cases**. In such cases, traditional models of referrals, repeat assessments and care pathways are inappropriate as they do not match the reality of learning disability as a lifelong condition with some individuals requiring on-going care coordination with options to step-up and step-down matching the changing intensity of problem presentations.

As a result, **some individuals in contact with learning disability community teams require active interventions from senior health professionals, while for others it may be possible for oversight and care reviews by assistant practitioners, with the option for rapid step-up when problems arise and/or when mainstream solutions are insufficient and specialist care navigation is necessary.** This requires consideration of new ways of working and on-going team skill mix reviews matched to planned and presenting needs.

Community Learning Disabilities Health Teams specialist health professionals with the support of clinical assistants should carry individual specialist caseloads of clients with complex, severe and enduring problems and disorders related to learning disabilities (including people with disabilities and co morbid severe challenging behaviours, mental health difficulties, dementia, dysphagia, long-term conditions, epilepsy, autism, personality disorder or those who are part of the criminal justice system, and/or who have been victims of abuse or are otherwise at risk).

In these cases, the Community Learning Disabilities Health Teams specialist health professionals should provide:

- specialist and complex assessments of people with learning disabilities and summary formulations/ diagnosis based upon a good understanding of the person's history and what that person's life has taught. Without this, we are unlikely to provide an accurate person-centred service as we sometimes forget that people's understanding of the world is learned and that, for most people, this learning takes place quite early on.
- recognition and support for histories of abandonment or abuse, or where lives have been socially isolated. Such a learning history that can be overwhelming and the emotional impact of this must not get overlooked by critically understanding the answer to questions such as:
    - Who is this person?
    - What are the person's needs?
    - What are the non-negotiables?
    - What would it take to get those needs met?
- complex individual care plans for the treatment/management of a person's problems
- a range of complex highly specialist clinical interventions, employing methods based on proven efficacy, for individuals, couples and groups, adjusting and refining clinical formulations drawing upon different explanatory models - for individuals and groups
- physical health support
- specialist information, consultation, advice and support to relatives and carers
- skilled evaluations and decisions about treatment options
- specialist responses to complex, sensitive, distressing and emotional information in relation to mental and physical health issues, where there may often be difficulties in terms of acceptance or understanding
- effective communication of confidential and specialist condition-related and personal information obtained through assessments, formulation, therapy and interventions, adapting models sensitively
- complex risk and risk management programmes for individuals presenting vulnerability, self- harm and/or risk of physical, sexual or emotional harm to others
- care coordination, where appropriate, including initiating, planning and review of care plans under CPA/CHC mechanisms
- expert specialist advice, guidance, consultation and support to other professionals in a wide range of settings where care is discussed, planned and organised
- broader theoretical knowledge and specialist clinical skills to develop or support the ability of others
- staff supervision, development and working relationships with relevant statutory, voluntary and community groups and organisations
- access to bed-based services only where health input is highly intensive or unpredictable
- support to any admissions which result in real and meaningful assessment and treatment
- an eclectic range of interventions **beginning from an assumption that ordinary housing and support with specialist clinical health input added on locally (thereby more likely to be the best value and lower cost effective options) is the first option to be explored**. This includes a commitment to using the 'least restrictive alternative', support for the supporters (i.e. well-staffed, managed, trained, clear principles and flexibility built in including time for training), and access to an assertive outreach model taking resources to the person as opposed to removing the person, and expertise in establishing supportive boundaries to enable 'wounds to be healed'.

Community Learning Disabilities Health Teams specialist health professionals need to be tolerant, gentle, patient, empathetic, mature and respectful, and must be open to intense analysis of how their actions or the situations they operate in may be the 'problem' that needs addressing rather than adopting a traditional treatment model. This calls for high-quality clinical supervision to enable health professionals to fulfil their tasks. Staff in Community Learning Disabilities Health Teams must be able to 'step back' and attempt to analyse what is happening, and take on the critical roles of teachers, mentors and anchors to facilitate an inclusion agenda and avoid out-dated traditional assumptions. This is **best achieved through ensuring some on-going direct clinical and personal contact with people with learning disabilities, even for Community Learning Disabilities Health Team managers**.

Some people need health care support for a very long time. This can be provided in people's own homes, care homes, or through health care centres and teams. Joint or 100% NHS funding can be provided where the conditions present severe, unpredictable, intensive and/or complex challenges. National guidance is clear that the presentation of behaviours that challenge are not a sole basis for 100% NHS Continuing Healthcare responsibility, especially as in many instances these challenges relate to unmet needs that most people take for granted (i.e. being healthy, happy, busy and recognised).

However, where CHC funding responsibility has been agreed, or where joint funded complex care packages such as S117 aftercare arrangements apply, specialist health professionals within the Community Learning Disabilities Health Teams are expected to:

- Facilitate specialist and community care assessment and care/treatment plans
- Support the completion of any specialist assessments
- Develop detailed individual client-level and service-level specifications
- Undertake a monitoring and service review/assurance function role, recording any key risks and issues.

This type of work has also enabled other quality review and monitoring mechanisms of wider health and social care systems, and so enabled Community Learning Disabilities Health Teams to directly influence commissioning and contracting strategies. Further moves towards pooling budgets will support this.

4. Responding Positively and Effectively to Crisis

It is known that 10-15% of people with learning disabilities known to services present with behaviours that challenge and two thirds of this group can present with more demanding support needs. This equates to approximately 350 people of all ages with learning disabilities known to services in a local population of 100,000, and therefore more than 50 people presenting with behaviours that challenge and an estimated 35 individuals with more complex support needs. Given the common 3:1 ratio between adults to children**, it is likely therefore on average, that 25 adults and 10 children in each 100,000 population will be seen as more demanding with severe reputations of severe behaviour that challenges and at risk of exclusion.**

Community Learning Disabilities Health Teams specialist health professionals must identify and work with all these individuals, and everyone else supporting them, to plan ahead for when things might be difficult. Given most crises are usually predictable, they should try and avoid surprises and stop crises from happening. **If a crisis does happen, they should make sure that the right sort of help is at hand to rapidly defuse and stabilise the situations**.

For all in this 'core group' of people often 'famous for the wrong reason', there should be in place a well thought out contingency plan which should assist the effective management of emergency and demanding situations.

As such, Community Learning Disabilities Health Teams need to take a multi-faceted approach to rising to the challenge of dealing effectively with crisis, **responding on at least 3 levels:**

- **Proactive crisis prevention**
- **Reactive crisis management and immediate resource deployment**
- **Proactive Strategic planning and service development** (informed by the first 2 levels)

Clearly, **continuing to respond only reactively as crises arise is most likely to lead to high-cost, unnecessarily restrictive and out-of-area placements** (including inappropriate use of Winterbourne View-type options).

The Department of Health published the ***Positive and Proactive Care*** guidance in April 2014, replacing the previous DH non-statutory guidance document on reducing the use of restrictive physical interventions first published in 2002. This new guidance is relevant to the role of Community Learning Disability and Mental Health Teams with the emphasis **on significantly improving care through day-to-day practices that:**

* **Are based upon Positive Behaviour Support**
* **Ensure that services provide strong leadership, assurance, accountability**
* **Are transparent about both the care they provide and when restrictive practices are used**
* **Provide effective monitoring and oversight through CQC and local professional/service inspections**.

The accompanying Positive and Safe 2-year programme to reduce use of physical interventions will be reviewed to assess the extent to which it results in:

- ending the use the deliberate use of face-down restraint and reduce the use of all restrictive interventions, including physical, medical, chemical, mechanical and seclusion
- working with services to create safe, compassionate, therapeutic health and care environments that are respectful of patients' dignity.

Changing the common scenario of restrictive care away from local areas and restrictive practice critically requires that Community Learning Disabilities Health Teams retain accurate up-to date knowledge about all those locally with severe support reputations and their histories of crisis situations, to avoid surprises.

Both commissioners and Community Learning Disabilities Health Teams should work proactively and take steps to prevent crises from happening, but are dependent on providers being proactive in referring people. If they do happen, Community Learning Disabilities Health Teams must make sure that the right sort of help is at hand at the right time in the right way. This includes ensuring:

- Comprehensive summary assessments are already in place for all clients in transition, families homes and agency placements – critically defining the things that help and make things worse

- Positive health action and behaviour support plans (with potential crisis/emergency situations identified and clear relapse prevention plans) for the on average 50 individuals in each CCG locality with severe reputations at any point in time clearly described and understood by key stakeholders (i.e. what to do ifs .... and what works and what to avoid)

- On-going monitoring and review systems in place for those with complex support needs

- Having someone to talk to at short notice

- Problem solving learning to see where things go wrong and how they could be put right.

- Having sufficient Community Learning Disabilities Health Teams capacity for responding with extra professional support around the person in situ

- Contingency options of going somewhere else for a period of time as a crisis respite or refuge breaks whilst things get sorted out (such as social crisis and planned respite/breaks service) rather than pathologising/blaming people as in need of treatment

- Access to crisis Mental Health and Learning Disability home treatment and admission to in-patient facility options through stepped care pathways

- Supporting a spectrum of local longer-term service options ranging from supported living/residential options through specialist learning disability nursing homes to the very rare on-going use of long-stay hospitals.

When people are experiencing a serious problem or crisis, it is essential that a service can respond to their needs with appropriate effective advice and intensive support 7 days a week and outside office working hours. As well as improving service accessibility and responsiveness this can positively impact on the number of out-of-area placements, high-cost care packages and inappropriate admissions to in-patient units.

This also means that access to the Community Learning Disabilities Health Teams should also be more than a traditional weekday office-hours service model, as clearly **preventing admissions is not a 9am-5pm task**. Community Learning Disabilities Health Teams should follow the practice being introduced into community mental health services whereby some Community Learning Disabilities Health Teams cover is available from 8am to 8pm weekdays and some day-time access at weekends. In line with Crisis Concordat action plans, **responsive services need to be around when people need them.**

Access to some form of 24-hour emergency on-call and community crisis centre or in-patient outreach resource can be essential, including access to psychiatric cover as part of the agreed enhanced local crisis response system that now needs to be put in place across the country.

As most people's health needs will be able to be met in community settings (and only a small number of people should need to access specialist in-patient beds appropriately), it is **likely that collaborative commissioning across several CCGs will be necessary with respect to the crisis support services and handful of needed short-term crisis access beds and intensive in-reach/out-reach assertive outreach and home support teams**. Given the relative limited need for such a service in any locality, this work requires collaborative commissioning across localities (usually at the level of existing Mental Health Trust or Local Area Team boundaries).

A small number of people with mental health or offending problems need admission to in-patient services for more intensive help than can be provided in the community. These should offer time-limited (no longer than 6 months for non-forensic presentations) active assessment, care and treatment, and then link in with other services to enable a return to the community as soon as possible. For those with mental health or forensic presentations, support should be formalised with specialist mental health services and/or tie them into the developing liaison and diversion schemes to prevent further such needs as much as possible.

While admitted to crisis centres, people should:
- be clear how long they will stay in an in-patient unit or emergency respite resource
- understand what their rights are
- feel supported and safe
- be offered assessment and treatment and effective care co-ordination
- know who is in charge to make sure things get done
- be helped to return home as soon as possible.

Where longer-term admissions are suggested in line with specialist mental health section requirements, these should be subject to regular independent challenges through securing alternative assessments, care and treatment reviews.

In-patient services therefore need to be part of the whole system of service delivery for people with learning disabilities and have a defined place and purpose. Services need to be able to demonstrate their relevance to local needs and not promote or perpetuate inappropriate long-term use of 'out of area' placements, including for respite while more effective wrap-around support options are put in place.

As such, **good local services should include interim (*step down/step up*) support mechanisms to assist when people face difficulties and it is no longer possible to return home, and while more permanent less restrictive living arrangements are being developed**.

Where people are placed away from their own locality, it is even more important that the Community Learning Disabilities Health Team regularly review services in order to ensure it is still safe, effective and appropriate.

Support networks should also be established to help stakeholders learn from and cope with stresses arising from responding to crisis situations. In particular, regular service dialogue must be apparent between Community Learning Disabilities Health Teams and colleagues in the Acute sector, Mental Health services, Court Liaison and Diversion schemes, and Social Care providers, to ensure effective partnership working relationships remain in place over time.

5. Quality Assurance and Strategic Service Development in Support of Commissioners

Community Learning Disabilities Health Teams health professionals should play an active operational or micro-commissioning role in strategic planning, care package contract oversight and policy development, in support of local commissioners. This service planning and micro-commissioning development role should include activities to:

- Support the involvement of people with learning disabilities and family carers.
- Gather information on individual and wider population health needs and inequalities, including those groups with complex support needs (e.g. autism, challenging behaviour, dementia, epilepsy, long-term and life-limiting conditions, mental health, profound and multiple PMLD, sensory impairments, children and older people)
- Clarify actions to support better health and health care, and the contribution of health services to independence and inclusion (e.g. support for intimate care and community care tasks policies that enable complex care packages in the least restrictive settings with support staff able to access adequate specialist training and supervision)
- Highlight the future impact of early intervention and support for inclusion in services for children and young people with learning disabilities.
- Identify health and well-being outcomes for monitoring, audit and review of service effectiveness
- Develop and apply the best available research evidence and evaluative thinking in all areas of practice, including service contract service specifications and reviews.

Community Learning Disabilities Health Team health professionals should contribute to the design, creation, and monitoring of provider support arrangements for individuals, particularly for those people who need a lot of support from family and community, and a range of agencies. This should mean that there are clear plans and arrangements put in place to deliver on the national learning disabilities commissioning framework for services that place an emphasis on individualised services in community settings (rather than in-patient options) achieved through person-centred planning and informed high quality clinical practice. As such, commissioners should recognise and utilise the knowledge and experience

of specialist learning disabilities community health team professionals in reviewing the performance of commissioned services, especially in implementing care plans and recommendations. On occasion, this may require more active service improvement programmes.

Work related to this will **include professional expert support prioritised to support commissioners ensuring adequate policies, procedures and safeguarding support structures to ensure that the *Transforming Care* agenda can be achieved through which people with complex support needs and behaviour that challenges have their identified needs met through effective local support and care arrangements.**

This will include providing support to design, develop and deliver an adequate local capacity support and development programme with sufficient:

- practical family support
- training/supervision for support staff teams
- transition joint working with children's services, ensuring there is good cooperation and coordination between services, support into adulthood
- access to a spectrum of appropriate supported local accommodation options designed around people's individual needs, together with small local specialist services that can provide residential or nursing care to meet particular needs
- respite breaks/activity arrangements able to meet the needs of people with behaviour that challenges and complex support needs
- agreed crisis-management pathways to prevent placement breakdown
- access to in-patient services in both learning disabilities and mental health services, with admissions that provide skilled and appropriate focused and time-limited support, with a well-defined admission and discharge pathways
- service monitoring and review mechanisms, specifically looking at length of stays in any restrictive settings and use of step-down arrangements (including those placed in secure settings)
- organised support to repatriate people from distant out-of-area and in-patient placements.

As such, **Community Learning Disabilities Health Team specialist health professionals should be expected to be both individually and collectively responsible for ensuring effective care co-ordination related to all individuals who receive long-term funded public services from the Local Authority, the NHS and the Independent Sector**. This thereby enables **monitoring mechanisms to be put in place that avoid 'surprises'.**

Whilst co-ordination/care management is often a major role for social workers and care managers, some **members of other disciplines within Community Learning Disabilities Health Teams may be expected to carry a care co-ordinating role for a limited number of clients (in addition to providing professional advice, and where necessary, therapeutic/remedial interventions)**.

This care co-ordinating role should be allocated based on the primary needs of particular clients and agreed by senior health and social work managers in support of the micro-commissioning role. This will require close working with CCG Continuing Health Care and/or Individual Care Package leads, and support through completion of relevant assessment and update reports to support Funding Panels in both the CCG and Local Authority.

More senior practitioners are likely to carry a smaller caseload than their junior colleagues, thereby enabling them to take on a greater focus on service development and training activities. This should mean that **all clients within local services have a named care co-ordinator, involving at least face-to-face contact on a minimum annual basis for reviews of care packages**. This work can be more efficiently undertaken with the inclusion of assistant practitioners and reviewing officers or teams.

Since no two people share identical needs, one element of a good service is that they 'fit' more closely to the person than to a pre-existing model. As a result, the variety of service options increases. This requires Community Learning Disabilities Health Teams to continually develop their capacity to respond to local needs and adapt the skills base to match changing demand. To manage this over time, **careful consideration is needed to critical mass issues**, especially when access to competent specialist health professionals is limited.

It is the responsibility of the service to report any serious health and safety or protection from abuse issue as soon as any concerns arise. All safeguarding issues should be recorded and reporting in line with the local Safeguarding Vulnerable People policies and CQC standards. This care coordination and review work must include the use of outcome evaluation tools such as the Health Equality Framework, as means to providing on-going intelligence to commissioners, operational service managers and public health teams of both good and poor practice and recognition of relevant legislative processes such as the Mental Capacity and the Court of Protection.

Community Learning Disabilities Health Teams are expected to be key agents that support the effective functioning of Local LD Partnerships Boards and Forums, and should play a significant leadership role in the related Better Health sub-groups coordinating and demonstrating action in line with the National Joint Health and Social Care LD Self-Assessment Framework or SAF.

Core Specialist Community Learning Disabilities Team Professional Practice

Community Learning Disabilities Health Teams should operate as fully inter-disciplinary teams which include specialist health professionals who collectively work to support individuals with learning disabilities in respected and high status activities in the community, and provide co-ordinated specialist advice and practical help to accomplish such lifestyles.

At a minimum, this should include sufficient numbers of: registered practitioners and assistant practitioners across all these professions. A Community Learning Disabilities Health Team without easy local access to all these core professional staff resources is likely to be inadequate to the tasks assigned to them. There will need to be a range of staff skills commissioned and recruited as part of these community health infrastructures. **This will include (but not necessarily be limited to): clinical psychologists, learning disability nurses, occupational therapists, physiotherapists, psychiatrists, speech and language therapists**, **arts therapists).** Although there are a variety of models for Community Learning Disabilities Health Team services, **access should be available from a full range of core registered health professionals working to nationally defined standards for 'fitness to practice'.**

However, the particular mix, number and form of the local team must be based on the identified local needs and required functions to be served at a point in time, and to deliver on the requirements of *Transforming Care* and *CIPOLD* agenda, there will need to be particular attention to ensuring access to a critical and adequate mass of senior experienced staff with the range of specialist knowledge, skills and capability.

Those team members who are not a registered professional (e.g. behaviour analysts delivering positive behaviour support who are not registered professionals or support workers/ assistants**), must be supervised by a registered professional with clear accountability arrangements clear to all.** In addition to this, in Scotland all non-registered professionals must complete Mandatory Induction Standards for Healthcare Support Workers (HCSW) which has been designed by NES (NHS Education for Scotland) within the first 3-6 months of joining the NHS in Scotland.

The key roles of all Community Learning Disabilities Health Team health professionals are to reduce risks; promote relationships and build capacity and capability. As such, all these health professionals should have a basic understanding of the needs of people with learning disabilities, have knowledge of the role of other professionals and services (eg residential/day/respite) , and know when to escalate issues to the relevant team specialist and/or senior operational and commissioning officers. This is particularly important following procurement programmes resulting in any changes to support plans and working arrangements, as transitions need to be positively managed. Critical here are the recognition and up-to-date understanding of the differential responsibilities of different stakeholders.

This also means valuing the positive contribution and role of learning disability social workers to enable health interventions to work in supportive social contexts. This can include effective social work practice in: responding to complex needs; effective safeguarding and risk management of cases of abuse, neglect and vulnerability; addressing adversity and social exclusion; promoting independence and autonomy through case work and brokerage to empower people to live independently**;** prevention and early interventions across spectrums of need.

As such, it is expected that key lead professionals will be in place as senior members of Community Learning Disabilities Health Teams, supporting Team Managers across health and social work agencies, and in co-ordinating and managing work to provide high quality practical health guidance and personal support, with a range of effective operational management, supervision and training strategies/resources across teams and for individual professional disciplines to ensure 'fitness for purpose'.

Lead Areas of LD Health and Social Work Professional Activity

Clinical Psychology

- Specialist neuropsychological/behavioural assessments, diagnostic, therapies and wider service support to prevent and reduce the incidence and impact of psychosocial/health difficulties.
- Clinical formulations and support to individuals with severe reputations for presenting with challenging behaviours and the most complex support needs (caseloads will include people with the complex needs involving abuse/trauma/forensic histories, autistic spectrum disorders, challenging behaviours, mental health/physical health difficulties, people who usually present a serious degree of risk of harm to themselves or others, including those who have offended or are at risk of offending). A key consultancy role at both an operational and strategic level, as well as at individual/family/systemic levels. Also clinical supervision of others providing psychological based approaches (such as Behavioural Activation Therapy, PBS and Behavioural Family Therapy)

Nursing

- Specialist nursing practice and public health/well-being support to prevent and reduce the incidence /impact of physical/mental health/challenging behaviours difficulties and health inequalities, including long-term clinical case management and practical support for the delivery of packages of care through collaborative working with colleagues within primary and secondary care in line with the 2014 RCN position statement on the role of the learning disability nurse
- Support to individuals with health facilitation/access issues for people with learning disabilities with accompanying challenging behaviours, mental health and profound multiple physical/sensory disabilities across health and social care communities, and the provision of interventions around complex support needs such as those seen as community-based health-focused healthcare tasks/health action planning with challenging cases

Occupational Therapy

- Specialist occupational therapists deliver personalised assessments and interventions that focus on individuals' occupational needs; specifically barriers to occupation. Barriers can be either 'personal' (cognitive and/or physical); and/or 'environmental' (social and/or physical). People are intrinsically active and creative, needing to engage in a balanced range of activities in their daily lives in order to maintain physical and mental health.
- Support an understanding of the relevance and role of occupation in health and well-being with specific skills in activity analysis, assessment of function, collaborative goal setting and evaluation. By supporting individuals to access a range of meaningful occupations, particularly in relation to leisure, productivity and self-care, the impact of complex health and social issues such as mental illness, multiple sensory/physical disabilities, challenging behaviour and social isolation can be reduced, issues surrounding occupational deprivation addressed, quality of life improved and health inequalities reduced. Specialist occupational therapists utilise a wide-ranging specialist assessment process with an aim to improve individuals' functional abilities, and develop existing and new skills. Occupational therapists contribute to the development of correct care packages by working closely with other health and social care services. This is particularly important at times of life transitions, for example from child to adult services, moving from family home or residential services to supported living and as health needs change such as with the onset of dementia.

Physiotherapy

- Specialist physiotherapy practice and health service support to prevent and reduce the incidence/ impact of complex health issues and profound or multiple physical/sensory disabilities, including clinical case management for the delivery of packages of care through collaborative working with colleagues within primary and secondary care

- Support to individuals with health facilitation/access issues for people with learning disabilities and their carers across health and social care communities, including issues in relation to primary/secondary health care access, and the provision of specialist moving and handling assessments, respiratory /dysphagia/postural care, mobility assessments, specialist equipment/access issues, systematic skills teaching/rehabilitation and complex support needs

Psychiatry

- Specialist psychiatric assessments, diagnoses (where applicable) and interventions to ensure effective evidence-based support for co-morbid presentations of mental health difficulties, challenging behaviour, epilepsy, dementia, and forensic issues relevant to multi-agency protection panels, including community out-patient reviews, and in-patient support in line with the Mental Health Act.
- Support through participation in multidisciplinary gate-keeping assessments for suitability for community psychiatric liaison support, medication reviews, psychotherapy, admissions, discharge and on-going risk assessment/management plans as part of formal CPA and multidisciplinary processes

Speech and Language Therapy

- Specialist Speech and Language Therapists provide person centred assessments and multi-layered formulation and treatment for complex speech, language and communication needs. They reduce the risks associated with limited comprehension, challenging behaviour and difficulties expressing one's self by supporting the best possible understanding between people with learning disabilities, carers and staff, reducing diagnostic overshadowing, and promoting safe, proactive and ethical communication strategies and effective intervention. Improved communication promotes well-being and prevents social isolation.
- Specialist Speech and Language Therapists reduce the risks associated with eating, drinking and swallowing difficulties, improving health in relation to respiration, nutrition and hydration by increasing safety around swallowing, reducing the risks of choking, getting chest and other infections, and preventing hospital admissions.

Dietetics

- Although uncommon as core Community Learning Disability Teams, the needs of people with learning disabilities, and the particular care and social networks in which they live, can be too complex for main stream services alone to succeed despite attempts to make reasonable adjustments. As with Special Care Dental practice, access to specialist dietetic resources in Community Learning Disability Teams resources can in these cases reduce the incidence and impact of complex health presentations, such as dysphagia through collaborative working with primary and secondary healthcare services.

Arts Therapies

Arts Therapies (Art Psychotherapy, Dramatherapy, Music Therapy and Dance Movement Psychotherapy)

- Specialist person centred psychological assessment and therapeutic treatment utilising art, drama, music and dance as a mode of communication with the aim of identifying issues relating to mental health, trauma, abuse, challenging behaviour, forensic histories and complex needs including wider service support to reduce levels of anxiety, distress and challenging behaviour.
- Using predominantly psychodynamic principles provide therapeutic formulations and therapeutic support to all individuals regardless of their level of cognitive and physical abilities thereby giving all individuals a voice, through which they may share their story and experience themselves and others in a different way. By supporting the individual with accessible approaches to self-expression and communication, challenging behaviour, social isolation anxiety and distress can be reduced and quality of life improved. This work is understood in the context of the individual's family/care situation and community in which they live, with contributions to the development and clinical case management of

health treatment packages (for example PBS plans) through close liaison with other health and social care professionals, the family and the individual. Activation of the individual's creativity can extend beyond the therapeutic space and support mental health needs and promote lifelong learning in the community. Arts therapists can act as lead consultancy and offer clinical supervision of professionals wishing to explore their work with people, the meaning of non-verbal behaviour and its relationship to increased mental health difficulties.

Social Work

- Social workers bring a different and complementary set of skills and knowledge to constructing the support package. They see the service user in the context of their human and civil rights and will help to ensure that the process is one of co-production, based on the strengths of the individual and their aspirations for a life as independent as is possible given the circumstances.
- Social workers see the service user in the context of their family and/or the community in which they live and work to ensure that the wishes and needs of the service user and those of the family and the community are balanced. There will be a need to assess in each locality the particular impact of care management demands on the access and availability of social work in lien with this role description.

Community Learning Disabilities Health Teams Eligibility Criteria

Commissioned Community Learning Disabilities Health Teams **must be available to all people with learning disabilities in the commissioning CCG locality and in all locations where CCG- registered patients reside (even where these involve placements out-of-area), with clear feedback mechanisms in place to inform commissioners of any practice issues and concerns**. All professional work must ensure that individuals are safe and healthy, and not subject to restrictive practices and settings, irrespective of the severity of an individual's learning disability.

The detailed information concerning the presenting learning disabilities and complex support needs should be assessed by an appropriate professionally registered Community Learning Disabilities Health Team member with the requisite skills and experience able to develop a formulation about causal, maintaining and risk factors.

The **priority target group for Community Learning Disability Health Teams must include people with learning disabilities and complex support needs**, including all those adults, with issues related to:

- The extent of their intellectual impairment
- Having physical disabilities which severely affect their ability to be independent
- Having sensory disabilities, which severely affect their ability to be independent
- Having a combination of physical and/or sensory disabilities
- Any behaviour that can severely challenge services
- Having a form of autistic spectrum condition
- Having complex health support needs
- Having enduring mental health needs and /or psychological issues
- Having a forensic offending or criminal justice system interface history
- Having receptive or expressive communication difficulties
- Parenting support unrelated to court reports
- And their needs require health or social care organisations to provide on-going support and assistance, no matter how this is funded.

Although Community Learning Disabilities Health Teams often include both health and social care workers**, specialist health services must not be restricted to only those individuals with severe learning disabilities or social care criteria for vulnerable adults. This is not in line with NHS Responsible Commissioner guidance.** Services must be provided on the basis of assessed clinical needs.

Community Learning Disabilities Health Teams are also commissioned in line with national policies such as the 2013 'Who Pays' NHS Responsible Commissioner Guidance in England. These note that '***The safety and well-being of patients is paramount. The underlying principle is that there should be no gaps in responsibility - no treatment should be refused or delayed due to uncertainty or ambiguity as to which CCG is responsible for funding an individual's healthcare provision'***. As such, the health and social care elements of local jointly commissioned Community Learning Disabilities Teams are likely to closely aligned, but at times they may operate as separate elements working to different eligibility criteria. This can be a challenge where it becomes necessary to draw distinctions between defining people with learning disability requiring health service support alone and those meeting defined as meeting social care eligibility criteria.

After the events uncovered at Winterbourne View, the need was highlighted for CCGs and their commissioned services to **have in place robust local safeguarding arrangements and communications between services in different areas**. In practice, this clarified **required notification and joint working-funding responsibilities**, which Community Learning Disabilities Health Teams should be aware of and support the local Safeguarding Boards and national Out-of-Area protocols.

Transition of Children into Adult Services

As a practical and pragmatic solution, and in line with the national drive to develop comprehensive life-course long services that minimise unnecessary service transitions, and support the outcomes of the Children's and Families Act and Care Bill (including reference to the SEND reforms requiring combined health, education and social care plans and changes in Annual Health Check criteria), **specialist Community Learning Disabilities Health Teams should be available for joint working with young people with complex health support needs and behaviours that challenge from 14 years +.**

Clearly, there is a need for the recognition of any other local Community Learning Disabilities Health Teams service access age limits, determined in line with locally agreed protocols for transitions from adolescent to adult services and wider moves to all-age services. A parallel paper on Children's Specialist Learning Disability Health Team services is currently being prepared by the National Senate.

There should also be in place **a specific local Transition action plan** that highlights how:

- **local action will resolve any identified problems in the support to young people with complex needs in transition to adulthood** (including reviews of the clinical and other support models in place from local CAMHS and Children's Complex Additional Disability Needs Teams), including:
    - Health action plans and reviews
    - Intimate and/or community care support task policies
    - Practical impact of changes to a full-time structured education programme to a more limited adult daytime, educational and respite options
    - Defining vulnerable individuals with autism or learning disabilities or difficulties that will not be eligible for adult Community Learning Disabilities Health Teams, community mental health or other services in the same way that they had in children's services

- **information and decisions on any complex or high-cost placements** (especially those involving young people aged 14 years+) **involving high-cost or out-of-area education, social or health-funded care**

packages is shared with adult Community Learning Disabilities Health Teams, commissioners and funding panels (especially CHC and Exceptional Individual Packages of Care arrangements).

This work **involves a call for significant changes in the whole health and social care system to truly *Transform Care* across the lifespan provided through ensuring the on-going access to competent, credible, committed, capable specialist Community Learning Disability Services**.

For this positive outcome to be realised, commissioners of and clinicians across the lifespan need to:

- **secure better practical early support for children and families to tackle issues 'upstream'** through earlier detection/interventions of emerging problems especially in the transition to adulthood from 14+ and earlier targeted work with families (especially where there may have been long-standing problems and disputes)
- **promote, from point of diagnosis, good health care support and well-being of individuals and their families with access to practical effective support**
- **encourage staff to care, connect and deliver practical short full life plans, interventions and care packages**
- **agree common access to care criteria that recognise the changes in expectations and resource demands from child to adult services.**

As noted previously, the Senate is developing a parallel document clarifying the best practice guidance relevant to the commissioning, operational delivery and evaluation of effective services for children with learning disabilities, their families and other key stakeholders such as schools.

Desired Outcomes of Effective Community LD Health Teams Health Support

"Everybody in this world today needs support of one kind or another. People need support to go ahead and do things whether this support comes from a good friend, parents, a social worker, or guardian. There is no person so independent in the world that they don't need anybody. We all need support, but with that support, we don't want somebody coming in and taking over our lives"
Kennedy (1993)

If the core purpose of the NHS is to protect life and maintain health, this applies equally to people with learning disabilities and their families across the lifespan. In many ways, given the past repeated failings whereby the collective actions of services and society resulted in poor care and reduced life expectancy for a vulnerable and marginalised group, the challenge now of responding effectively to the learning disabilities challenge can be seen as a critical test of the effectiveness of the wider NHS.

Community Learning Disabilities Health Teams can then only be seen to be effective if they address two essential priorities for action '***Reducing Restrictive Practices and Reducing Health Disparities***' through delivering the 5 identified core functions to:

- **Assist people with learning disabilities and those supporting them to better understanding the causes of ill-health and then supporting access to good primary care, community and specialist acute/mental health services, and wider valued mainstream opportunities in society**

- **Practically reduce health inequalities and improving access to a wide range of health supports, including access to annual health checks, screening programmes, diagnostic assessments and health action planning** which:
  - maintain optimum health and reduce dependency on continued intensive health/social care
  - prevent illness and requirements for on-going and extensive health supports

- identify and reduce reliance on medications and restrictive practices where alternative positive behaviour supports are appropriate
- prevent hospital admissions, restrictive services and out-of-area placements

- **Support health and well-being through supported access to a wide spectrum of local supported homes, work and lifestyle options, that also reduce the likelihood of people presenting complex support needs and challenges being placed into inappropriate services and unstructured support arrangements**, through:
  - monitoring effectiveness of personal health/social care packages against agreed specifications and providing feedback through contract review mechanisms
  - designing, organising and reviewing specialist reasonable adaptations and alternative 'non-ordinary' community services where complex presentations warrant this
  - supporting when times get hard, and staying in the original community setting is not possible, access to short term flexible practical assistance and a wide spectrum of support resources

The work of the Learning Disabilities Public Health Observatory IHAL has confirmed the main reasons for poorer health as: (1) increased risk of exposure (and possibly greater vulnerability when exposed) to well established 'social determinants' of poorer health such as poverty; (2) some specific genetic causes of learning disabilities associated with some specific health risks; (3) people with learning disabilities often have communication difficulties and poorer understanding of health; (4) people with learning disabilities less likely to lead 'healthy' lifestyles; (5) people with learning disabilities at risk of being discriminated against when trying to access or use health services. The Health Equalities Framework tool is useful to review the impact of these factors at an individual level and across teams/services, as well as changes over time.

Evaluating and Reporting on Performance

An effective Community Learning Disabilities Health Team is there to: help people with learning disabilities to enjoy better health outcomes and health care access, in ways which open up opportunities for independence and inclusion while reducing inequality; help people with learning disabilities use ordinary health services that are responsive to the needs of people with learning disabilities and their families; ensure opportunities for good health and well-being for vulnerable people; design, develop and deliver high quality local services that reduce reliance on high-cost, restrictive and out-of-area placements.

Community Learning Disabilities Health Teams need to demonstrate their value in meeting this agenda and provide evidence of how national minimum standards in relation to recognised best professional and service performance standards are addressed through individual and team performance in relation to a comprehensive set of targeted service activity and quality measures. This will necessitate valuing professional interventions that commonly require more than face-to-face activity. As a result, commissioners will need to agree a wider range of activity reports and measures related to indirect patient support in line with the 5 essential functions of specialist community learning disability services. This work should be in line with NICE and CQC guidance on evidence-based interventions and effective service arrangements, and meeting the varying cultural needs of local communities.

They should make sure that services are provided equitably to all who need them, including people with complex disabilities and circumstances so that that there are positive experiences, such that:

- ❑ *It is easy to get in touch with services, and they respond quickly to requests for help*
- ❑ *It is easy find out where services are and what they do, and the choices people have*
- ❑ *Staff talk in a respectful way and work to get to individuals*
- ❑ *Individuals get high quality care that is linked in with other support arrangements in people's lives*
- ❑ *Service surroundings are clean, comfortable and friendly*
- ❑ *Services listen carefully to the views and experiences of people with learning disabilities and their families, using different ways to communicate and provide information*

- *Services offer people choices about 'where' and 'when' they get help, as well as 'what' and 'how' someone wishes to be helped with*
- *Services help people make decisions about health matters, providing the right kind of support and they are clear when someone cannot make a decision, and who can best represent them*
- *Services take care over issues of confidentiality*
- *Services give people copies of letters written about them*
- *Services support person-centred plans*
- *Services build on what people can do for themselves and other people who can help.*
- *Services are focused on the whole person, being clear about what else is going on in a person's life. They work closely with other people and organisations providing support to a person, so that the right things happen at the right time.*
- *Health professionals and support staff are trained and good at what they do.*
- *People with learning disabilities and family carers are involved in teaching them.*
- *Health professionals and support staff find out what works best and use this in their everyday work*
- *They are good at working in partnership with people with learning disabilities and their families*
- *They are good at working in teams and with other agencies supporting people and families*
- *They are treated fairly by their organisation, and supported to work flexibly for people*
- *They have good management and professional leadership*
- *Services focus on getting good results for people with learning disabilities and the community*
- *Everyone understands that the laws relating to discrimination and human rights apply equally*
- *Steps are taken to help ensure that people with learning disabilities are safe, and specialist staff know what to do if they are worried about people being harmed or abused in other services*
- *Services ask for feedback from people with learning disabilities and families about the services they get*.

Closing Comments

The importance of the work of Community Learning Disabilities Health Teams has been brought to the fore through the results of the Winterbourne View review and Confidential Inquiry into Premature Deaths in people with learning disabilities. Community Learning Disabilities Health Teams and their commissioners now need to invest considerable energy and the focus of their specialist health service role to achieve change in the status quo. Good outcomes require person-centred thinking, creativity, commitment, flexibility and clinical expertise balanced by accurate risk assessments and management. **Success will only be apparent if this group of vulnerable people live lives with more opportunities, with less exposure to harm and that are healthier for longer more in line with the general population.**

The vision for Community Learning Disabilities Health Teams that are relevant to the wider NHS agenda is to ensure they enable directly and indirectly, access to high quality effective mainstream and specialist services that are equally accessible to all, and designed to meet the needs and aspirations of individuals with learning disabilities, thereby reducing health inequalities and restrictive practices.

Evidence and best practice confirms that:

- All individuals with disabilities can and should live in the least restrictive local community settings. The key is the availability of adequate and appropriate skilled and timely support (including knowing people well, anticipating surprises through early proactive detection and managing crisis with contingency plans providing more help to 'survive with dignity', not removal away from families and localities)

- Too often insufficient flexible and planned support has been provided to families and carers (including access to additional funding, social, professional clinical and practical support - especially planned and crisis 'respite breaks' in and out of home). Families and services that report a balance between stressors and resources want to and do keep together well

- When individuals with disabilities or their families/carers are provided with individualised support (and involved in the design, development, implementation, monitoring and evaluation of services) there are greater chances of success and satisfaction

- People with disabilities who move out of large residential environments do better in smaller ones

- When there is sufficient attention paid to a person's individual characteristics and real needs through person-centred planning and positive behaviour support, matched with high levels of technical and emotional support for staff and carers, outcomes are better for all

- People grow and behaviours that challenge commonly reduce in homes that encourage social interactions, vocational development and independence by adopting a 'wrap-around' support and recovery model, rather than attempting readiness 'medical model-based' care assessment pathways or treatment

- In addition to being placed in local community settings, individuals with disabilities need active support to integrate into community and work settings. Change does not just happen, it requires careful on-going thought and planning

- People with disabilities and their neighbours should be encouraged to develop lasting meaningful social mixed heterogeneous relationships as it is safer, less stressful for all and better value-for-money. Grouping people with learning disabilities who challenge together in services increases the likelihood of problems

- Spending lots of money alone does not guarantee good care or support outcomes for people with disabilities and their families

- For redesigning and commissioning or re-commissioning services, equal attention needs to be paid to both clinical and non-clinical evidence and factors (especially leadership and commitment over time in community teams, professionals and services).

NHS health commissioners retain overall responsibility for the performance and outcomes of the health support available to people with learning disabilities and their families, including any access problems and health inequality outcomes. This applies even where the lead commissioning responsibility has been delegated to Local Authority commissioners and/or Community Learning Disabilities Health Teams are managed through Pooled Budgets.

So while, while w**hat people in a Community Learning Disabilities Health Team do should be agreed locally, this must be in line with national best practice guidance and evidence-based clinical practice**. As such while, people in Community Learning Disabilities Health Teams will do different things, they should all help to put national policies such as *Valuing People* or *Keys to Life* principles into practice with:

- **sufficient skilled clinical support to individuals with learning disabilities and their families to access respected and high status community opportunities and activities, and**
- **co-ordinated professional advice and practical help to accomplish such lifestyles without being displaced out-of-area or into restrictive settings, and being faced with continued health access and outcomes disparities, as a result of** local models of residential living and care options being put in place to meet the full diverse needs of the individuals concerned.

As such, Community Learning Disabilities Teams should:

- Have clearly agreed aims and goals, whereby it is possible to assess whether the Team is succeeding

- Be structured in such a way that each member has independent responsibilities, and knows what these are together with relevant performance and activity measures
- Be collectively responsible for a clear and identifiable areas of work in line with the 5 core functions, delivering on the Transforming Care and CIPOLD agendas
- Contains members and a mix with varying degrees of professional skills, abilities, experiences and problem-solving strategies
- Ensure sufficient opportunities for team members to interact and meet both easily and frequently - formally and informally

Throughout history, people with learning disabilities, and their families, have been at particular risk of social exclusion with worse health outcomes. As a result, many individuals need additional support to ensure fairness, equity and opportunities. **Community Learning Disabilities Health Teams and services are important in helping face this challenge. To do this, they must focus on the really important goals of 'Reducing Restrictive Practices and Health Disparities', acting with professional integrity and flexibility, and continuing to raise the bar of expectations for person-centred valued outcomes for all through delivering effective evidence-based support**.

References and Sources of Further Information

Atkinson D, Boulter P, Hebron C, Moulster G, Giraud-Saunders A, Turner S (2013). *The Health Equalities Framework (HEF)*. Improving Health and Lives Public Health Observatory

The CIPOLD Team (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report. Bristol.* Norah Fry Research Centre, University of Bristol.

Department for Education (2012). *Support and aspiration: a new approach to special educational needs and disability. Progress and next steps. London: DFE*

Department of Health (1993) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* (The Mansell Report). London: DH

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. White Paper. London: DH

Department of Health (2002) *Guidance for restrictive physical interventions: How to provide safe services for people with learning disabilities and autistic spectrum conditions* London: DH

Department of Health (2007c) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs – Revised Edition* (The Mansell Report Revised). London: DH

Department of Health (2007d) *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance*. London: DH

Department of Health (2008a) *Healthcare for All, Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: DH

Department of Health (2008e) *Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities – Making It Happen for Everyone (Rights, Independent Living, Control and Inclusion)*. London: DH

Department of Health (2009b) *World Class Commissioning for the Health and Well Being of People with Learning Disabilities*. London: DH

Department of Health (2009c) *Valuing People Now: A new three-year strategy for people with learning disabilities*. London: DH

Department of Health (2011). *Pathways to Getting a Life: transition planning for full lives.* London: DH

Department of Health (2012). *Department of Health Review: Winterbourne View Hospital. Interim report.* London: DH

Department of Health (2012a). *Transforming care: A National response to Winterbourne View Hospital***.** London: DH

Department of Health (2012b). *Winterbourne View Review: Concordat: Programme of Action.* London: DH

Department of Health (2013). *Winterbourne View: Transforming Care – One Year On*'. London: DH

Department of Health (2014). *Winterbourne View – Time for Change: transforming the commissioning of services for people with learning disabilities and/or autism.* London: DH

Department of Health and Partners - the Association of Directors of Adult Social Services, Care Quality Commission, Health and Social Care Information Centre, Local Government Association, NHS England and Public Health England (2015) *Winterbourne View: Transforming Care Two Years On.* London: DH

Department of Health, Social Services and Public Safety (2015). Service Framework for Learning Disability – Northern Ireland. Belfast. DHSSPS

Emerson et al. (2011) *Health Inequalities and People with Learning Disabilities 2011.* Improving Health and Lives Learning Disabilities Public Health Observatory (IHAL).

Francis R (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry.* London: The Stationery Office

IHAL, RCGP, RCPsych (2012). *Improving the Health and Wellbeing of people with learning disabilities: an evidence-based guide for Clinical Commissioning Groups*.

Mencap (2007) *Death by Indifference: Following up on the Treat me Right! Campaigns*. London: Mencap

Mencap (2012). *Death by indifference: 74 deaths and counting. A progress report 5 years on.* London: Mencap

National Audit Office (2015). *Care services for people with learning disabilities and challenging behaviour*. London. NAO

NHS England (2013). *Who Pays? Determining responsibility for payments to providers*

NHS England (2013). *Everyone Counts: Planning for Patients 2014/15 - 2018/19*

NHS England (2014). *NHS England's Business Plan 2014/15 – 2016/17: Putting Patients First*

NHS England & Local Government Association (2014) *Ensuring quality services: Core Principles Commissioning Tool for the development of Local Specifications for services supporting Children, Young People, Adults and Older People with Learning Disabilities and / or Autism who Display or are at Risk of Displaying Behaviour that Challenges* London: NHS England & LGA

Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009) *Six Lives: The Provision of Public Services to People with Learning Disabilities.*

Public Health England (2013). *Joint Health and Social Care Self-Assessment Framework 2013: Detailed report and thematic analyses*. London: PHE

RCGP (2011). *Mental Capacity Act (MCA) Toolkit for Adults in England and Wales.*

Royal College of Speech and Language Therapists (2013). *Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings.* London: RCSLT

Sanderson H. Lewis J. (2012) *A Practical Guide to Delivering Personalisation: Person-Centred Practice in Health and Social Care*. London: Jessica Kingsley Publishers

Social Care, Local Government and Care Partnership Directorate (2014). *Positive and Proactive Care: reducing the need for restrictive interventions.* London: Department of Health

The Scottish Government (2013). *The Keys to Life - Improving Quality of Life for People with Learning Disabilities.*

Appendix

NHS Sample Service Specification – Community LD Health Team Service – To Follow

Appendix

NHS Sample Service Specification – Community LD Health Team Service – To Follow

MAHI - STM - 118 - 2323

National Development Team for inclusion

Guide for commissioners of services for people with learning disabilities who challenge services

Foreword

The purpose of this Guide is to provide practical advice to both Local Authority and NHS commissioners on how to commission effective services to people with learning disabilities whose behaviour challenges services, in line with Government policy as set down in the Mansell Report[1]. This document has been produced by the National Development Team for Inclusion (NDTi) and was funded by the Department of Health as part of the roll-out of the Mansell Report (co-ordinated by the Challenging Behaviour National Steering Group) and the wider Valuing People Now delivery plan. The aim of the guide is to support commissioners to turn the evidence-based expectations described in the Mansell report into practical commissioning actions. It is based on evidence collected and analysed by studying locations[2] that have made good progress in supporting people who challenge in ways similar to those envisaged in the Mansell Report.

National Development Team for Inclusion

Montreux House
18A James Street West
Bath BA1 2BT

T: 01225 789135
F: 01225 338017

www.ndti.org.uk

December 2010

[1] Services for People with Learning Disabilities and Challenging Behaviour and/or Mental Health Needs (revised edition) DH (Ed Prof. J Mansell). March 2007

[2] We particularly learnt from meeting with and studying commissioning and provision in Birmingham, Great Yarmouth, North East Lincolnshire, North Lincolnshire and Oxfordshire. We would like to place on record our appreciation of the assistance and co-operation of people from these locations and the work they have done over a number of years to help improve services and outcomes for people.

Contents

Executive summary

This good practice advice has been written primarily for NHS and local authority commissioners of services to assist them to commission high quality, cost effective services for people with learning disabilities whose behaviour challenges services. It follows the principles of DH policy as described in the Mansell Report (which are totally in line with the personalisation agenda) and is based on reviewing the experience and learning from commissioners who have made progress in implementing that policy.

Seven broad areas of evidence are identified – each with a number of specific elements. The full report explores these in more detail and recommends specific actions by commissioners that will help achieve positive outcomes and cost-effective service delivery:

1. Basing all decisions on a clear vision and set of values

- A commitment to achieving outcomes based on 'ordinary life' principles
- Working in partnership with individuals and their families
- A local understanding of evidence based practice
- Taking a medium to long term approach to progress and not expecting unrealistic short-term gains
- All partners being willing to do 'whatever it takes' to achieve positive outcomes, even when the going gets difficult

2. Strong, knowledgeable and empowered leadership

- Active involvement and leadership from commissioners

- Identifying and supporting innovators and risk takers
- Strong clinical leadership that is committed to the vision and to partnership working

3. Strong relationships and a 'no-blame' culture

- People and their families being at the centre of decision making
- Commissioners (including care managers) and clinicians working together well and using each others' expertise
- A trusting relationship between commissioners and providers rather than one based on arms-length contracting
- Providers and clinicians seeing themselves as partners
- The NHS and local authority bring their resources together and agreeing clear boundaries based upon shared responsibility

4. An evidence-based Service Model

- Starting with proper person centred planning and individualised services
- Service design for individuals being a shared responsibility – including providers
- The use of positive behaviour support and non-aversive techniques by staff
- The ready availability of clinical leadership
- Contracting housing and support separately so that people have housing rights and security
- Not imposing arbitrary maximum cost limits on services

5. Having skilled providers and support staff

- Choosing providers having a positive attitude to partnership and to people

labelled as challenging and their families.

- Choosing providers that are outwards looking – always willing to learn and seeking out community focused support options
- Providers following advice of appropriate professionals whether from a clinical or social care perspective.
- Finding providers that are in there for the long haul and not giving up in difficult times
- There being active senior management involvement in service delivery and working relationships
- Staff being recruited on the basis of their attitude, in particular towards positive risk taking, at least as much as their formal skill base
- Not using agency staff
- Investment in training that is tailored to the needs to the individual being supported

6. Evidence Based Commissioning

- Developing a local outcomes framework to evidence progress
- Tracking and reporting on changes to the cost of services over time

7. Other Commissioning Actions

- Starting with up-front investment to ensure the risk skills and resources are available from the outset
- Having flexible ways of choosing providers that enables long term relationships to be developed
- Adopting flexible contracting systems that can rapidly respond to changes in the needs of people being supported

- Using continuing healthcare criteria creatively
- Sharing financial risk between the NHS and local authority
- Targeting financial savings over time – based on evidence of improvements in people's lives

Main Report

Introduction

This guide uses the term challenging behaviour as described the Mansell report[3]

"The phrase "challenging behaviour" is to include people whose behaviour presents a significant challenge to services, whatever the presumed cause of the problem. Wherever it is used, it includes behaviour which is attributable to mental health problems. ***When the term 'challenging behaviour' was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate and the term is used in the original sense****."*

Some people prefer to use the term 'people who services label as challenging' to make this point about placing the responsibility with services rather than the individual.

The number of people identified as challenging services is small in any given area. Estimates vary but it is likely that about 24 adults with a learning disability per 100,000 total population present a serious challenge at one time[3]. The numbers of young people who challenge services and are in transition to adulthood are believed to be increasing and so will also need consideration. The length of time needed for support also varies but it is likely to be long term, and many people may present a serious challenge for much of the time or throughout their life.

[3] Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (Revised Edition), DH (Ed Prof J Mansell) 2007

However, this comparatively small number could increase substantially if learning disability services as a whole are not skilled at supporting people with less complex behaviour who, if supported inappropriately, have the potential to place greater demands on services. Commissioners therefore need to pay attention to ensuring a general level of service competency in working with people who challenge, as well as ensuring that there are specialist skills available for working with the smaller number of people whose behaviour challenges services significantly.

This report is primarily concerned with this smaller number of people who will require highly specialist, flexible, long term support. The Mansell Report described three broad approaches to commissioning in response to this challenge. It states that commissioning bodies can be identified as one of:

Removers - that do not want to, or have the capacity to, develop locally the competence to serve people whose behaviour presents a challenge (perhaps because they perceive the task as currently too difficult, or not worth the effort). They seek instead to place people who cannot currently be served locally in out-of-area residential placements, often at considerable expense and for long periods.

Containers - that seek to provide local services (perhaps because of the high cost of out of-area placements) but seek only to contain people in low-cost (and therefore poorly-staffed) settings as a result of which outcomes for people are poor.

Developers - that seek to provide local services that really do address individual

needs, and therefore give higher priority to funding services which, with more

staff and more training and management input, are more likely to deliver positive outcomes.

This Guide is concerned with assisting commissioners to become **developers** by building on the experience of those who have already embarked on that journey. Whilst being written with commissioners as the intended audience, almost all the conclusions and recommendations can also be interpreted from other people's perspectives – in particular service providers.

This approach is totally in line with the 'personalisation' agenda, in that it starts with person centred planning, leads to individualised service design based upon evidence based best practice and (crucially) the person's own wishes and needs and must be evidenced by outcomes that achieve the purposes for which public funds are being provided. Taking the next step to people (with their families and supporters) having direct access to the funds through individual budgets would in many ways be the logical next step for commissioners.

At the time of writing this report, the Coalition Government has just produced its White Paper ‘Liberating the NHS’ which proposes radical change to commissioning arrangements with consortia of GPs taking a lead role. It may be some time before the implications of this in terms of roles for commissioning integrated NHS/local authority services for people who challenge are fully understood. For this reason, this document uses the phrase ‘NHS commissioners’ to refer to PCTs in the immediate future and potentially GP Consortia at a later date.

The report is divided into sections based on the factors that were identified to be important for success in the selected locations, with descriptors of good practice and advice for specific actions that, based on experience elsewhere, are likely to result in more effective commissioning and thus better life outcomes for people who are labelled as challenging.

1 Vision and Values

A common starting point for commissioning services is the importance of having a shared understanding about the desired goals and outcomes – with this being 'bought into' by all the key players and organisations (see also Section 2 below). Four aspects of this appear to be particularly important:

1.1 A Commitment to Ordinary Life and Inclusion

Progress is being made where all key players agree that the objective is to support people to live as ordinary a life as possible in their communities, with supports being designed to help achieve that. The desired outcomes are understood as being about improved lifestyles for individuals and not just reduced demands or pressures on specialist services or cost (important though those things are). This also involves a positive attitude to risk taking and a recognition that sometimes things will go wrong (see 1.3 below). Service solutions that segregate individuals from other non-disabled people are not seen as a natural part of service design (see Section 5).

For example
In Birmingham the whole system's philosophy is described as aiming to make people "admission proof" – i.e. no matter how difficult things get, people will be supported in the new service and not re-admitted to hospital. This principle underpinned discussions and decision-making around services when they were in crisis.

1.2 An Understanding of Evidence-Based Best Practice

We found a common theme was that the sites had been influenced by the original[4] Mansell Report, and had direct contact with research centres or development agencies championing the report. This inspiration helped to shape the local desire for change which came from a resolve that enough expenditure was enough

For example
In Birmingham it was the "local champions" who knew and understood the need for changing the mind-set that out of area placements were acceptable. Starting out by using evidence about costs and quality, this group of local partners led the debate that brought about the decision to look at the most complex and challenging people first. The rationale being if it worked for people with the most complex needs, it would work for others too.

4 1993, DH 'Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs'.

– something had to change in terms of outcomes for people; or that local services were not good enough and a new way of working was required. Key players understanding how evidence based practice could be applied locally was an essential component (see Section 2). Whilst there is obviously benefit in this being set down in a written strategy as part of wider commissioning plans, interestingly this had not happened in most of the places we reviewed. What seemed more important was an organisational commitment to working for better outcomes (see 1.1), and the empowerment of knowledgeable leaders who had authority to be creative (see Section 2).

1.3 A Medium to Long Term Time Horizon

People who are labelled as challenging will need in-depth support over a long period of time. It may be months or even years before some people are successfully supported to achieve fully inclusive outcomes. Commissioning decisions may not lead to swift results and substantial cost savings but the evidence is that these will be achieved in the medium term. The commissioner has to understand and to convey this message effectively and consistently. Data on costs and outcomes is essential to help this discussion (see Section 6). Progress is being made where the commissioners and other organisations recognise that investment in people who challenge (in terms of both finances and organisational strategies and time) will need to be made over a long period and there will be few 'quick wins'.

For example
In Great Yarmouth, success was made possible by the commitment of all agencies, not just the NHS and local authority, but families and carers, and the business and voluntary sector to the idea of developing skilled local provision. Proposals were taken to, and agreed by, as many and varied decision-making fora as possible. This early involvement and understanding of the need for a lengthy commitment ensured that as the individual representatives of organisations changed, the shared ownership and purpose continued.

1.4 Whatever It Takes

Progress is being made where all the organisations involved commit themselves to doing whatever it takes to support people to live better lives – with an understanding that this will involve doing things in new and different ways - sometimes 'breaking the rules' (see 2.1 below) to get the desired outcomes and going that extra mile in terms of hard work. The most important point here is a shared commitment to keep going when new services

For example
In North East Lincolnshire, a young lady was known to local services but she lived in local supporting people accommodation at no additional cost to the system. When the challenges she presented proved difficult, cross agency working ensured that she was then offered a single-person 24/7 supported service. Despite significant challenges to the service over the last two years, including frequent police involvement due to her criminal and offending behaviour, agencies have worked together to enable her to stay in this local service and have prevented her from moving into an out of area secure unit.

go wrong or people's challenges continue. A recognition that further 'tweaking' and sometimes more, of service delivery will be required rather than giving up early on is an essential pre-requisite of success.

Vision and Values – Actions for Effective Commissioning:

1 **Build a local case for change** by collecting data on known cases of people who challenge services, both costs and outcomes, to inform a debate with key people about how best to improve services and reduce costs in the medium term.

2 If it helps the local case **bring in external experts if necessary** to share best practice and the evidence base and inspire change – build on local champions in doing this.

3 **Engage the wide range of partners in this work** – including family carers, voluntary sector, providers, GPs and the police to add value to the case and local debates.

4 **Get certain key principles agreed,** preferably through a written strategy, such as (i) commitment to ordinary life objectives (ii) commitment to non-restrictive settings (iii) avoiding readmission at all costs (iv) evidence based outcomes (v) commitment to driving down costs based on outcomes achieved (vi) a financial return over the medium term.

2 Leadership

Leadership is an essential component of success – leadership that is committed to the belief that people who are labelled as challenging should be supported to live better lives. This leadership, whilst ideally involving those in most senior positions, can and should be found in a variety of places – clinicians, provider managers, front line staff, family members. It needs to be nurtured and supported. Three aspects of leadership appear to be particularly important:

2.1 Active commissioner involvement

Progress is being made where commissioners (from both the NHS and Local Authority) are actively involved and are been given support and freedom by senior managers to find solutions. This means them being knowledgeable about the issues, the policy and what works and does not work. However, this does not necessarily mean the commissioner being the central person in developing and leading the delivery of a strategy. The development of strong relationships (see Section 3) and empowering others to take responsibility (see Section 2.2) means that others who may have more expertise and time available can take on effective leadership roles.

For example
In Oxfordshire the Joint Commissioner has good support from both PCT and the local authority, has control of budgets in both health and social care (and is pooled fund manager) and has the authority to take issues to senior officers in either organisation as they arise. She knows that senior managers will make decisions based on a sound knowledge of the issues.

2.2 Supporting Innovators and risk-takers

Good commissioners can and do challenge the system and the status quo. Getting services right for people who challenge has to involve innovation. All the sites reviewed had successfully tried to do things in new and different ways. This often involved doing things that were untried in terms of local experience and sometimes involved 'breaking the rules' of how things were normally done and thereby changing rigid policies that had not

previously been questioned. Individuals in key places need to be willing to innovate and take informed risks and senior managers and the formal organisations should be willing to support and encourage those leaders in this approach.

Successful services are individualised and thus this agenda fits well with the move to personalisation and in the limited occasions where we found direct payments being used, the effect appeared beneficial. A wider move into using individual budgets for people who challenge, this would be a logical next step given the importance of costing services individually, and having explicit outcomes required that are then monitored.

For example
In Oxford a gentleman, T, was challenging services in extreme ways, for example physical aggression towards his family and support workers. Following admission to a short-term assessment unit he moved through a series of residential placements, which broke down as a result of his challenges, including aggression. T's mother agreed to manage a Direct Payment on his behalf and so he moved to his own shared ownership home supported by staff employed by his mother. This arrangement has been very successful with a dramatic drop in the number of incidents - currently nearly a year without any violent incidents following 70 and 30 incidents in the previous two years.
The Direct Payment is in the region of £3600 per week with 2:1 staffing at most times. Whilst clearly very expensive, there is an active dialogue between care managers and the family to introduce changes that will reduce costs over time.

2.3 Strong clinical leadership committed to the vision and partnership working

Without exception, strong clinical leadership, committed to a social model of disability and the approach described in the Mansell Report, was at the heart of successful initiatives – in particular consultant psychiatrists and psychologists. People who challenge cannot be supported to live more inclusive lives without expert clinical support and so clinicians are important local leaders. However, it is true that many poor quality services for people have arisen because of clinical advice that did not reflect recognised best practice. The empowerment of clinicians therefore needs to be linked to their full support to the vision and values and knowledge of best practice as described in the Mansell Report and elsewhere (see Section 2.1). The Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists have produced joint advice, called 'A Unified Approach', for their members on appropriate clinical approaches[5].

This is most effective when linked with effective leadership from social care managers in order to ensure that there is appropriate and active local authority involvement. Where we found success, the needs of the individual drove the joint working arrangements and clinicians and social workers respected each other's views and skills rather than one service seeking dominance.

[5] Challenging Behaviour: A Unified Approach. *College Report CR144*. Royal College of Psychiatrists June 2007

Leadership – Actions for Effective Commissioning:

5	Identify one or more people with commissioning responsibilities who will champion this work on behalf of both the NHS and local authority. If this person does not have the time or knowledge to be the main leader of this work (you will need one), identify who that person is and vest them with the authority to lead it effectively.

6	Ensure that the people you identify as key leaders are prepared to take sensible risks and be innovators – if they are not, they are not the right leaders. Put in place organisational systems that give them the confidence to do that.

7	Identify and/or listen to clinicians who are champions for the Mansell Report and fully believe in it. Give them a central role in developments. If they do not exist locally, you will have to recruit them.

3 Relationships and a 'No Blame Culture'

Probably the clearest common factor across all sites making progress was the strength of positive relationships between key players. These relationships helped to encourage, build and then sustain the capacity and capability needed to deliver services. People from different organisations and from different parts of the same organisation demonstrably showed respect to one another, trusting in their particular area of expertise and responsibility is a positive way that fostered a growth of mutual trust.

This was an important factor in helping to overcome the challenging situations that will always occur as services get into difficulty and people have differing views about how to move forward. Most important across all sites was the nurturing of a 'no blame' culture between organisations where, rather than start from an assumption that one organisation had failed, the belief system was based on it being possible to find out what went wrong in an open and trusting manner, look at the issues that brought about crisis or the breakdown of packages and thus agreement of how to move forward. However, use of the 'no blame' in this context does not imply that managers and staff within organisations are not to take responsibility, or be held responsible internally, for their actions in the event of them failing to follow best practice and agreed ways of working.

For example
In Birmingham all agencies agreed that the underlying and agreed belief should be that the fault for any crisis or breakdown in a service was within the system as a whole and that this had let the individual down. This helped create a 'no blame' culture and enabled solutions to be sought without starting off by arguing about who had failed or seeing the failure as being by the person themselves.

Five different types of relationships merit particular comment:

3.1 Commissioners and Clinicians

As noted in 2.3, trusting and responding to clinical advice is an essential component of success. Effective commissioning therefore involves developing a positive relationship with clinicians, rather than seeing them as arms-length people whose service is purchased and operated by contract. Similarly, care managers and health clinicians see each other as partners working for the person with learning disability and respect and use each other's expertise. Clinical advice is built into commissioning and purchasing decisions about individuals (including individual service plans) and their knowledge and expertise is trusted. Correspondingly, clinicians respect and understand the role of the commissioner and care manager, including their responsibility and need to operate within financial boundaries.

3.2 Commissioners and Providers

Where progress was being made, the relationship between commissioners (including care managers) and housing and support providers was fundamentally different to that often found nowadays. It was not an arms length relationship governed totally by contractual process and underpinned by mutual suspicion. It was seen by both as a long-term partnership – clearly linked to the 'whatever it takes' requirement (see Section 1.4). Whilst financial probity has to be in place (see Section 6) the same mutual trust and respect described in 3.1 applied. The expertise of providers and their knowledge about the person was respected by commissioners and their advice built into service plans and contracts. Providers recognised the need for honesty in relationships and an openness with commissioners in reporting quality and financial needs.

For example

"We brought the provider in – as experts in the field – to advise on the planning and development phase of new services and found it was a positive experience for both parties. As commissioners we had an opportunity to evaluate whether our core values are shared and also to influence the development of the culture within the provider organisation". (North East Lincolnshire commissioner)

In Oxfordshire, where providers had been involved in service developments and planning, they described the benefit of not having a service model "inflicted" on them and of the development of trust and respect with the knowledge that there is no "hidden agenda" from the commissioners.

3.3 Providers and Clinicians

Where progress is being made, a central role of clinicians was to advise on the design of support plans and ways of working on a daily basis that addressed potential causes of behaviour that challenged and innovative 'reasonable adjustments' to encourage and enable access to mainstream services. Both parties understood the importance of providers following these plans and ensuring staff had the knowledge and skills to do this. Equally, the clinicians respected the knowledge gained by provider staff in working with individuals on a daily basis and their additional knowledge about how to support people live integrated community lives.

For example
In Birmingham, it is an explicit expectation in the contracting and working relationships that providers will follow clinical advice in relation to how they support people. Systems are in place to ensure that, if a difference of opinion arises or the experience of the provider suggests that clinical advice will not work as intended, meetings are rapidly held to discuss the different perspectives and agree a shared way forward.

3.4 The person and the family

As yet none of the initiatives we studied involved people and families as central decision makers in the planning and running of the services as a whole, but they all placed the individual and their family at the centre of decision making about the person's life and daily actions – usually by using effective person centred planning (see Section 4). Families were also encouraged to directly and quickly raise issues and concerns they had with both commissioner sand providers. The prime accountability of all staff and organisations was understood as being to the person who they were supporting. Greater family and user involvement in wider service issues was seen as the next stage of development.

For example
F had been placed out of NE Lincolnshire, partly because he left the places he lived to try and return to his parents. This led to police involvement and parental distress. His family were concerned about his return to the local area as he turned 18 because of his offending, lack of road sense and potential hostility from local people. Several meetings between the family, existing and new support providers, health professionals, care manager; and the Trust's MCA/DOLS Advisor resulted in an agreed Risk Management Plan that actively taught F how to get home to his parents safely; set up frequent and regular, reliable home visits; detailed what they should do if he turned up unexpectedly; and involved them trusting the new support providers to support F back to his place with limited distress. The family's involvement in developing the plan has enabled a successful move for F from out of area to his own home just a few miles from his parents from which he enjoys regular and positive contact with his family.

3.5 The NHS Commissioners and the Local Authority Commissioners

Whilst the quality and depth of partnership varied, a sense of shared responsibility and ownership between NHS and local authority commissioners was an important component. (See also Section 7). Ideally, this involved the whole organisation, but sometimes waiting

for that to develop would have meant inaction and so individual commissioners from the two organisations developed their own understanding and ways of working.

Central to this was clarity between the two main (or joint) commissioners about where responsibility rested for assessing, designing and the purchasing services for individuals. This involved moving away from arbitrary boundaries between NHS and social care responsibility and the local authority recognising that 'provider' clinicians were operating as proxy commissioners for the NHS.

Relationships – Actions for Effective Commissioning:

8. Agree a 'no blame' culture as the starting principle especially when learning from all cases where services get into difficulty.

9. Create or adapt existing structures (including informal ones) where the leaders from different organisations can come together to share ideas and take things forward. Ensure these systems are formalised and review expenditure, activity, risk factors and blockages as well as discussed principles and ideas.

10. Actively foster a positive working partnership with providers and clinicians. Ensure these working relationships with commissioners and each other are described in contracts/service agreements.

11. Ensure that individual service plans (whoever designs them, care managers etc) are based on 'ordinary life' outcomes and explicitly build in and address clinical advice without compromising contracting arrangements.

12. Identify a small number of providers who are committed to a long-term relationship around people who challenge, and work with them as partners whose expertise is used in commissioning decisions.

13. Place an expectation in contracts, reinforced by informal communications, that support providers will respect and follow clinical advice.

14. Do not plan any services for individuals without the person and their family being at the centre of that work unless there are overwhelming reasons to argue against this at a specific point in time. (e.g. absence of any family involvement or major breakdown in the family relationship).

15. Be clear, between the NHS and local authority, where responsibility rests for assessing, planning and designing individual services across both sectors and then agree budgetary responsibility in a way that rapid decisions in support of those individual service designs can be made.

16. Draw up contingency arrangements for situations where shared risk and partnership agreements are themselves at risk.

17. Put in place robust local communication opportunities – e.g. a provider forum, joint management group, clinical support networks etc. in order to share knowledge, learning and new plans and ideas.

4 The Service Model

The Mansell Report describes key components of an effective service model to support people who challenge that will not be repeated here. Six aspects of the service model came through in our work that merit particular comment.

4.1 Person Centred Approaches

Successful services are individualised in a number of ways; everyone involved recognises the individual's needs. The starting point is the person's aspirations and not the way they challenge services or the staff's perception of what they might want. Ways of supporting them to live a full life are the key consideration. Nurturing their friends, family and relationships are central considerations. Packages of support are constructed for the individual and costs are individualised. A true understanding of person centred planning underpins this work – which as previously noted provides a strong basis for extending the arrangement to an individual budget. If a family member is not actively involved, then independent advocacy (where necessary the local IMCA service) and support is brought into play.

For example
In Oxfordshire, after a history of involvement with Assessment and Treatment units, forensic medium secure and community orders, it was agreed that R needed a single flat due to finding it difficult to share with others. The landlord was keen to be involved and an architect was commissioned to draw up design. The conversion took place of a single flat, with assistive technology linked to a nearby supported living centre. Without this it is likely that R would not have been able to remain locally as there would have been a long wait for a flat through conventional channels. Due to his health problems he needs a high level of support staff available but also wanted his own space. R is able to enjoy time alone in his flat and the staff team have confidence that all is well but that they can intervene if required rather than have to continue to visit to assess the situation.

4.2 Shared service design

Progress was being made where the individualised service design was developed and agreed by all parties; the person (as far as possible), their family, the clinicians, the provider and the commissioner. It was not seen as just a matter for the commissioner/care manager or the clinician to determine on the basis of what they thought or what was available. Shared ownership was a key component of people then feeling committed to do 'whatever it takes' to make the service work for the person.

For example
In North East Lincolnshire, J was frequently buying tablets, threatening to take overdoses, and then refusing staff entry when he told them he'd taken the tablets. J had regular support from the Clinical Psychologist, but the anxiety levels in the staff were too high for them to hear what J was trying to tell them. The support provider was therefore requesting a more 'looked after', risk avoidant approach. J did not have any family who could advocate on his behalf so an Independent Advocate was provided by Rethink. Joint meetings between J, his Advocate, Support Provider and Psychologist resulted in him being able to move to a different part of town and live with his girlfriend with a new support package around their joint needs. The Advocate's involvement was important in helping develop a risk managed rather than risk avoidant approach. J has not engaged in this suicidal behaviour since.

4.3 The use of non-aversive techniques

The sites we reviewed used positive behavioural support and non-aversive techniques as these were considered to underpin both the potential for progress and the person's rights. We found that good providers were already dealing with this and had ongoing staff training on the issue.

For example
In Birmingham, there is a policy decision that all services supported by the SLOT team will involve people having proper tenancies. Housing partners are often sourced through support providers, who identify housing agencies they know will work flexibly with them – whilst still retaining a separation between housing and support contractual arrangements.

4.4 Availability of clinical leadership

As noted in Section 2.3, the availability of clinical leadership, that is listened and responded to (see Section 3) is a central component. Sometimes, but not always, this was through a dedicated team of people working with those labelled as challenging. Even where there was not a dedicated team, the clinicians had a very active involvement in both planning and service delivery, they built strong relationships with partners from other

organisations and crucially were always available and accessible if a crisis arose – no matter what time of day. An additional valuable role was seen to be enabling greater access to mainstream services and in promoting treatment for the whole needs of the individual.

For example
A man in Oxfordshire has been receiving support for eight years since involvement with the police and a number of local and out of county placements that have failed. In 2006 he moved back to his hometown supported by an independent social care provider and a clear person centred service specification. He was proactive in designing his support package and deciding where and when he wants support. Commissioners agreed to the initial very high service costs , and to support it for as long as is needed, believing that costs will reduce in the long run and give better results than periodic in-patient costs at circa £3,500 per week or comparable residential services at about £2,000. The current cost of this man's flexible 30 hours support has now reduced to £500 per week plus additional care management, psychologist and care co-ordination by a specialist learning disability nurse.

4.5 Separating housing and support

Where the most effective progress was being made with individuals, a clear separation of housing and support provision had been instigated. This gave the person housing rights and the knowledge that they would remain supported in the same location – in part removing the temptation and the ability of services to move the person on in difficult times to a more restrictive environment. This involved flexibility in finding suitable housing stock. Sometimes this was done by partnerships with private landlords[6]. Elsewhere the support provider performed a role of sourcing housing through a partner agency. The quality and location of housing was an important factor in ensuring the success of support.

4.6 Cost limits

Whilst recognising overall financial constraints, progress was being made where no arbitrary financial limits of service cost were imposed – resisting the temptation to 'cap' services at a particular price. The learning was that, at least in the first instance, commissioners needed to invest what is necessary to make a service work, derive positive outcomes and thus create the setting from which future reductions in cost could be achieved (see also Section 7.5). Where the RAS formula for individual budgets set such a limit, this was, at the time of our review, not being applied.

[6] The NDTi's Housing and Social Inclusion Project is a source of advice on this issue. For example: 2010 NDTi "Tenancy Rights and People with Learning Disabilities" and "Supported Living – Making the Move"

The Service Model – Actions for Effective Commissioning:

18. Invest in training around true person centred planning for all people involved in designing individual services and support staff in provider organisations.

19. Before agreeing any new service proposal, validate the proposals by comparing to identified stated goals from a person's own person centred plan.

20. Ensure all individual service designs are developed by involving all parties – including the proposed provider as soon as they are identified.

21. Take a policy decision that the use of positive behavioural support and non-aversive techniques is required by all services and include this in contracts.

22. Invest in sufficient skilled, clinical capacity that is available whenever it is needed – either as a dedicated team or with identified capacity within mainstream learning disability community services.

23. Take a policy decision to design all services with separate housing and support to increase people's housing rights.

24. Invest time in developing a range of possible routes into housing stock – including encouraging support providers to develop their own 'preferred housing provider'.

25. Take a policy decision not to impose an arbitrary maximum cost on services.

5 Skilled Providers and Staff

Alongside skilled and values driven clinical support (as previously described), a partnership with a skilled support provider (and housing partner) was an essential component. Support providers deliver the day to day inter-action with people who challenge that will either make or break a support package, and their selection and ongoing role therefore require particular attention. The Providers working in the sites we viewed had developed an organisational culture that encouraged partnership working, innovation and supportive of staff who have the right attitude, are highly trained and motivated.

5.1 Outward Looking

The providers involved in successful services looked outwards in two important ways. Firstly they were willing to learn and take advice from others rather than believing they knew best. Secondly, they looked to the wider community resources for opportunities and relationships for the people they supported. An ability to evidence these characteristics was an important reason why the commissioners selected them in the first place.

For example
In Oxfordshire, service specifications clearly describe the service to be covered within a continuum of support as individual's needs change. This has resulted in contracts being awarded to a range of providers who have shown they are outward looking (able to link with the community supports) for different levels of support, each describing clearly the type of work to be undertaken and the level of staff training needed. The specification requires the provider to demonstrate commitment to the core values of Valuing People and how staff will be supported around the specific needs of the individual they will be working with and operate with a "can do" attitude. The qualities, attitude and skills of the team leader are seen as crucial and the organisation has to demonstrate how they will recruit the right person. The commissioner requires the provider to ensure that they have sufficient numbers of appropriately trained staff so that agency staff are not required or used.

5.2 Knowledge and skill-base

Whilst it was important that providers were able to demonstrate their ability to support people labelled as challenging services, in many ways this was less important than other factors described elsewhere in this document; i.e. a positive attitude to people who

challenge; a willingness to work in partnership with others; the potential for good inter-personal relationships and a willingness to learn and do things differently were all more important factors than a pre-stated 'expertise' in working with people labelled as challenging services. (see also Section 7)

5.3 Following clinical advice

As noted in Section 3.3, successful providers were willing to follow and be accountable for implementing clinical advice in support programmes. Where there were differences of opinion, these were resolved amicably through the partnership approach to relationships described above.

For example
In North East Lincolnshire, service specifications now include a requirement to work with local specialist services available including the Intensive Support Team and health professionals. Local support providers have embraced this and now request and expect support for their staff in the form of access to 24 hr telephone support, debriefing sessions, regular consultation meetings, role modelling on shift and bespoke training around the needs of the individual.

5.4 Providers that Will Not Give Up

As noted in section 1.4, successful providers were willing to do 'whatever it takes' and not give up on people when the going got tough. This particularly required management and leadership in the organisation that would get directly involved in such situations and support their staff through difficult times. Successful providers, with support from the commissioners and the implications described in Section 7.4, were clearly in the partnership for the long term.

For example
In North Lincolnshire the ethos of the multi agency senior manager's forum is that people do not get excluded from services because of their behaviour and the aim is for prevention to avoid crisis. They promote the learning from difficult situations and find ways to deal with issues, find new and innovative solutions and to challenge each other.

5.5 Active senior manager involvement

All these, and other characteristics, required active senior management involvement in (i) the daily life of the delivery of the service (ii) relationships with key partners and (iii) knowledge of the individual being supported. Again, this was a characteristic of organisations that was actively sought by commissioners when placing contracts. In general, this implied a preference towards smaller, local organisations where that active senior management involvement was possible – though larger organisations with significant delegation of authority to local managers could also achieve it.

5.6 Staff skills and attitude

The attitudes and motivation of staff is vitally important. Staff need to understand and see the person they are supporting in a positive light and this will have a direct effect on the interaction between them. Traditionally, many staff are reluctant to be innovative risk takers or instigate change because of concern about the consequences for them personally or for their clients. This reinforces the previous point about active senior management support and involvement. Additionally, it implies that providers should recruit on the basis of attitude and capabilities rather than (primarily) qualifications.

5.7 No use of agency staff

A common success factor was a decision not to use agency support staff. This avoided bringing in people who did not know the individual and would (probably) fail to follow the agreed support plan and interventions. This was avoided by strategies such as a provider having its own regular 'bank' of occasional staff, regular staff working limited overtime, managers covering in times of staffing crisis and crucially having adequate staff numbers to start with in order to avoid 'burn-out'.

5.8 Specified training provided

Successful services ensured that staff training was seen as an important investment. For example, staff must have a basic understanding of the principles of person centred approaches and be trained in the implementation of individual behaviour support programmes. Training delivery was generally specific to the individual being supported and their support plan. Significant elements of this were designed and delivered by clinicians and this was a recognised part of their role. The costs of this were built into the contracts. High quality supervision and support was a non-negotiable.

For example
In Birmingham, the SLOT Team are centrally involved in specifying and designing training programmes for support staff when new services are opening. They help to deliver that training and continue to provide ongoing training support to new and existing staff and families as part of the contractual arrangements.

Skilled Providers and Staff – Actions for Effective Commissioning:

26. Create a framework for provider competencies that is significantly based upon elements such as (i) attitudes towards partnership working (ii) attitudes towards people who are marginalised/labelled (iii) willingness to learn/change, (iv) innovation (v) understanding of community inclusion as well as challenging behaviour.

27. Ensure that service specifications include the need to follow clinical advice in day-to-day service delivery. Establish a 'no blame' mechanism for resolving disagreements.

28. Develop an expectation that providers will have a strong organisational culture and structures as described above to support service delivery, and will continue to try new things when services are not working rather than give up. Ensure providers see that performance in this area is a significant factor for commissioners when awarding new contracts and terminating existing ones.

29. Require active senior management involvement in both your relationships with providers and the regular operation of services for people who challenge. Monitor this.

30. Encourage providers to place staff attitude and behaviour as a prime recruitment requirement. Require evidence from providers of how they encourage staff to take sensible risks and be innovators.

31. Place significant emphasis on training for provider staff and fund it in the contract. Require training to be regularly updated and based on the identified needs and individual plans of individuals and monitor this. Ensure clinicians are resourced to deliver parts of this training.

32. Ensure supervision and support for staff are part of contractual arrangements and are regularly monitored.

6. An Evidence Base

The availability of an evidence base about the impact of services and outcomes for people was important for two main reasons. Firstly, commissioners and providers need hard evidence to know whether the services being provided are working. From a commissioner perspective, some providers have learnt the words of being person centred whilst doing different things in practice, and hard evidence is needed to demonstrate actual outcomes. For providers, such data will help internal management decisions as well as evidence contract delivery to commissioners.

Secondly, services to people who challenge that work and deliver good outcomes are often expensive. In difficult financial times they can be an easy target for cuts. Being able to demonstrate that they provide good outcomes and sound value for money is therefore important in order to protect medium/long-term investment.

6.1 Outcomes for People

Whilst there was limited development of outcome methodologies in the sites we reviewed, where they had been developed this was an important tool in informing commissioning and evidencing progress. Nowhere were the traditional NHS and LA datasets viewed as helpful so new indicators were being developed, sometimes in partnership between commissioners and providers and with support from individuals and families.

Providers were happy to have a small number of mutually agreed measures that were relevant and testing rather than a large number of meaningless indicators to report.

For example
North Lincolnshire's "Bigger and Better Lives Now" Commissioning Strategy for people with learning disabilities details their progress in establishing local outcome measures.

"To measure an outcome we need to apply the "Three way thinking" approach. Firstly to understand the ACTIVITY that is delivered to meet the outcome, the QUANTITY of activity, the how much and lastly the QUALITY. This is known as Triangles. Looking at one measure alone will not give the whole picture."

At the moment the outcome measures are those used for Self Directed support and the objective is to move to further focus the outcomes on the wishes of the individual rather than the narrow focus of the assessed need.

These varied from a local adaptation of the REACH[7] standards to assess outcomes for individuals, through to process measurements that could evidence changes such as reductions in medication, use of on-call, person centred planning, stability of staff team, reductions in incidents and reductions in referrals to other health teams. In the future CQUIN and QIPP measures are likely to be relevant, but at the time of writing, details had not been developed sufficiently for this specialist service.

6.2 Financial cost

All the places we reviewed had developed, to varying extents, data on the financial impact of their service developments. (An ability to be able to demonstrate that their work was cost-effective was a pre-requisite of us reviewing them as a site of good practice). The collection of financial data on service costs prior to intervention and/or support from the challenging behaviour support service and then costs of that individual's service over time were a crucial tool in both commissioner decision making and arguing for continued investment in services.

For example
In Birmingham the Commissioners have used existing cost analysis systems to ensure there is an ongoing breakdown of costs and potential savings. The information is shared regularly with clinicians and providers and informs commissioning decisions.

An Evidence Base – Actions for Effective Commissioning

33. Agree with partner organisations (including families) what you will monitor in terms of outcomes across the whole population of people who challenge. This should be a mix of real outcomes in people's lives and process changes that will tell a real story about what is happening.

34. Instigate a system for recording and analysing financial data – i.e. cost of services over time.

[7] Paradigm – "Reach Standards in Supported Living" 2002

35. Create the capacity to track and analyse these two sources (outcomes and costs), and regularly report to all partners to inform about progress and (hopefully) retain momentum and support for the work.

7 Specific Commissioning Actions

A section on commissioning has intentionally been left until last because all of this document is about what commissioners should be doing. However, there are a number of specific commissioning actions that are not explicitly covered by the previous sections.

7.1 Up-front investment

Responding effectively to people who challenge services involves making an up-front investment. Firstly, this is because there is a need to get into place the particular expertise to do the job well (e.g. skilled clinicians, commissioning/care management capacity). Secondly, it will probably take a year or two before people's new services are working effectively to the extent that costs can then be reduced (see also Section 7.5). Places that have made progress have done this initial investment, sometimes through identifying short terms funding sources such as Invest to Save monies. Elsewhere, commissioners were able to revisit existing contracts and either change them or amend funding levels in order to create the capacity to develop the necessary expertise. Similarly, contracts with providers have been renegotiated to change their ways of working with people who challenge services.

For example
In Birmingham the Supported Living and Outreach team (SLOT) was started with Invest to Save funding (£500K over 3 years) and this resulted in the PCT then fully funding the team on the basis of dealing with a number of cases per year. Recurrent savings of nearly £900K have been built up over an eight-year period against a growing number of people being supported to move into local rather than remote services. This evidence demonstrates the cost effectiveness of both the original investment and the ongoing expenditure.

7.2 Provider selection processes

This was a crucial issue. Other points in this document have emphasised the importance of strong relationships based upon trust rather than traditional arms-length contracting systems.

A starting point has to be existing providers. Some will want to work in these new ways and be able to do so. Others will not. Some new providers will therefore probably need to be identified. Use of a 'framework' contract has been successful – inviting providers to present themselves as having the right ethos and commitment to become preferred provider partners for working with people who challenge services. From this, within contracting regulations, rather than then tender all services, what has worked is a process of mutual understanding that good performance will result not only in retaining the existing contracts, but will also result in new contracts being offered. This helps build and foster the important spirit of long-term partnership that we have identified is desirable. Such long-term partnerships result in the provider being able to spread good practice and retain good staff whilst also enhancing their own credibility.

For example
The use of a framework agreement with potential providers enabled the commissioner in Birmingham to "talent spot" organisations not currently active in the learning disability field. As a result, they brought in a new provider previously working with asylum seekers who is now a trusted and long-term partner in the City.

7.3 Contracting Processes

Linked to this, flexibility in contracting processes is something that will help improve outcomes and value for money. The needs of people who challenge can change at short notice. Quick and effective systems are needed to achieve contract variations and introduce new types of support that might be outside the scope of normal Social Services contracting. This issue will obviously change if and when individual services for people who challenge are purchased through personal budgets as such flexibility will need to be an inherent part of the new arrangements.

For example
In North East Lincolnshire, the commissioner brought in external expertise to manage a 'Reshaping the Market' project. He was able to provide both focus and containment for the local champions, keeping things moving forward even when things seemed overwhelming and impossible within the timeframes.

In Oxfordshire, the choice of the person themselves is the key criteria for call off under the umbrella of framework contracts. This allows for very flexible contracting in which people can take their allocated budget and move to a different contract (or a Direct Payment) if they wish. Their personal budget can also be increased or decreased if their needs change, and under the contract the provider is required to support the person in line with their person-centred plan.

7.4 Continuing Healthcare Funding

Good progress has been made where a positive and shared approach to continuing care funding has been developed. The simplistic approach used is some places of more complex people being deemed to be 100% NHS funding and people with less complex needs 100% local authority funding fosters neither a spirit of partnership nor a person centred approach to services. A pragmatic approach, possibly based on using the DH's Decision Support Tool[8], with the shared aim of using funding creatively and crucially sharing the financial risk has been shown to help commissioning decisions. Without this being in place, continuing care debates risk delaying and even blocking people getting the support they need and risk failing to make best use of the appropriate support from local health and social care systems.

7.5 Shared financial risk

For example
In North Lincolnshire we heard that a shared ethos of willingness to develop and change was needed from the provider rather than just to bring people back from out of county. We found providers willing to take a risk on running at 50% capacity and putting resources into winning over the local politicians and residents. The longer-term benefits for this provider were what made them willing to do this.

The development of good relationships and common values described elsewhere has led in the sites we reviewed to the establishment of local risk-sharing arrangements. Shared investment along with the potential for shared financial benefit as outcomes and costs improve was important 'glue' in the relationship. This applied both between commissioners and also between commissioners and providers. Such mechanisms might operate through "Panel" settings or joint funding meetings – but these only worked where speed of action and delegated authority were also in place.

Maintaining the partnership, even when relationships are challenged, is important. Allowing even a temporary break risks significant resources being used for assessing and reassessing eligibility. Sites that were continuing to work actively in partnership, being aware of the changing pressures on each other, were more likely to find local, pragmatic solutions that strengthened the working relationships.

Section 8 notes some of the particularly 'vulnerable' areas, including NHS/local authority partnership that, if allowed, can undermine progress towards delivering the Mansell Report recommendations. Risk sharing arrangements thus need to be able to sustain local processes and progress in the face of changes brought about by, for instance, changes in national policy or in local personnel.

[8] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103329.pdf

7.6 Targeted financial savings

Even prior to the current financial constraints facing the NHS and local government, the sites we reviewed understood the importance of, over time, reducing the costs of expensive services for individuals. The experience is that, if done sensitively, this can have a positive impact in that it encourages a focus on positive risk-taking, natural supports and 'ordinary life' rather than always retreating to models based upon large numbers of paid staff supporting people. However, any such strategy which actively seeks reduction in costs has to be associated with the other elements described in this document, e.g. retaining individual focus, respecting clinical advice and measuring outcomes.

For example
It is an inherent expectation of the work in Birmingham that costs will reduce over time. All partners (including providers) are aware of and accept the explicit requirement to drive down costs and make packages less intensive, while still being person centred and individualised.

Related to this, most commissioners had sought to plan individual services in ways that enabled access to funding sources beyond the NHS and Social Services – for example the Independent Living Funds, Access to Work and Supporting People.

7.7 Do what is shown to work

In essence, this is what this document is about. Where progress has been made, commissioners have acted on the basis of what is shown to work for people who challenge – both in terms of the national evidence base and also the experience of individual people they are supporting. In other words, commissioners are strongly advised to do all the things that this document recommends!

Specific Commissioning – Action for Effective Commissioning

36. Identify at the outset how you will create sufficient skilled resources to respond to the Mansell Report. Think about clinical input, individual planning, overall management/liaison, evaluation, provider skills etc. Review existing contracts and effectiveness of current service delivery. Try to identify 'invest to save' monies with a three year time-horizon. Some disinvestment in other things will

probably be inevitable. Give this resource time to influence behaviour and services before you start setting up new services for individuals.

37. Following the 'provider competency' analysis (Action point 26) review existing providers against this and then also invite new providers to create a set of preferred providers who will be awarded contracts. In doing this, think "outside the box" and look for new or different partners.

38. Take into account the track record of providers in working in partnership and delivering person centred outcomes when awarding new contracts. Ensure that you consider all available contracting options, such as framework contracts or preferred provider lists, which can lead to a stable group of providers able to develop partnership with commissioners over a period of time rather than always use open tendering.

39. Discuss with contracting and procurement colleagues how they can maximise flexibility and speed of response in order to support delivering the vision and values for people who challenge. (e.g. finance, contacting, commissioners of MH, LD, prison, primary care and children's services).

40. Agree principles for CHC funding that promote (i) shared funding responsibility (ii) ordinary life service solutions and (iii) quick decision making.

41. Agree a financial risk-sharing protocol around both investment and potential future savings.

42. Agree the principle of seeking to reduce costs of individual services once they are firmly established – but in the context of demonstrable outcomes and safe practice and not as a fixed or arbitrary figure per year with reference to possible results if changed funding.

43. Bring together budget management of both health and social care funding for people who challenge so there is clarity about what funding is available and how it is to be used.

8. Areas of High Risk

We are aware that the agenda outlined above is a challenging one, but we have found places in England that have made significant steps forward with it. These things are possible and achievable. In our analysis of progress that is being made, we identified five particular 'areas of risk' where there is significant vulnerability across different locations that could result in the whole progress to better lives for people who challenge services falling apart. There are no specific additional actions proposed in relation to these items, as they are all already covered in the previous sections, but particular attention does need to be paid to these issues by commissioners and their partners.

8.1 Getting started

Surprisingly we found that few places had addressed this issue in a strategic way. Progress had generally been made because a few people got together, decided to do something, and persuaded other people to let them get on with it. Generating a sense of shared ownership – rather than a written document - was often the starting point. Whilst it is good to encourage this sense of 'entrepreneurship', it means there is always a risk that the work will stop if some key people leave or the organisations decide to withdraw support. Also, it means that different people may have different understandings of what the work is about and what it is trying to achieve. There is a need to ensure that there is an agreed strategy for people who challenge services, as part of wider health and social care strategies such as the Joint Strategic Needs Assessment, that is part of the investment and development plans of both the NHS and local government. Seeing this as a strategy that starts in childhood – with an emphasis on prevention and links with children's services - will increase the chances of success and managing future service demands more effectively.

8.2 Breadth of Involvement

Linked to this, it can be difficult to get the issue of services for people with challenging behaviour on the wider agenda within organisations. In a number of places, the initiative to improve services for people who challenge is only 'owned' by a handful of people. If they departed, there would be a serious risk of the good work falling apart. Where senior staff are aware of the long term implications (usually financial) of good local services, services are more easily able to implement sustainable change. However, as the numbers of people needing this intensive support are small, and the issues they present costly in terms of staff time, it is often difficult to gain whole organisational support. Senior level understanding, committed leadership and whole-system involvement are therefore vital.

8.3 NHS/Local Authority Partnership

Although this commissioning partnership was important – it was also something that was a continuing source of concern for the people leading work on improving services for people who challenge. Time had to be invested in managing the interface between the two authorities that could have been better spent on working directly on improving services for people. Different processes and systems delayed decision making and service change. Arguments about funding continued. It is essential that senior managers agree and take action to ensure that administrative and organisational tensions between the two sets of commissioners are not allowed to inappropriately impede good services being developed and delivered for these highly vulnerable people.

8.4 Flexible Purchasing processes

Most sites we reviewed were continually struggling with pressures from the general local authority or PCT contracting processes to 'kick back' against the flexibility they were using that was demonstrably working for people who challenge services. For example, having to follow complex procedures to amend service contracts when people's needs changed resulted in delays and people's behaviour going backwards. Corporate decisions to re-tender all services even those that were demonstrably working for vulnerable individuals created uncertainty and undermined relationships. These things meant that managers and clinicians working with people who challenge had to spend excessive time negotiating the bureaucracy rather than working with more people and achieving better outcomes. It is important that the whole commissioning and contracting system understandings the importance of flexibility and creativity when working with people with such complex needs.

8.5 Place of clinical involvement

As previously noted, whether the clinical support was dedicated in a specialist team or accessed through wider resources varied. Research has highlighted the strengths and weaknesses of both models e.g. if a specialist team the risk is of boundaries appearing and generic clinicians not seeing people who challenge services as ‘their business’ or developing the necessary skills. On the other hand, if services are generic there is also a risk that the necessary skills will not be retained and/or that the close relationships and in-depth knowledge will not be available. These tensions were evident in the sites we reviewed and need continuing attention to ensure that, whichever approach is taken, the right skills are available and sustained.

MAHI - STM - 118 - 2365

MMcG-269

Commissioning Specialist Adult Learning Disability Health Services

Good Practice Guidance

Commissioning Specialist Adult Learning Disability Health Services

Good Practice Guidance

Prepared by Office of the National Director : Learning Disabilities

DH INFORMATION READER BOX

Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	**Social Care / Partnership Working**

Document Purpose	Best Practice Guidance		
ROCR Ref:		**Gateway Ref:**	8530
Title	Commissioning Specialist Adult Learning Disability Health Services		
Author	DH. Office of the Dational Director: Learning Disabilities		
Publication Date	31st October 2007		
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Directors of Nursing, Directors of Adult SSs, PCT PEC Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads		
Circulation List	Learning Disability partnership Boards. People with learning Disabilities. Family Carers.		
Description	Good practice guidance on the commissioning of specialist learing disability health services for adults, in particular to assist in responding to shortcomings identified in these services in recent Healthcare Commission reports including those into abuse in Cornwall and Merton and Sutton.		
Cross Ref			
Superseded Docs	N/A		
Action Required	N/A		
Timing	N/A		
Contact Details	Rob Greig Office of National Director: Learning Disabilities Westward House, Lime Kiln Close Bristol BS34 8SR 0117 984 1799		
For Recipient's Use			

© Crown copyright 2007
First published date

Published to DH website, in electronic PDF format only.
http://www.dh.gov.uk/publications

Executive summary

The commissioning of specialist health services for people with learning disabilities is an important function of Primary Care Trusts – in partnership with their local authority colleagues. A number of recent reports, most noticeably the Healthcare Commission reports into abuse in Cornwall and Merton and Sutton, have shown that these services are not always commissioned effectively and in line with best practice. In response to this, Ministers promised that the Department of Health would produce this good practice advice on commissioning these services.

This advice draws on best practice from across the country and provides direct help to commissioners that, if followed, will result in an improved quality of specialist learning disability health services. It covers descriptions of:

- The changing demand for and supply of services
- How these services fit into the wider changes in the NHS
- The policy context
- Detailed descriptions of the different component parts of specialist learning disability health services
- A resource guide for further information and support

The Valuing People Support Team are available to help both commissioners and providers make use of this good practice advice over the coming months.

Whilst the Valuing People policy is, quite rightly, a policy based on promoting the rights of people with learning disabilities and their social inclusion, this can only be achieved if people have the right services and supports to meet the health needs that arise directly from their learning disability. Such services have not always, in the past, been delivered in a way that helps to promote social inclusion. This guidance is an important tool in helping to ensure that this is the case in the future.

Rob Greig
National Director: Learning Disabilities

Contents

Purpose of the Guidance

1. Government policy (*Valuing People)* states 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 high standard, and with additional support where necessary*'. This relates to both mainstream (primary, acute and preventative care) and specialist learning disability health services.

2. There is growing concern that some areas of the country have found it difficult to develop commissioning strategies for specialist adult learning disability health services that reflect both current policy and best practice. (In the context of this paper, specialist health services means services that are commissioned to respond to health needs directly relating to or arising from a person's learning disability. Specialist staff refers to staff who are trained and employed to specifically focus on health needs arising from a person's learning disability).

3. This has led in places to inappropriately funded services, outdated service models, the poor development of a community infrastructure and an over-reliance on bed based services (including NHS campuses and distant NHS & independent sector placements). Additionally, the lack of appropriately funded and skilled specialist learning disability health services can be a major cause of failure by social care services that are commissioned by local authorities.

4. These, and associated problems, can mean that

    - people with learning disabilities are getting 'stuck' in the NHS system or independent health placements often for many years and sometimes many miles from their home and/or,
    - people are often placed in increasingly expensive and inappropriate social care services that are failing to meet their needs.
    - People experience serious difficulty getting their healthcare needs met and are at risk of neglect and, at worst, abuse.
    - Both family carers and paid carers receive inadequate support and training by specialist health care staff, resulting in an increased demand for health interventions at a later date.

5. These problems have been highlighted by the Healthcare Commission and Commission for Social Care Inspection report into abuse in NHS learning disability services in Cornwall and the Healthcare Commission's Merton and Sutton investigation. In both cases, poor quality or absent PCT commissioning, along with a lack of investment in specialist community health services were identified as significant causal factors of the organisational failure and abuse.

6. The Disability Rights Commission Formal Investigation into the health inequalities facing people with learning disabilities identified how mainstream primary care services are failing to properly include and meet the general health needs of people with learning disabilities. The Mencap report 'Death By Indifference' identified similar failings in acute hospital care and has resulted in the Secretary of State establishing an Independent

Inquiry to produce recommendations for national and local action. A failure to invest in specialist learning disability health professionals who can facilitate and support primary care staff and general hospitals to meet the needs of learning disabled people is a causal factor in these failures.

7. Ministers undertook to provide good practice guidance on commissioning specialist learning disability health services in the light of these reports. This is that guidance. It describes and clarifies existing government policy in relation to these services and good practice from across the country. Its purpose is to provide advice, support and a steer to local leadership in both the NHS and local government in order to achieve improved performance, better outcomes, reduced health inequalities and prevent abuse and neglect.

8. In line with other commissioning guidance from the DH, this document is underpinned by the wider approach to commissioning policy and implementation. A summary of this is contained in Annex A.

Target Audience

9. This good practice guidance is primarily written for

- PCT commissioners
- Local authority commissioners where lead commissioning responsibility for learning disability services has been transferred to them using Health Act (1999) flexibilities
- Specialist and regional commissioners of learning disability health services
- Learning Disability Partnership Boards in their strategic overview role in planning learning disability services and to assist them in advising PCT or local authority commissioners on this issue
- Providers of specialist learning disability health services & specialist professionals
- The Healthcare Commission, Commission for Social Care Inspection and the Mental Health Act Commission to assist in their regulatory and inspection roles.

10. An easy-read summary of this document is available to assist self-advocacy organisations & family carers to participate in planning and commissioning of these services.

<u>Background</u>

11. In addition to the overarching issues described above, a number of factors are driving the need of commissioners and providers to pay attention to specialist learning disability health services.

Demand for services

12. Three major factors are creating change in the demand for specialist learning disability services:

- Significantly increased numbers of people with learning disabilities, partly caused by people living substantially longer as a result of medical and technological advances

– and thus people needing additional support around illnesses linked to old age, in particular dementia and people with Downs Syndrome.

- Significant changes in the demographic profile with increased numbers of people with complex needs requiring input from specialist health professionals. This particularly applies to young people with multiple disabilities and, together with the above point, will require commissioners to consider levels of investment in both mainstream and specialist health services.
- The increasing empowerment of people with learning disabilities and their families, resulting in them expecting and demanding better quality services located nearer to their home and communities.

In addition to these major causes, patterns of spending are changing as a result of factors such as an increasing demand to support people with autistic spectrum disorders better diagnosis and early identification of need.

Supply of services

13. There has been significant changes in healthcare provision for people with learning disabilities in recent years, including the process of closing and replacing learning disability long-stay hospitals organisational re-configurations, and changes in commissioning patterns. This has resulted in a highly variable specialist health services across the country. In some places there are resourced and skilled services working well in partnership with the local authority and the independent sector. Elsewhere, either outdated and poor quality services have remained in place, or the NHS has withdrawn too far from learning disability services and there is insufficient investment in specialist health capacity. In particular:

    - There are up to 3000 NHS campus beds which government policy states should be closed and replaced with ordinary housing and support run and managed outside the NHS. (It would be inappropriate for an NHS Trust seeking Foundation Trust status to include the continuing provision of NHS campus style beds in its business planning assumptions).
    - There is a growing use of independent sector hospitals and residential social care services that are often many miles from a person's home and community. .
    - A significant proportion of NHS assessment and treatment services, including those with higher levels of security, are effectively out of use (blocked) as people have lived in them for years due to delayed discharge and lack of investment in non-bed based provision.
    - The numbers, skills and availability of specialist health professionals vary considerably as do the arrangements and robustness of team structures. In some places the provision is clearly inadequate. Elsewhere, professional skills are not always used to best effect.

Transactional Reform

14. The responsibility for commissioning specialist learning disability health services for people with learning disabilities falls to Primary Care Trusts (with certain exceptions regarding secure regional and national provision). This has to be undertaken in partnership with the local authority. This responsibility often rests with a Joint Commissioner who is responsible to both the LA & PCT -usually employed within the

local authority. In a small number of locations, this responsibility has been formally delegated to the local authority using the lead commissioning powers contained within Health Act (1999) flexibilities.

15. A lack of expertise and capacity within PCT's to commission evidence-based learning disability services in partnership with the local authority has been identified as a problem in a number of places including the recent Healthcare Commission reports. The Chief Executive of the NHS wrote to all SHA and PCT Chief Executives in November 2006 stressing the importance of ensuring the existence of capacity and expertise around commissioning learning disabilities.

16. The Department of Health, in partnership with the Healthcare Commission, has produced advice as part of the Better Metrics programme to assist PCTs in developing local performance measures for both specialist learning disability health services and the inclusion of people with learning disabilities in mainstream health commissioning.

17. Learning Disability Partnership Boards and in particular health sub-groups, should be key players in shaping the design and delivery of local health services. The appropriate senior lead official from the PCT should be an active member of the local partnership board.

18. Recent reforms to the NHS need to be applied in relation to learning disability services. For example, the provision of information to assist people and their families take informed decisions and make meaningful choices about the available services. Given the importance of these services being strategically commissioned in partnership with the local authority – or possibly being 'lead commissioned' by the local authority on behalf of the PCT, it is inappropriate to use practice based commissioning for specialist learning disability health services. However, PBC will need to ensure that people with learning disabilities are fully included in the commissioning of all mainstream healthcare provision, in line with Disability Discrimination Act requirements.

19. The largest proportion of learning disability funding within the NHS is dedicated to the funding of social care services. This represents the historic NHS investment in learning disabilities from when the NHS ran large long stay hospitals (for around 40,000 people) This funding should be transferred to local authorities using either section 256 (formerly 28A) or section 31 powers, to enable local authorities to lead the commissioning of all social care services. It is government policy that this transfer should continue beyond the deaths of individuals previously living in the hospitals in order to help meet the costs of the new generations of people entering services who historically would have been supported in NHS long-stay institutions.

20. Ministers confirmed a commitment to strengthen the commissioning of learning disability services in the light of the Healthcare Commission report on the abuse in Cornwall. As part of this process, consideration will be given to a stronger role for local authorities. Further details will be available in the near future.

Policy Context

21. In the Government White Paper for Learning Disabilities – *Valuing People (DH 2001)* the main objective for health 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 high standard, and with additional support where necessary'.

22. *Valuing People* builds on several pieces of health policy and guidance related to the health of people with learning disabilities. Specifically, *Signposts for Success (DH 1998), Once a day (1998), Mansell Report (DH 1993) Reed Report (DH/Home Office 1992)*. Since then, policy has been further developed by publications such as *Action for Health (DH 2002),* and *Commissioning services close to home (DH 2004).*

23. These documents form a framework for the commissioning of specialist learning disability services and together emphasise that services should aim for the following outcomes:

- Specialist learning disability health services that both support mainstream practice and directly serve those with the most complex needs
- Specialist learning disability health services that promote safe, person-centred support and evidence based practice.
- Integrated planning and the development of care pathways that promote individualised services that are closer to home
- Service development that directs people away from institutional responses to crisis and, wherever possible, supports people in their everyday surroundings.
- Support to people and families when needed through swift access to the services of specialist professionals including medical, nursing and allied health professionals.
- Investment in training and development not just for specialist professionals but also for families and for front line support staff to enable them to better support people where they live.
- A robust community infrastructure that takes a broad view on addressing health needs and considers the range of factors associated with poorer health and other risks associated with social exclusion. For example by ensuring that responses to health problems do not preclude options to achieving paid employment or independent housing.
- New alliances and approaches to secure better and more inclusive services (including the decommissioning of poor quality and inappropriate provision e.g. NHS Campuses)
- Ensuring that the 'voice' of people and families is heard and there is evidence of appropriate representation, including independent advocacy,
- Fulfil all legal requirements, including those arising from the Mental Health Act, Mental Capacity Act and Disability Discrimination Act.

24. These principles are endorsed in other generic policies for the NHS including "Our Health, Our Care, Our Say". This White Paper contains three policies of particular relevance to specialist learning disability health services:

- A commitment to close and replace NHS campuses by 2010 (see para 50 below)
- A commitment to implement previous policy undertakings to introduce comprehensive health checks for people with learning disabilities (see para 37 below)
- A commitment to introduce individual budgets NHS healthcare money cannot be used for individual budgets, but resources transferred to the local authority under section 256 arrangements for social care purposes can form part of an individual budget.

Equalities Considerations

25. As noted in paragraph 16 and elsewhere, commissioners have legal duties in relation to equalities. Commissioners will therefore need to ensure that the impact and effectiveness of their commissioning of specialist learning disability health services is integral to Disability and other Equality Strategies and may need to carry out equality impact assessments in relation to disability, race, gender and other aspects. Specifically, it will be important to ensure that specialist health services have the skills and capacity to recognise, respect and respond to people's individuality – including their race, gender, age, religion and sexual orientation. For example, there is some tentative evidence from the Mental Health Act Commission (ref) of a shortage of gender specific in-patient beds for women with learning disabilities who are detained under the Mental Health Act.

Description of Learning Disability Specialist Health Services

Specialist community health staff

26. The most critical component of specialist learning disability health services is the commissioning and employment of a range of staff with the skills to support people with learning disabilities in all settings, providing specific and additional input as required to respond to their health care needs.

27. Such staff have an essential clinical and therapeutic role, which will include:

- support to people and their families when their needs cannot be met by mainstream services alone. This will involve partnership working with other mainstream health services and appropriate specialist services.
- support to people and service providers in the provision of longer term support for people who may have complex and continuing health needs.
- As well as planned evidence based interventions, specialist health staff and their social work colleagues (see below on CLDT's) should be able to provide emergency support. This should be in partnership with local mental health colleagues and joint protocols should be in place to ensure appropriate support to people and families (DH 2005)

28. Valuing People describes how "in addition to their clinical and therapeutic roles, specialist staff should take on the following complementary tasks:

- the health promotion role; working closely with the local health promotion team
- the health facilitation role; working with primary care teams, community health professionals and staff involved in delivering secondary healthcare
- the teaching role; to enable a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health needs met
- the service development role; contributing their knowledge of health issues to planning processes."

29. Specialist learning disability health staff are most likely to be employed within the local NHS, with those not in in-patient settings, operating as part of, and being accountable

within, a multi-disciplinary structure such as a community learning disability team (CLDT) that is led or jointly led by the local authority. Employment within the NHS alongside other health professionals is important in order to maintain appropriate clinical governance, professional development, relationships and learning from colleagues working in other specialisms and to avoid recruitment and retention problems. However, day-to-day operation within a multi-agency framework is essential for the achievement of good person centred outcomes. Being recognised as part of the NHS is particularly important for staff working to promote access to mainstream primary care and acute hospitals in order to facilitate day to day working relationships with NHS colleagues. The Chief Nursing Officer is issuing 'Good Practice in Learning Disability Nursing in December 2007.

30. In determining who to work with, specialist health professionals will pay regard to joint eligibility criteria established as part of joint working arrangements. However, specialist health professionals have a specific health role to play and may find themselves working with people who are not eligible for access to social care services, as determined under 'Fair Access to Care'. Professional judgement, interpreted within the framework of local PCT commissioning decisions, should determine who receives input within the available resources.

31. There will need to be a range of staff skills commissioned and recruited as part of these community health infrastructures. This will include (but not necessarily be limited to):

- learning disability nurses,
- clinical psychologists
- psychiatrists
- physiotherapists
- speech and language therapists
- occupational therapists

Further information on the roles of each profession can be accessed from the website of the relevant professional body (see Annex B).

32. Commissioners need to ensure that investment in specialist community health staff and other forms of community based health support is commensurate with changes in NHS in-patient provision i.e. there is a robust community infrastructure to support people with complex needs living in their own home – particularly:

- campus closure,
- the need to reduce distant specialist health placements, and
- the fact that they will be concentrating on supporting people with more complex needs

Specialist teams

33. In some localities, the drive to support people close to home and to avoid hospital admission, has led to the development of specialist support that is either part of, or works in partnership with, the CLDT and/or Community Mental Health Teams (CMHTs).

34. Many focus on supporting people who challenge services, have additional mental health needs or a history or risk of offending. They offer advice and support to other professionals and those who provide care on a day to day basis, as well as direct intervention with people and families.

35. Although they may not use the same titles or terminology, the functions that many of these teams perform are similar and include:

- **early intervention** – community based treatment and support, including a focus on young people and their families
- **crisis resolution** – preventing admission to hospital by providing 24hour community based treatment
- **assertive outreach**. – supporting people with complex and enduring needs within the community

36. It is critical that commissioners ensure there is investment in the provision of these functions within local strategies if an over reliance on inappropriate hospital or nursing home provision is to be avoided. Further advice will be provided by the Valuing People Support Team on models for such services.

General health needs

37. Part of the focus of specialist community health staff commissioned by the PCT should be on supporting the mainstream health service to ensure the delivery of good quality general health care to people with learning disabilities. The DRC formal Investigation report offers a framework for issues to consider when commissioning such services. Whilst aspects of this are part of the role of most specialist community health learning disabilities staff, there is emerging evidence that the good outcomes can be achieved by identifying and resourcing specialist staff (this is often learning disability nurses though can also be a role for Allied Health Professionals) with the explicit role to liaise with, train and support the primary care and acute sector to better meet the healthcare needs of people with learning disabilities. In some places specialist professionals formally 'link' with particular GP practices. This is particularly important in supporting the delivery of comprehensive health checks for people with learning disabilities. Advice has been produced on how best to do this (see Annex B).In the case of acute hospitals the appointment of an 'acute liaison nurse' has been resulted in many examples of improvements in the quality and delivery of services. Relationships with 'end of life' services such as hospices should also be considered.

38. In addition, it is critical to ensure there is an effective and identifiable ***strategic*** presence within the Primary Care Trust to inform and support the commissioning and delivery of accessible, high quality health care for people with learning disability. In many places 'Strategic Health Facilitators' have been appointed to undertake this role and have been instrumental in meeting this need, in providing strong leadership and in promoting health facilitation and health action planning for people with learning disabilities. Such a role can also act as a resource to public health colleagues.

Inpatient services

39. Whilst many people's health needs will be able to be met in the community, for a small number of people access to a specialist learning disability hospital bed will be appropriate to their diagnostic and treatment needs at that point in time. It is likely that, for each PCT, there will be need for no more than a handful of such beds at most.

40. It is critical that commissioners are able to distinguish and make appropriate investment in services to meet this genuine need whilst preventing inappropriate admissions to isolated and outdated models of service provision or purchasing services commissioned by other PCTs a long distance from peoples' home community. Where people are placed away from their own locality by PCTs, it is even more important that the PCT regularly reviews the service in order to ensure it is still appropriate and the person should not be brought back to their own locality.

41. In-patient services need to be part of the whole system of service delivery for people with learning disabilities and have a defined place and purpose. Services need to be able to demonstrate their relevance to local needs and not promote or perpetuate inappropriate 'out of area' placements.

42. It will not be feasible for all localities to provide the whole range of in-patient services that may be required. However, PCT commissioners will need to ensure that people are able to gain access for the assessment and treatment of their needs without undue waiting or recourse to services a long way from home. This may be achieved by working together with neighbouring authorities and strategic commissioners and in particular, those concerned with mental health and forensic services.

43. Commissioners will need to invest in the development of care pathways that prevent people getting 'stuck' in NHS or independent sector assessment and treatment beds. This is best done through effective partnership with the local authority who will be leading on the commissioning of the social care services that are essential to enable people to leave assessment and treatment beds. Such an approach should also indicate where there may be an over reliance on beds and under investment in community based supports.

44. Whether inpatient services are provided by the NHS or independent sector, they will need to ensure and demonstrate that they are person centred, high quality and providing evidence based assessment and treatment with demonstrable positive outcomes for people.

45. Where possible and appropriate, in-patient mental health services should be delivered as part of local mental health service provision. However, such services can lack skills in working with people with learning disabilities and as a result people may be placed in a vulnerable position. The review of the Mental Health NSF taking place shortly will specifically consider how to promote the effective inclusion of people with learning disabilities in the improvement of mental health services.

Forensic services

46. An important component of specialist learning disability health services is that of services that will support people who offend or are at risk of offending. Commissioners have a responsibility to ensure that the following basic principles for forensic services set out in the Reed report (DH 1992) are met

- services should be designed with regard to the quality of care and proper attention to the needs of individuals;
- as far as possible in the community rather than institutional settings
- under conditions of no greater security than is justified by the degree of danger they present to themselves and others
- in such a way as to maximise rehabilitation and their chances of sustaining an independent life
- as near as possible to their homes and families, if they have them

47. Such services may include a specialist team as outlined in para 35 above, along with access to appropriate locally based services where and when necessary. However, the linkages and working relationships of such services are at least as important as the services themselves. Commissioning consideration needs to be given to:

- links to specialist learning disability and mental health services (including alcohol and substance misuse programmes)
- the interface with the criminal justice system such as police, probation and courts and support to court diversion initiatives.
- The involvement of other agencies such as housing, employment, and education to help facilitate pathways away from the criminal justice system
- The role of Learning Disability Partnership Boards in facilitating this broad involvement and in particular in ensuring that the needs of those who are placed out of area are not 'forgotten'.

48. As with some other forms of inpatient provision it may not be possible, or appropriate, to provide a local service. Commissioners should ensure that there is a 'good fit' between local, regional and national commissioning strategies and that they are informed by robust information about the needs and wishes of people who use such services.

49. For people with learning disabilities who go to prison there should be health screening programmes that identify their learning disability, physical and mental health issues, access to appropriate education and rehabilitative programmes and links to the specialist learning disability community teams described in this guidance.

Other bed-based services

NHS campuses and similar accommodation

50. Government policy is clear that it is inappropriate for people with learning disabilities to live with the NHS as their long term 'landlord'. Therefore, the NHS should not be managing services where people live on a long-term basis. This particularly applies to the NHS campuses where up to 3000 people live with the NHS as their long-term landlord and care provider. Policy is that these should close and be replaced by appropriate

housing and support (and increased community specialist health care infrastructure) by 2010 and the resources transferred to local authorities to help fund future services. This policy decision is based on a combination of the evidence base of poor quality of people's lives in NHS campuses and concern about the lack of rights accorded to people in such settings.

Continuing health care

51. Some people may need health care for a long time and their health needs may be met through primary care, in their own homes or in care homes. People with learning disabilities should not be using NHS commissioned beds for continuing care unless they have highly complicated or unpredictable health needs, or a rapidly deteriorating or unstable, or terminal condition which requires regular supervision by medical staff.

52. The general principle underpinning continuing care as described in Valuing People is that people with complex needs and people who particularly challenge services, should be provided with" ordinary housing and support services, in the least restrictive environment possible, with opportunities to lead full and purposeful lives." i.e. additional and specialist continuing healthcare support should ideally be provided into a person's ordinary living environment rather than in a separate NHS bed. The Department of Health has recently produced new guidance on continuing care following public consultation.

53. It is not appropriate for people who are sometimes described as 'challenging services' to automatically become the sole responsibility of the NHS nor for intensive NHS continuing care to be assumed to be the most appropriate service response. The DH is re-issuing the 'Mansell Report' which describes appropriate commissioning and service responses for people who challenge. (This content is thus not repeated in this document). That report emphasises that best outcomes for people who challenge services are most likely to be achieved through individually designed services rather than in congregate settings based on a diagnostic or treatment label. Such services need to recognise each individual's needs and wishes for the same outcomes and lifestyles as other members of society.

Annex A:

A Summary of DH Commissioning Policy Intent

Health reform in England: update and commissioning framework (DH, July 2006) set out the policy framework for commissioning within the wider context of the health reform programme.

The health reform programme is refocusing the NHS to meet the challenges of rising expectations, the demographic challenge, the revolution in medical technology, and continuing variations in the safety and quality of care. To address these challenges, we have a clear vision: to develop a patient-led NHS that uses available resources as effectively and fairly as possible to promote health, reduce health inequalities and deliver the best and safest possible healthcare.

The new NHS will not be created in the old way through command and control. In the next stage of improvement and reform, we need a decisive shift from top-down to bottom-up as we develop a devolved and self-improving health service where the main drivers of change are patients, commissioners and clinicians, rather than national targets and performance management.

This revitalised, patient-led and locally-driven NHS is designed to achieve a central goal: improving dramatically the quality of patient care and the value we get from the public money spent on health services.

The Commissioning Framework set out a range of measures to strengthen commissioning. These included:

- Stronger clinical leadership through practice based commissioning
- A stronger voice for people and local communities
- Better information to underpin commissioning decisions
- New incentives available for commissioners to attract new service providers and improve service quality
- More effective levers for commissioners to secure financial stability, including new model contracts
- Measures to build commissioning capacity and capability.

The next phase of development for commissioning policy was signalled with the C*ommissioning Framework for Health and Well-being*, which was published for consultation in February 2007. It provides guidance for health and local authorities in commissioning community health care, social care, public health, well-being, and primary care (with the exception of the nationally negotiated GMS contract), as well as other relevant services, support and interventions.

This framework signals a clear commitment to greater choice and innovation, delivered through new partnerships. Its key aims are to achieve:

- A shift towards services that are personal, sensitive to individual need and maintain independence and dignity;
- A strategic re-orientation towards promoting health and well-being, investing now to reduce future ill health costs;
- A stronger focus on commissioning the services and interventions which will achieve better health, across health and local government, everyone working together to promote inclusion and tackle health inequalities.

Guidance for practice based, PCT, joint and specialist commissioners has an important role in driving up the quality of care to patients and the public but guidance is just that. The responsibility for taking decisions about the scope and range of services rests with local commissioners based upon their local needs assessment and evidence of how to maximise the health gain for their population.

Annex B:

Good practice resources and supports

The Valuing People Support Team is funded by the Department of Health to provide practical support and advice to the NHS, local government and independent sector on the delivery of the Valuing People policy. Part of the programme is focused on the delivery of modernisation in the NHS. This includes:

- a range of good practice support materials on the website (details below) www.valuingpeople.gov.uk
- a range of learning networks to support people leading change. These are regionally based.

For more details contact the Valuing People support team-contact details available on the web site

Further good practice advice

The following list of websites offers access to a range of additional information on specific issues covered in this good practice guidance.

Health Inequalities

DRC Formal Investigation Report – Equal Treatment Closing the Gap
& Equal Treatment – One Year On
http://www.equalityhumanrights.com

Mencap Reports – Treat Me Right! & Death by Indifference
http://www.mencap.org.uk

Primary Care Support

Primary Care Service Framework for Learning Disabilities
http://www.primarycarecontracting.nhs.uk/204.php

UK Health and Learning Disability Network
http://www.fpld.org.uk

A range of useful papers and resources relating to primary care
http://valuingpeople.gov.uk/dynamic/valuingpeople144.jsp

Role of Community Learning Disability teams

http://valuingpeople.gov.uk/dynamic/valuingpeople130.jsp

NHS Campus Closure

http://valuingpeople.gov.uk/dynamic/valuingpeople216.jsp

Reviewing Institutional Bed Based Provision

Outside the Box – an ideas pack
http://valuingpeople.gov.uk/dynamic/valuingpeople147.jsp

Commissioning Services Closer to Home

DH Clarification note for Commissioners
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4093322

Autism

Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065242

Mental Health

Green Light Toolkit - How good are your mental health services for people with learning disabilities?

http://valuingpeople.gov.uk/dynamic/valuingpeople146.jsp

Performance Tools

Better Metrics – Learning disability metrics
http://www.healthcarecommission.org.uk/_db/_documents/Learning_disabilities_metrics_master11Dec06.pdf

Sources of Health Professional Advice:

For further information on the role of specialist health professionals please refer to the following websites. Please note that the content of these websites is not necessarily endorsed by the DH.

Nursing:
Royal College of Nursing
http://www.rcn.org.uk
Learning Disabilities Nursing Forum
http://www.rcn.org.uk/development/communities/specialisms/learning_disabilities
National Network for Learning Disability Nurses
http://www.nnldn.org.uk

Psychology

British Psychological Society
www.bps.org.uk
BPS national standards for clinical psychology services are at:
http://www.bps.org.uk/downloadfile.cfm?file_uuid=1B2935C2-7E96-C67F-D43C0F6A8A0576F7&ext=pdf

Psychiatry
Royal College of Psychiatry
http://www.rcpsych.ac.uk
Learning Disability Faculty http://www.rcpsych.ac.uk/college/faculties/learningdisability.aspx

Physiotherapy
http://www.csp.org.uk

Speech and Language Therapy
http://www.rcslt.org

Occupational Therapy
http://www.cot.org.uk

MAHI - STM - 118 - 2386

MMcG-270

Innovation and Development in Community Care

TIZARD

UNIVERSITY OF KENT

Challenging BEHAVIOUR foundation

making a difference to the lives of people with severe learning disabilities

Developing better commissioning for individuals with behaviour that challenges services - a scoping exercise

Peter McGill, Vivien Cooper and Gemma Honeyman

"The Tizard Centre is one of the leading UK academic groups specialising in learning disability and community care"

The Tizard Centre

The Tizard Centre is one of the leading academic groups in the UK working in learning disability and community care.

The Centre's primary aims are, through research, teaching and consultancy, to:

- find out more about how to support and work with people effectively
- help carers, managers and professionals develop the values, knowledge and skills that enable better services
- help policy-makers, planners, managers and practitioners organise and provide better services.

The Challenging Behaviour Foundation

The Challenging Behaviour Foundation is a charity supporting families, professionals and other stakeholders through education, information, research and partnership working.
It aims to:

- provide information and support to parents and professionals caring for individuals with severe learning disabilities and challenging behaviour
- demonstrate how local service provision for individuals with severe learning disabilities and challenging behaviour can be improved, and actively facilitate such provision on a national basis
- highlight the needs of those with challenging behaviour and influence policy on their behalf
- promote research into challenging behaviour associated with severe learning disabilities and disseminate the results of such research so that practical benefits are gained.

The authors

Peter McGill is Reader in the Clinical Psychology of Learning Disability in the Tizard Centre at the University of Kent. Vivien Cooper is Chair of the Challenging Behaviour Foundation and the parent of a young man with learning disability and challenging behaviour. Gemma Honeyman is Family Support Policy Officer at the Challenging Behaviour Foundation.

Acknowledgements

The work reported here was funded by the Department of Health. We thank Sue Carmichael for her support of the work and comments on the draft report. We are grateful to the families and commissioners who were interviewed for this report.

Copyright

The authors of this publication assert their moral rights in accordance with the provisions of Section 78 of the Copyright, Designs and Patent Act 1988. Provided a full citation is given and no commercial use is involved, this report may be reproduced or distributed in any form without the prior written permission of the authors.

This report should be cited as McGill, P., Cooper, V. & Honeyman, G. (2010) *Developing better commissioning for individuals with behaviour that challenges services – a scoping exercise.* Canterbury/Chatham: Tizard Centre/Challenging Behaviour Foundation.

© (2010) Tizard Centre and Challenging Behaviour Foundation

Table of Contents

1 Summary

1.1 Background

- The revised Mansell Report (Department of Health, 2007) identified a number of continuing problems faced by people with learning disabilities whose behaviour presents a challenge:
    - Break down of community placements,
    - Increasing use of out-of-area placements,
    - Persistence of poor quality institutional solutions;
- The Valuing People Now delivery plan included a commitment to a "scoping exercise to develop better commissioning for individuals with behaviour that challenges services" (Department of Health, 2009b).

1.2 Aims and Methods

- In-depth consultations with the families of six individuals with behaviour that challenges services aimed to provide an up-to-date picture of the outcomes of services for individuals and their families;
- Extended interviews with eight local authority and health commissioners sought to both identify obstacles to progress and consider the kinds of supports that might help in the process of local service development;
- As a scoping exercise the overall aim was to map out the issues "from a distance" and determine where future work was likely to be most useful.

1.3 Family Consultation

- Families reported a lack of expertise and capability in understanding and responding to challenging behaviour in local services. This was seen as an important factor in the use of out-of-area placements;
- Access to services was reported to be extremely difficult by families other than at times of crisis. As a result opportunities for crisis prevention were missed;
- Families reported a lack of support and training for themselves in their roles as carers, with often detrimental effects on their physical and mental health;

- A lack of information and training hampered the extent to which families could plan realistically, and hopefully, for the future;
- Families consistently reported not being included as essential partners in planning for their relatives;
- It was noted that all of the experiences reported by families have been commonly reported in the past and are well-documented in the professional and academic literature.

1.4 Commissioner Interviewers

- There was no evidence of significant, ongoing local work to implement the recommendations of the revised Mansell report;
- Commissioners reported continuing difficulties around the development of local services for people labelled as challenging;
- Discussions with commissioners identified a range of barriers to local service development:
    - Lack of coordination between adult and child services;
    - Lack of a systematic commissioning framework based on good quality information about the quantity and nature of local need;
    - Lack of confidence in the ability of locally available providers to deliver high quality supports to people labelled as challenging;
    - Wide variation in the application of NHS continuing care criteria and associated inter-agency perverse incentives;
    - (with exceptions) continuing difficulties between local authorities and the NHS in coordinated and integrated working;
    - Lack of specification of the commissioner role so that wide variation in the nature and quality of commissioning practice;
    - Family preferences (sometimes) for specialist, out-of-area placements perhaps in the context of earlier, local placement failures;
    - Lack of collaboration and understanding (in some areas) between commissioners and clinical support services;

- Commissioners considered and commented on a range of possible supports for their local practice.

1.5 Recommendations

- National action:
    - The Challenging Behaviour National Strategy Group (CB-NSG) should co-ordinate and drive the process of improving the quality of outcomes for individuals whose behaviour challenges and their families;
    - The Office of the National Director should encourage care providers to review and enhance their capacity to work collaboratively with local commissioners in the development and delivery of personalised supports for individuals whose behaviour challenges;
    - The CB-NSG should, in collaboration with the Care Quality Commission, Skills for Health and Skills for Care, explore the possibility of establishing nationally accepted standards around the training and qualification of staff supporting individuals;
    - The Office of the National Director should encourage the use of existing mechanisms (such as the Big Health Check and Partnership Board annual reports) to monitor and hold to account commissioners for their performance in developing better, more local provision;
    - The Department of Health should review the application of continuing care criteria in order to clarify the reasons for the wide variation in numbers between areas and with a view to reducing perverse incentives;
    - The Learning Disability Public Health Observatory should be asked to support commissioners to gather and use local information on need;
    - The Department of Education should be asked to review policy on the use of out-of-area placements for children and young people with learning disabilities, with a view to the need for continued data collection and the development of prevention and early intervention efforts;
- Support for commissioners:

- A programme of nationally-coordinated work should be developed to support a number of local commissioners (in every Region) to implement existing guidance. This programme should include attention both to the development/redevelopment of personalised supports and the more systematic commissioning of provision which has the capacity to prevent and intervene earlier with challenging behaviour and mental health problems;
- A programme of dissemination activities centred on a new website should be developed to share lessons with all commissioners, collate evidence and examples of good practice in a manner accessible to commissioners, and encourage the development of specialist networks within the commissioning community.

2 Introduction

This report, and the work it describes, were commissioned by the Department of Health as a “scoping exercise to develop better commissioning for individuals with behaviour that challenges services” as part of the delivery plan for the Government’s strategy for people with learning disabilities (Department of Health, 2009b, p.31).

The report draws on three sources which are introduced below.

2.1 Family consultation

The involvement of family carers has been a key element of the Valuing People Now strategy. Their reports of their experiences provide a very direct picture of the effectiveness of provider and commissioner practices. In the absence, as yet, of more comprehensive evidence on need, consultation with families is one way of finding out about the extent to which currently commissioned services meet need.

The Challenging Behaviour Foundation drew on its extensive experience of supporting families and consulted in depth with 6 families. These families were selected from those who had received information and support from the CBF and who were willing to be interviewed about their family experience, While inevitably repetitive of previous work it was hoped this would provide a very up-to-date picture of the outcomes of services for individuals with behaviour that challenges and their families.

2.2 Interviews with commissioners of learning disability services

Commissioning is seen as a key element of changing and developing services. There is limited evidence, however, that the extensive guidance that has been provided has led to significant changes in the nature and quality of the services provided for individuals with behaviour that challenges. It seemed useful, therefore, to talk to a number of commissioners about their local experiences and their perceptions of both the factors influencing their current practices and potential drivers of changed practice in the future.

Eight commissioners were interviewed. Interviews lasted, on average, just under 2 hours. All commissioners were from the London or South East Regions. Some were from local authorities, some from health, some were joint. Local authority commissioners came from a mixture of metropolitan and county authorities.

By scoping commissioner experiences and perceptions it was hoped that:

- Issues (such as obstacles to development) requiring more detailed investigation would be identified;
- a better informed range of supports for commissioners could be provided.

2.3 The literature

The report is informed throughout by the professional and academic literature on both challenging behaviour and commissioning.

There have been many reports on commissioning and many on challenging behaviour. While reference will be made to these, it would be foolish to repeat their contents at length. The report's intention is to take a slightly different approach to the issues which acknowledges the difficulties of producing change in this area. The report will focus on understanding some of the reasons why change has proved difficult. It is, however, only a "scoping" report, intended to map out the issues "from a distance"and without, necessarily, being able to detect the detailed nature and generality of each issue.

3 The Problems

The revised Mansell Report (Department of Health, 2007) identified three central problems faced by people with learning disabilities whose behaviour presents challenges:

- Community placements break down;
- Out-of-area placements increasingly used;
- Poor quality institutional solutions persist.

These problems are, of course, closely linked. Placements competent to meet the needs of people who present a challenge are often not available in peoples' local areas despite continued guidance that they should be made available (Department of Health, 2004). Over 1/3rd of people with learning disabilities supported by local authorities are placed out of area and there was a slight rise in the percentage between 2006 and 2008 (Whelton, 2009). While there is no definitive evidence concerning the comparative quality of out of area placements it is clear that they are inadequately monitored (Beadle-Brown, Mansell, Whelton, Hutchinson, & Skidmore, 2006; Emerson & Robertson, 2008) and that the quality of at least some is dubious (Beadle-Brown, et al., 2006; Becker, 2006; Emerson & Robertson, 2008).

People placed out of area are by no means exclusively people presenting challenging behaviour but are more likely to be so (Emerson & Robertson, 2008). While the current report starts from a consideration of the commissioning of services for adults who present challenging behaviour, it is important to note that the process of exclusion underlying these problems often starts in childhood. Children whose behaviour presents a challenge are frequently excluded both from school (including from special school) and from other local services such as short breaks. As a result, out of area residential placement is relatively common (McGill, 2008). Such placements are, from the point of view of the commissioners of adult services, literally 'out of sight and out of mind'. As a result, substantial numbers of those placed in residential schools continue in out of area placements, often in services provided by the same provider[1]. Others, having remained with their families throughout childhood, leave their local areas at 18 or 19 when it becomes apparent that

[1] In a recent evaluation by Peter McGill of a residential care provider, 2/3rds of the residents (average age 24 years, almost all in out of area placements) had previously been placed in a residential school, many in schools run by the same provider.

there is no local college at which they can continue their education and no local process for developing the personalised, supported accommodation and employment opportunities that they need. Others, either during childhood or adulthood, in the wake of a mental health crisis and their typical exclusion from local mental health services, go off to an out of area private psychiatric hospital. Once out-of-area, a return to a local community placement is relatively difficult. Typical transition protocols are challenged by the difficulty of including people now living some distance away (Heslop & Abbott, 2007). The whole process of developing a local service, relying as it does on a good understanding of the person's needs and wishes, is made more difficult. Families, experienced in the failures of local services and used to the apparent safety of the out-of-area provider, may oppose any move. Providers, often relying on economies of scale and based in areas of the country where property and land are cheaper, have a vested interest in maintaining the status quo.

Many out-of-area placements are relatively institutional, e.g. in "village" or "campus" or "hospital" settings. Concern about their quality inevitably arises given the increased difficulty for local authorities of monitoring outcomes for individuals. The very nature of the settings often reinforces the view (amongst commissioners, providers and/or families) that the individual could not succeed in a local, more inclusive placement. But there is considerable evidence that this is not true. First, studies of the resettlement of people from the long-stay hospitals demonstrate very clearly that individuals whose behaviour is challenging are able, when supports are tailored to their needs, to live in ordinary, local community settings (Mansell, McGill, & Emerson, 2001). Second, there are practice examples of individuals returning successfully from out-of-area residential school placements as children to local life (Emerson & Robertson, 2008). Third, there is considerable variation in the use of out-of-area placements suggesting that some areas are much more successful than others at including people in local service developments (Whelton, 2009).

4 Family consultation

There is a well documented history of families of people with learning disabilities leading and driving change in support and services for their relatives (Brown, Orlowska, & Mansell, 1996). Most children with learning disabilities and a majority of adults live with their families. Even when individuals leave the family home, they do not leave the family and relatives often continue to provide considerable support. Families are therefore important partners, often providing lifelong support and care to their relative and it is essential to engage them appropriately and to recognise and value their experiences and knowledge.

In 2009 the Challenging Behaviour Foundation invited a number of families to share details of their experiences. Six families from across England took part in in-depth interviews about their experiences of caring for a son/daughter with learning disabilities and behaviour described as challenging and about the support they received.

Several key themes emerged from the interviews:

- a lack of local expertise and capable local services,
- a crisis management approach to accessing services,
- a lack of support for family carers,
- a lack of information and training,
- a lack of working in partnership with families to plan and deliver good outcomes.

These experiences are not unique to the six families interviewed and are consistently raised by family carers who contact the Challenging Behaviour Foundation, often in crisis, for information and support.

4.1 Lack of local expertise and capable local services

Families consistently identified a lack of local expertise in understanding challenging behaviour and a lack of capable local services. For some families this has led to an out of area placement for their son/daughter. This placement has occurred not as a positive choice but because it was the only option in the face of inadequate local services.

"My daughter was permanently excluded from our local special needs school aged 13 years. She now lives in a residential school 200 miles away, it takes about three and a half hours each way. We have to travel to that once every six weeks, I think it's terrible really, there should be something in the local borough, but that is the situation unfortunately." (Mother)

Families often identify what local support mechanisms they would find helpful, but these are not available or offered:

"If we had respite there is no way we would have put Adam in residential. If we were guaranteed respite every weekend, if we had a bit more support within the home, if I could phone social services and say this is the areas we are having difficulties with…. Just support me to help me take my son out, until my husband came in and respite, that would be my top. Our local authority… have got no respite facilities for autistic children or young adults, …it's always been 'it's in the pipeline' but how long this pipeline is and where it ends nobody knows." (Mother)

Most families acknowledge that many of the professionals who support their children are not equipped with the skills and knowledge to manage behaviour perceived as challenging:

"At my daughter's local special needs school the strategy was to isolate her in her buggy every time she lashed out. So this poor teacher was constantly taking my daughter, putting her in her buggy outside the classroom door and then a few moments later bringing her back in again, where my daughter would do it again. So she was in and out of the classroom door. After a couple of years of this her behaviour was dire because she actually preferred to be isolated…eventually the local educational psychologist said the school's not coping, they don't want her anymore, she's going to have to go to...a residential school" (Mother)

Interestingly, many families, despite the fact that they are the ones providing the majority of care without training or support themselves, indicate that the decision regarding out of area and/ residential placement is made when the support services are no longer able to cope.

4.2 Crisis management approach

Families consistently identified a crisis management approach to accessing services. Families identified and requested support and services early, yet it was only when they had reached crisis point that adequate services were offered.

"I just wanted to say I've had a very difficult time over the years. For years I've been asking social services to help with support during the holidays and it was refused and I knew something was going to happen. At the beginning of this year my son got arrested for smacking a baby….The police had no understanding, and it was only because he was arrested that social services were involved and I've been given support. It makes me so sad and cross that things have to get to that point before you are given the help you need. It shouldn't have to take a child being arrested to get someone to listen to you, it shouldn't." (Mother)

The impact on family members is often significant and substantial:

"I had a breakdown in February and this is when everything changed for my son…and this is the reason why at the moment he is in residential care. If we were getting the help that we needed earlier things might have been different but we find it so frustrating that every step of Adam's life we have had to fight." (Father)

4.3 Lack of support for family carers

Families consistently identified a lack of support for themselves in their role as a carer. The impact of not receiving adequate support had varying consequences affecting families financially, emotionally and physically.

"I wouldn't be able to count on two hands with spare fingers how many jobs

I have lost because I have put my son first" (Father)

The experiences of families demonstrate double standards when it comes to appropriate training – those who are trained and paid to provide support can exclude an individual and the responsibility for that individual rests solely with the family, who are untrained and unsupported:

"The last couple of times it has happened has really scared me as I have been unable to defend myself, that's frightening. And he hurts you know, he's big and strong and he hurts. …Domiciliary care was stopped because of health and safety, this is the underlying theme, health and safety, health and safety, but nobody thinks about my health and safety, it's like as a parent you don't count" (Mother)

The additional burden of trying to access appropriate support via the system, in addition to pressures of supporting an individual with behaviour that is challenging, can be unsustainable:

*"I mean last summer I was at the point of suicide really because when you are trying to deal with social services and the frustration that's there is just unbelievable. So it's just to get that point across really."(*Mother)

4.4 Lack of Information & Training

Negotiating the systems that are in place which are meant to support families was identified as a problem by the majority of those interviewed. It is difficult for families to find good practical information that will help them to get the support and services that their family member requires.

Over the last ten years the Challenging Behaviour Foundation has received a high number of requests for information on transition from family carers.

"I don't know where to start, who to contact. I think all this information should be put into a booklet for people with special needs kids to say, you know, when they are young you

are entitled to this and that and when they are older and transition you know, you need to contact this person or your local social services to just give people an idea of what they need to do, because they don't know, they really don't know. And I don't think this borough is much different to any other borough really." (Mother)

Poor experience of accessing support and services over extended time clearly has a negative impact on the expectations of families – they have no experience of services being able to meet the needs of their relative:

"Because over the years we've been rejected and, you know, you can't come here, we can't work with him, we don't want him, we can't meet his needs, that you think residential is the only option." (Mother)

"My son is in an out of area emergency placement and I am worried he will end up in an out of area adult service, out of our reach/input and very likely not suitable for him, as has been the case to date." (Father)

In order to meet the needs of family carers caring for a relative with severe learning disabilities and behaviour described as challenging an information pack "Planning for the Future" was developed. A version is available for: England, Wales (Welsh language & English language), Northern Ireland and Scotland.

Since publishing these information packs in 2007, family carers have highlighted that, when they request individualised support for their son/daughter, there are many barriers. One of the main barriers that families identified was a lack of local commissioning in response to need. They are offered "what is currently available" (usually an out of area residential care home), rather than what is possible:

"what I actually wanted for my son was a local support service designed around his needs. What I was offered was an out of area residential care home, because that just involved a few phone calls and negotiating the price. A local individual service would have

to be set up from scratch – somewhere to live and staff to support him - and no one seemed to be able to do it." (Mother)

To empower families to engage positively with their local commissioner and overcome one of the barriers to local support the Challenging Behaviour Foundation has created two new resources:

- Planning your house;
- Getting your house.

4.5 Lack of working in partnership with families to plan and deliver good outcomes

Families consistently report that they are not regarded as essential partners in planning support and services. Most families have a wealth of knowledge and expertise about how to support their relative well, and what works and what doesn't, and this is not recognised or utilised:

"No-one's ever asked me what I want. Never. Never, ever. And I have had to fight…I've never been asked. I've just been told. Scrapping for the most basic of help." (Mother)

"Now my son has a good multi-disciplinary team so everybody works together and we all make sure that we're singing from the same hymn sheet before we implement anything. But that didn't happen in the past. So we could have had a speech and language therapist telling us to do one thing. A social worker telling us to do another thing. School doing completely something separate. And maybe not even have a psychologist. What's had the greatest impact is working as a team. We all know that we are all doing the same thing and consistency has had a huge impact on the way that we manage our son, in all the environments that he is exposed to." (Mother)

While the experiences described above are those of only six families they are common amongst families both of children and adults (e.g., Allen, Hawkins, & Cooper, 2006;

McGill, Papachristoforou, & Cooper, 2006; McGill, Tennyson, & Cooper, 2006; McIntyre, Blacher, & Baker, 2002; Wodehouse & McGill, 2009).

5 Commissioner interviews

All interviews addressed the question of the extent to which work was being done locally to implement the recommendations of the revised Mansell report (Department of Health, 2007). No commissioners reported significant, ongoing local work. Indeed, most noted that the report had not been discussed either by the authority/PCT or the Partnership Board. This seemed to be to do with its being guidance rather than setting out mandatory requirements. There was also some feeling that its highly specific focus on relatively small numbers of people led to its being marginalised.

At the same time all interviewees noted that there were continuing problems around the development of effective, local services for people labelled as challenging with many people still in, or being placed in out-of-area placements. Interviewees generally identified two groups, members of which were more likely to be placed out of area. These were, firstly, people with severe learning disabilities and challenging behaviour, often also with a diagnosis of Autism or Autistic Spectrum Disorder and secondly, people with mild/borderline learning disability and forensic/mental health issues. A recent survey of high cost placements (most of which were out of area) made by local authorities in the South East region was consistent with this, finding that the largest group was people with (severe) learning disability/autism and challenging behaviour, with a significant minority having mild learning disability and forensic/mental health needs.[2]

5.1 Barriers to local service development

In the course of interviews commissioners were asked to comment on a range of possible barriers to local service development. They also identified additional barriers themselves. The barriers discussed in some detail below were all endorsed by at least half the interviewees as being significant concerns. In addition, at the end of this section, a number of other barriers (mentioned by less than half the interviewees) are discussed in less detail.

5.1.1 Lack of coordination between adult and child services

Most commissioners were aware that children placed in residential schools constituted a significant source of future out of area adult placements. While initiatives were being taken

[2] This survey was carried out in 2009/10 by Jo Poynter and Peter McGill on behalf of the Challenging Behaviour - National Strategy Group. 14 out of 19 local authorities responded.

to address this in some areas, most commissioners reported a lack of joint working with the commissioners of children's services. For example,

"I can tell you who my children's commissioner is but I don't see him very often... when I do I don't understand what he is talking about because we use completely different sets of language and data and jargon".

The concern with data, in particular, was widespread. One commissioner reported two cases in the last year where (s)he only found out about the person 3 months before adult provision was required. More generally, there remained problems about identifying the number and needs of individuals far enough in advance, in part because of the different databases involved (see also Emerson & Robertson, 2008):

"So what I have got is from 8 different teams including education, leaving care, learn to live team, children with disabilities team, out of borough education, respite, carers and the learning disability team is a whole cohort that I've have had to bring together and double check against one and other and come up with what I believe is a definitive list and it's ever changing".

Even where approximate numbers were known there was concern about the validity of the information available with some feeling that it was not always possible to rely upon children's services needs assessments:

"I think it is very difficult is to get a handle on what their needs are because they are so subjective so...you know this young man is on £4,500 per week placement and children's services are really promoting that this is somebody with incredibly high needs ... but we have learnt that you can't assume that he does have that level of needs. In fact we have got quite a few examples of individuals who were getting 2 to 1 input as children and we've assessed them and come out with our packages and they are managing absolutely fine with much, much less support".

Some commissioners noted the potential for preventative, early intervention at a younger age to reduce the likelihood of residential school placement but recognised that there were limited incentives for children's services to carry out such work as the costs during childhood were often shared across agencies and savings might primarily affect adult services. This prompted discussion of the value of a "whole of life" perspective:

"we start seeing people, stop seeing children or adults. You start to see somebody who has, if you like, 'a career of need'".

It was noted that such an approach could be associated with a funding mechanism in which money stayed with the person as they moved from children's to adult services.

The transition period was also associated with placement in out of area residential colleges. Such placements were often in the financial interest of adult services who, because of LSC funding, only had to

"Top up with the residential placement allowance - that's somebody that you're saving thousands of quid on because the top up is 23K for a residential placement and the LSC pays for the rest so for 3 years you get them off your books essentially for what you could pay for them in one year in residential home".

Placement in residential college was also driven by the lack of suitable local college provision and there was concern that, although it was early days, the transfer of LSC funding to the local authority was not making an obvious difference.

A couple of commissioners noted particular concern about future provision for young people with autism. In part there was some evidence of more people coming through to adult services than anticipated. In part, it was often difficult to identify suitable local providers who could continue the autism-specific approaches (such as TEACCH) used in residential schools/colleges.

5.1.2 Lack of a systematic commissioning framework

Commissioners generally welcomed the world class commissioning framework (DH Commissioning and System Management Directorate, 2009) but it was clear that most were labouring under a severe lack of, or difficulty in accessing, good quality information (see also Commission for Social Care Inspection, Healthcare Commission, & Mental Health Act Commission, 2009; Pritchard & Roy, 2006). Joint strategic needs assessments often contained only extrapolations from national data so that it was very difficult, for example, to establish the number of people displaying challenging behaviour in the local area. As a result services have been *"commissioned on the basis of demand rather than on need"*.

Many opportunities were missed to use existing processes to accumulate information that would assist in strategic commissioning. For example, amalgamated information from such things as person-centred planning or annual health checks could be useful. While it was clear these problems were recognised only one commissioner reported a concrete plan to improve the quality of information specifically related to challenging behaviour – the establishment of a short-term, jointly funded post to pull together information.

Another commissioner noted their use of the Person Centred Commissioning Now pathway (Fulton & Winfield, 2008) to help develop local services for individuals. While not a strategic framework this helped to offset the frequently reported difficulties facing care managers who were described as

"usually looking for placements in crisis which means that you don't have time to plan properly. You just place in what's available and hope. And what's available? Residential care is available".

5.1.3 Quality of provision

In line with previous reports (e.g., Royal College of Psychiatrists, British Psychological Society, & Royal College of Speech and Language Therapists, 2007), most commissioners reported difficulties in finding suitable local providers for people whose behaviour was challenging and might otherwise be placed out of area. While many providers described themselves as 'specialist' this was often mistrusted:

"on their lovely glossy website they have challenging behaviour specialist and autism and you name it, they're specialists in it...there must be a very, very, very small percentage of providers who are actually able to do what they say they can do".

Even where relatively sophisticated tendering and procurement processes had been used to identify the provider of a specific service there was concern about staff competence (see also Commission for Social Care Inspection, et al., 2009) and the extent to which extensive support from clinicians was required. Sometimes such support was delivered with mixed feelings as it was felt that such providers should really be able to sort themselves out. Commissioners reported beginning to invest more effort in service specifications and contracts which would include the training/qualifications that staff would be expected to hold and some commissioners were willing to consider financially supporting providers willing to train up their staff to meet such criteria. Some commissioners saw provider networks as being a useful (albeit long-term) way of sharing provider expertise over time.

The perceived limitations of providers were linked to commissioner difficulties in judging the quality of provision. It was widely accepted that standard judgements (such as CQC ratings) were not sufficient for such specialist services and that a much more detailed focus on, for example, the quality of staff support was required. But commissioners, themselves, usually had very limited direct knowledge of specific clients or services and relied on contract monitoring processes which did not always focus on outcomes and were, inevitably, much more difficult to operate with out of area placements.

Judging the quality of NHS provision was also difficult as the relationship between commissioner and provider was sometimes rather 'blunt' e.g.,

"I would be saying hang on a minute we haven't agreed that you should be doing that and that of course is the other side of the coin - the trust doing what it wants to".

Such providers also sometimes had a history of leading the service development process and were operating in an environment in which service specifications were absent or unclear.

5.1.4 Continuing care

Some commissioners reported *"that we have an awful lot of continuing care and that's where our money is going"* while another said *"there aren't big numbers"*. Figures published by the Department of Health suggest very wide variation across PCTs in the number of people classified as eligible for continuing healthcare – from 2 to 26 per 10,000 population in the 4th quarter of 2009-10 (see www.adass.org.uk).

Commissioners reported a number of problems associated with continuing care. First, many people so funded were placed out of area and there was little resource to support bringing them back to the local area. Second, care manager input from the local authority was difficult to obtain. Third, some commissioners reported concerns regarding the continuing care assessment arrangements with long waiting lists, and assessors requiring additional support to properly assess people with learning disabilities.

One commissioner felt that continuing care arrangements created a significant incentive (see also Allen, 2008; Mansell, Beadle-Brown, Skidmore, Whelton, & Hutchinson, 2006) for the local authority to

"allow behaviour to escalate because it will bring people within the round of continuing care and full payment by the health service".

Once receiving continuing care it appears to be difficult (though not technically impossible) to return to local authority funded care and there is a danger that the service provided is more restrictive (Emerson & Robertson, 2008) and monitored by a regime which stresses health outcomes. At the same time the continuing care regulations clearly support personalisation and one commissioner felt it should not have a significant impact on the nature of the person's placement.

5.1.5 Inter agency issues

The majority of commissioners reported problems between the local authority and the PCT regarding commissioning both generally and for people displaying challenging behaviour in particular. Pooled budgets were in the minority and there was *"no appetite for joint commissioning"*. In some areas this had clearly led to a 'bunker' mentality (*"I concentrate on health"*) with each agency seeing the other as having a *"different view of the world"*.

More specifically, the local authority was sometimes perceived to not be willing to take the lead on issues relating to challenging behaviour and there was a perceived danger of the NHS forgetting that *"there was still a job to be done"* in learning disability. On the ground, clinical teams in some areas were not integrated (Commission for Social Care Inspection, et al., 2009) and there were communication problems and possible duplication of function (e.g. between care manager and clinician). This problem sometimes became salient when the clinical team was attempting, perhaps with limited success, to support a local provider of residential support for one or more people who displayed challenging behaviour without jointly agreeing the aim of the work with the care manager responsible for contracting the service.

5.1.6 The Commissioner role

Commissioning of services for people with behaviour that challenges might reasonably be regarded as a problematic activity when compared with the commissioning of many other sorts of provision. Commissioners must focus much more on individuals since, unlike in, say, the medical context, challenging behaviour cannot be considered as a 'disease' and must be managed in a holistic way that takes account of the rest of the person's life. But demand for, and the effectiveness of, services remains difficult to predict and the evidence base is somewhat limited and poorly disseminated. Commissioners must, therefore, work with considerable uncertainty and also have to allow for the substantially greater role played by carers and the frequently limited capacity of service users to say what they want and to take decisions.

It is perhaps not surprising, therefore, that the interviews showed up a very wide variation in the ways in which commissioners fulfilled their responsibilities. Some worked closely with individuals and their families, clearly being driven by a concern for how their lives worked out – *"for me it's about getting to know them all really"*. Others saw their role as being much more strategic and *"commercial"*, focused on getting better outcomes and value for money from providers.

Although, in part, such variation is the result of different agency structures and responsibilities, it appears to also reflect a degree of uncertainty in the nature of commissioning itself. In a sense there is no 'job description' and in a few areas (not those where interviews took place) it remains difficult even for those closely involved to identify who is the commissioner.

This variation means that it is relatively easy to identify weaknesses in commissioning though the nature of the weaknesses will vary substantially from area to area. Some of these weaknesses may be inherent in the way in which the role is set up in particular authorities, some will reflect the varying backgrounds from which commissioners come:

- Tendency to attend to some issues more than others in a relatively reactive and random manner;
- Lack of profile, links, partnership and influence within the larger organisation(s);
- Lack of motivation for, or belief in the possibility of changing things;
- Lack of knowledge of learning disability and/or challenging behaviour;
- Lack of skill in overcoming financial and organisational obstacles within their own agency.

Commissioning arrangements in local authorities (as well as the NHS) are currently going through significant changes. There were different views about the impact of these changes. Some saw them as very positive:

> *"taking commissioning out of learning disability services and separating from providers...is a good thing...in the past commissioning has been driven by social workers, care managers, internal providers".*

Others saw these kinds of changes as being problematic in that they might limit the extent to which commissioners could promote whole systems change and would confine them to the 'carrots and sticks' contained in the contracting process.

Inevitably, changes in commissioning arrangements (both in local authorities and the NHS) create additional turbulence and uncertainty both within the system and for individual commissioners. Consequently, the risks of inaction increase.

5.1.7 Families and service users

A number of the commissioners noted that families were sometimes happy with out of area placements and resisted suggestions that their son/daughter might return to the local area -

"his mum and dad would hunt me down and shoot me because he's settled". Such views were understood by commissioners and considered to reflect the earlier failure (perhaps many years ago) to prevent the out of area placement. Commissioners also noted similar views amongst families of younger people and felt that they had to manage parental expectations, especially when the service user had lived in a residential school/college:

"often the residential colleges will have a nice unit in the grounds and they will then talk to families about finance... It's really difficult to shift all that".

More generally, commissioners felt that families had to be prepared for the *"change in the level of resource from child to adult services"*.

Some families, and individuals, will express a preference for out of area placements, perhaps especially if the local area offers less housing space and, arguably, a more dangerous environment for their son/daughter.

No commissioners (except in reference to short breaks) described services specifically aimed at family carers.

5.1.8 Clinical support services

As well as one or more multidisciplinary community learning disability teams, all areas had, or were developing, some kind of specialist behaviour support service. There is growing evidence of the effectiveness of the behaviour support team model (e.g., Hassiotis, et al., 2009).

There was a contrast between commissioners' perceptions of these services. In some areas they were clearly highly valued:

"staff work at putting hours to support that model [local provider] and in quite an intensive way that I have not come across in other areas and it is literally about supporting people with those challenging and complex needs".

Where such positive perceptions existed it was clear that the commissioner worked closely with the clinical support provider:

"I can then go to him [psychologist] for advice about...the specification and go to some providers and he provides the clinical support to the provider."

In other areas commissioner perceptions were rather less positive:

"we are not totally sure about this service as commissioners and we are actually starting to look at it very closely in terms of whether we want to continue with it in this way ... we are convinced about function, but in terms of the structure, and the way that it is delivered, we are not really sure about it."

5.1.9 Other barriers

A range of other barriers were noted by a minority of the commissioners. These included: a lack of emergency support that might help to prevent out of area placements; funding/finance issues such as the difficulty of securing money to 'double fund' the transition between an out of area and in area placement; and difficulties around the provision of services for people with mild/borderline learning disability which was often a source of dispute.

5.2 Support to commissioners

Commissioners were asked their views on a range of possible supports.

5.2.1 A learning set for commissioners from a number of authorities with ongoing individualised support

Response to this ranged from *"this would be good"* to *"been there and done that"*. Generally there was no great enthusiasm and a feeling that it would be difficult to match with local demands and any change would be hard to sustain.

5.2.2 A national programme board to drive the development of local services

Most commissioners thought this would be a good idea but there was also a general view that any such initiative should be 'mainstreamed' as much as possible within existing performance management arrangements.

5.2.3 Technical assistance to local commissioners/providers around the development and initial operation of services for specific individuals

Most commissioners were relatively positive about this. It was suggested by one commissioner that it would be particularly useful if could help manage finance, tendering and estates issues within his own organisation and by another that it could be linked to meeting the PSA 16 target on increasing the percentage of people with learning disabilities living in settled accommodation.

5.2.4 Technical assistance to local commissioners to engage in local strategic planning including attention to prevention and early intervention

Most commissioners were positive about this though it was suggested that the child/adult barrier would be difficult to bridge and it could perhaps be combined with individual-level technical assistance.

5.2.5 More training and support for provider organisations

Most commissioners were positive about this though with some concern about its targeting and how it would be financed. One commissioner suggested that it would be useful to have a nationally recognised module for care staff.

5.2.6 Other supports

Commissioners suggested a range of other possible supports though there was considerable variation and all of these suggestions were endorsed only by a minority of those interviewed:

- A network that could provide peer support around the development of bespoke provision. Such a network might be real or virtual, the latter possibly linked to a website or similar where materials, procedures and experiences could be shared;
- The collation of evidence on the effects, including the preventive effects, of different kinds of services;
- A national focus on mainstreaming learning disability (including challenging behaviour) into the equalities agenda;
- Clear guidance on what individuals and families should be able to expect locally;

- Support to incorporate an outcomes focus much more explicitly in contracting and monitoring.

5.3 Commentary

In the light of the interviews conducted with commissioners it is perhaps easier to understand the continuing high numbers of people living in out of area placements. In the absence of any significant attempt to prevent/intervene early around challenging behaviour and mental health problems, demand (especially from residential school and college leavers) may seem unremitting and remains somewhat unpredictable. Commissioners faced with difficulties in finding suitable local providers, and with variable clinical support available, use established, out of area providers even though this makes it more difficult to monitor and judge the quality of provision. Once so placed many service users and their families are reluctant to consider a more local placement and will resist, often with the assistance of existing providers, any attempt to move back to the local area. The problem is exacerbated in some areas by poor inter-agency relationships and the use of continuing care criteria to fund placements which create an incentive for local authorities to avoid supporting local competence in the absence of closer partnership working across the health and social care economy. Given the frequent lack of systematic commissioning frameworks and a clearly defined commissioner role such processes operate piecemeal and prevent the identification or strategic tackling of the issues.

A similar analysis is possible in respect of people with mild/borderline learning disabilities and mental health/forensic issues. For somewhat different reasons there is similarly unpredictable demand and a lack of clear local pathways.

6 Recommendations

The complex problem of the persistence of out of area provision for people who present challenging behaviour will not yield to a single, simple solution. In what follows a range of recommendations are made for action at different levels, with different groups, of different kinds, to try and match some of the complexities of the issues.

6.1 National action

6.1.1 Coordination by the National Strategy Group (CB-NSG)

The CB-NSG was developed in response to the perception of a lack of coordination and coherence in national and local strategy and policy around challenging behaviour. In five meetings during 2008-10, the Group drew together senior stakeholders from a range of national and local organisations and a range of backgrounds. It has sought to both identify obstacles and barriers and to initiate coordinated action to overcome these. It has developed a Charter laying out clearly the rights and values of individuals whose behaviour presents a challenge and their families and the practical action required. So far, nearly 60 organisations have signed up to the Charter including a number of large, national service providers and national professional organisations.

It is clear that this group has already served a useful function in raising awareness and triggering both local and national action. It is particularly significant that it is one of the few groups, nationally or locally, that bridges the child-adult divide, one of the major barriers to the development of better, more local services. This aspect of its work might usefully be further emphasised. The CB-NSG might also contribute to the task of collating evidence on the effects of services, develop its charter as the basis for the kind of 'offer' that should be available to individuals and families locally and the kinds of outcomes that should be measured locally, and, building on the human rights approach it has taken to date, use the equalities agenda as a driver for service improvement.

6.1.2 Provider development

Another of the major barriers identified by commissioners was the recruitment of providers (especially of residential support) who could deliver effective, local services without requiring extensive, local clinical support. While the development work described below should contribute to overcoming this barrier it also seems appropriate to focus on national

capacity in this area. It may be that the work already being done by the National Director with large private providers on the wider housing agenda will contribute to this. It may also be useful to consider broadening this work to large, national providers (across the third sector) who may be encouraged to review their own capacity and the extent to which they can develop in-house training and support services that would enhance the capacity of their own locally-provided services.

6.1.3 Workforce development

One aspect of the problem of recruiting providers is the extent to which care staff have limited skills and understanding of challenging behaviour. In part this may be tackled by more explicit contracts and specifications but it remains the case that anyone can establish a service and call it 'specialist' without any particular experience or qualification. It would be useful, therefore, to explore the possibilities of establishing nationally accepted standards around training and qualification. A previous attempt was made on this by the National Care Standards Commission (Wing & O'Connor, 2004) and it would be useful to revisit this in collaboration with the CQC, Skills for Health and Skills for Care, perhaps building on the recent work on knowledge sets by the latter. This stream of work might also play a part in the CB-NSG.

6.1.4 Prompting and monitoring better performance

At present commissioners are not held to account for their performance in respect of the development of better, local services. A number noted the value of such accounting but argued for its inclusion in existing mechanisms. Therefore, it is recommended that the use of existing mechanisms (such as the 'Big Health Check' and the Partnership Board annual report requirement) be reviewed with this in mind.

6.1.5 Reviewing NHS provision and continuing care arrangements

There has, of course, been extensive recent review of NHS and private hospital provision (Care Quality Commission, 2009) and this is not what is proposed here. Rather, given the apparently limited progress made between the two CQC audits coupled with the findings reported above, consideration should be given to whether the current pattern of NHS provided and/or commissioned care is likely to improve sufficiently to contribute to future personalised support arrangements. It is clear that learning disability is an increasingly marginal issue within the NHS other than in the entirely appropriate efforts to make

healthcare more accessible and equitable. The extent of variation in continuing care arrangements and the broader continued difficulties between PCTs and local authorities suggest severe commissioning problems. At the very least some kind of inspection of the implementation of continuing care criteria with people with learning disabilities is required but the risks associated with a separate system of funding support for a minority of people with learning disabilities should also be considered.

6.1.6 Prompting examination of the role, training and support needs of commissioners

Given the variation in backgrounds, experience and qualifications of commissioners it would be useful to examine the scope for a programme of commissioner development. Previous approaches to commissioner development have been well-received (Cornes, et al., 2010) but have not typically incorporated more specialist knowledge of learning disability. More specifically, the general absence of good quality, local information on need might prompt consideration of how to support commissioners to gather and use such information. The new Learning Disability Public Health Observatory might usefully be asked to consider providing such support.

6.1.7 Prompting greater collaboration between the Department of Health and the Department for Education

The problem of the extensive use of residential school placements has been recognised nationally for some time. From 2003 to 2008 the Special Educational Needs Regional Partnerships collected annual data on out of authority educational (and, latterly, social care) placements (South Central Regional Inclusion Partnership, 2003, 2004, 2005, 2006; The Regional Partnerships, 2007, 2008). This data contributed to two reports (Department for Education and Skills/Department of Health, 2004; Pinney, 2005) identifying a number of concerns about such placements and promoting a strategy of "redeploying resources towards sustainable local provision" (Pinney, 2005, p.51). Unfortunately, annual data are no longer gathered following the reorganisation of the Regional Partnerships, and there is now no visible national policy. Given the impact of such placements on adult social care (leaving aside their impact on children) it would seem appropriate to raise these issues with the DfE and seek the further development of policy and action in this area.

6.2 Support for commissioners

6.2.1 Development work to support personalisation

While there are examples of excellent initiatives in a number of areas, it is clear that the overall pattern remains one of the frequent out of area placement of people with learning disabilities who present challenging behaviour. This is a particular problem for young people who have already spent some of their lives in out of area residential schools or colleges. If this pattern does not change we can look forward to continued growth of out of area placements since it is much harder to 'repatriate' (Allen, 2008) people once so placed. Yet there is considerable evidence that the development of personalised services for this group is perfectly possible (e.g., Mansell, et al., 2001) and clear guidance has been provided to support the process (e.g., Fulton & Winfield, 2008). Development work should, therefore, focus on supporting a number of local authorities (and their partners including families, providers and health staff) to implement this guidance locally. Such work will only be effective if it gains commitment from local authorities so it is important that they contribute to the funding of the work and 'sign up' to it at the highest level. It would also be appropriate to use the process to encourage local authorities to focus more systemically on the potential for developing services which effectively prevent and intervene earlier with challenging behaviour and mental health problems. This would be consistent with the move, in health and social care policy more generally, towards an emphasis on prevention and the promotion of well-being (Department of Health, 2008, 2009a). Such a focus should attend to the experiences of families described earlier in this report by commissioning (or prompting the commissioning of) skilled family-centred support services. Such services would be likely to reduce preferences for out of area placements by providing good quality, local support.

6.2.2 Dissemination and networking

Not all areas can participate in the above development work and, indeed, many would not want to. It seems important, therefore, to also provide support in a way that provides greater coverage and creates more opportunities for good practice to be shared and innovative practice encouraged and supported. One cost-effective way to do this might be the establishment of a website. Such a website could have a number of different functions:

- Collation of evidence about the effects of services;

- Collation of examples of good practice (such as those identified by the current NDTi project on commissioning);
- Provision of opportunity for the development of virtual, ad hoc networks of commissioners around specific issues;
- Broader dissemination of lessons from the development work on personalisation.

The website would draw on examples such as that established by Research Autism (www.researchautism.net) and that for the Commissioning Support Programme (www.commissioningsupport.org.uk). It would be important that it was as interactive as possible to encourage active commissioner involvement.

References

Allen, D. (2008). Failing to plan is planning to fail: out-of-area placements for people with learning disabilities. *Advances in Mental Health and Learning Disabilities, 2*(3), 3-6.

Allen, D., Hawkins, S., & Cooper, V. (2006). Parents' use of physical interventions in the management of their children's severe challenging behaviour. *Journal of Applied Research in Intellectual Disabilities, 19*, 356-363.

Beadle-Brown, J., Mansell, J. L., Whelton, B., Hutchinson, A., & Skidmore, C. (2006). People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placements. *Journal of Intellectual Disability Research, 50*(11), 845-856.

Becker, P. (2006). Assessing the quality of service provision for people with challenging needs placed out of borough. *Tizard Learning Disability Review, 11*(4), 12-18.

Brown, H., Orlowska, D., & Mansell, J. (1996). From complaining to campaigning. In J. Mansell & K. Ericsson (Eds.), *Deinstitutionalization and Community Living* (pp. 225-240). London: Chapman & Hall.

Care Quality Commission. (2009). *Specialist inpatient learning disability services: follow-up audit of services 2008-9*. London: Care Quality Commission.

Commission for Social Care Inspection, Healthcare Commission, & Mental Health Act Commission. (2009). *Commissioning services and support for people with learning disabilities and complex needs: national report of joint review*. London: Commission for Social Care Inspection, Healthcare Commission, Mental Health Act Commission.

Cornes, M., Manthorpe, J., Huxley, P., Waddington, P., Stevens, M., & Evans, S. (2010). Developing world class commissioning competences in care services in England: the role of the service improvement agency. *Health and Social Care in the Community, 18*(3), 249-256.

Department for Education and Skills/Department of Health. (2004). *Disabled Children in Residential Placements*. London: Department for Education and Skills/Department of Health.

Department of Health. (2004). *Commissioning service close to home: Note of clarification for commissioners and regulation and inspection authorities*. London: Department of Health.

Department of Health. (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs: Revised edition (Chairman: Prof J.L. Mansell)*. London: Department of Health.

Department of Health. (2008). *Making a strategic shift to prevention and early intervention: a guide*. London: Department of Health.

Department of Health. (2009a). *New Horizons: a shared vision for mental health*. London: Department of Health.

Department of Health. (2009b). *Valuing People Now: The Delivery Plan*. London: Department of Health.

DH Commissioning and System Management Directorate. (2009). *Improving the health and wellbeing of people with learning disabilities*. London: Department of Health.

Emerson, E., & Robertson, J. (2008). *Commissioning person-centred, cost-effective, local support for people with learning disabilities*. London: Social Care Institute for Excellence.

Fulton, K., & Winfield, C. (2008). *Person-centred commissioning - now: a pathway approach to commissioning learning disability support*. London: Improvement and Development Agency.

Hassiotis, A., Robotham, D., Canagasabey, A., Romeo, R., Langridge, D., Blizard, R., et al. (2009). Randomised, single-blind, controlled trial of a specialist behaviour therapy team for challenging behaviour in adults with intellectual disabilities. *American Journal of Psychiatry, 166*, 1278-1285.

Heslop, P., & Abbott, D. (2007). School's out: Pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. *Journal of Intellectual Disability Research, 51*(7), 489-496.

Mansell, J., Beadle-Brown, J., Skidmore, C., Whelton, B., & Hutchinson, A. (2006). People with learning disabilities in 'out-of-area' residential placements: 1. Policy context. *Journal of Intellectual Disability Research, 50*(11), 837-844.

Mansell, J., McGill, P., & Emerson, E. (2001). Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behavior. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation* (Vol. 24, pp. 245-298). San Diego, CA: Academic Press.

McGill, P. (2008). Residential schools for children with learning disabilities in England: recent research and issues for future provision. *Tizard Learning Disability Review, 13*(4), 4-12.

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health and Development, 32*(2), 159-165.

McGill, P., Tennyson, A., & Cooper, V. (2006). Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: Their perceptions of services received and expectations of the future. *British Journal of Social Work, 36*, 597-616.

McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research, 46*(3), 239-249.

Pinney, A. (2005). *Disabled Children in Residential Placements*. London: Department for Education and Skills.

Pritchard, A., & Roy, A. (2006). Reversing the export of people with learning disabilities and complex needs. *British Journal of Learning Disabilities, 34*, 88-93.

Royal College of Psychiatrists, British Psychological Society, & Royal College of Speech and Language Therapists. (2007). *Challenging Behaviour: A Unified Approach*. London: Royal College of Psychiatrists.

South Central Regional Inclusion Partnership. (2003). *Analysis of Out of Authority Placements 2003*. Hove: SEN Regional Partnerships.

South Central Regional Inclusion Partnership. (2004). *Analysis of Out of Authority Placements July 2004*. Hove: SEN Regional Partnerships.

South Central Regional Inclusion Partnership. (2005). *Analysis of Out of Authority Placements July 2005*. Hove: SEN Regional Partnerships.

South Central Regional Inclusion Partnership. (2006). *Analysis of Out of Authority Placements July 2006*. Hove: The Regional Partnerships.

The Regional Partnerships. (2007). *Analysis of Placements in Independent and Non-Maintained Special Schools (aka Out of Authority Placements) July 2007*. Hove: The Regional Partnerships.

The Regional Partnerships. (2008). *Analysis of Out of Authority Placements July 2008*. Hove: The Regional Partnerships.

Whelton, B. (2009). Recent trends in out-of-area placements for adults with learning disabilities in England. *Tizard Learning Disability Review, 14*(2), 44-48.

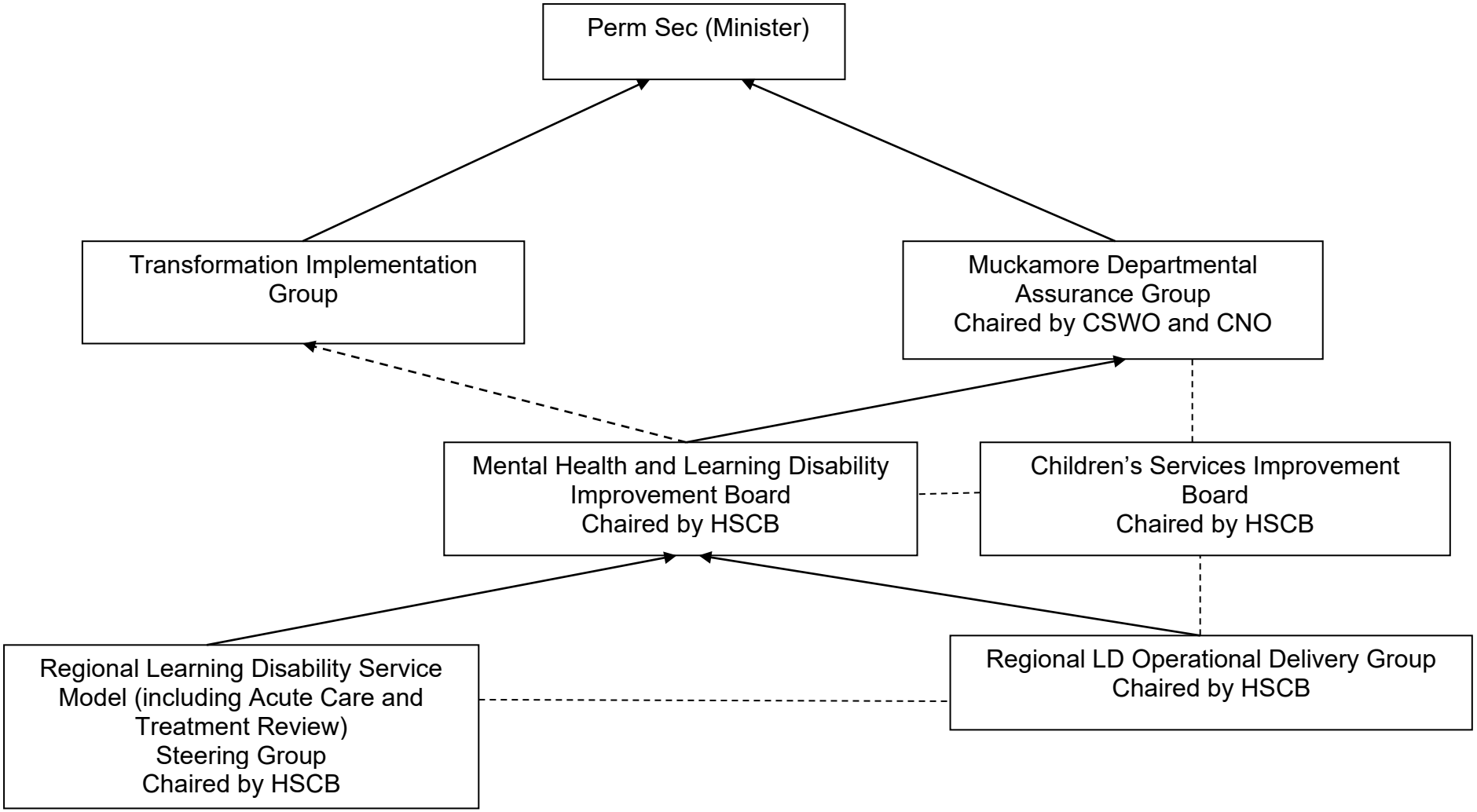
Wing, H., & O'Connor, P. (2004). *Best practice guidance on the operation and management of registered care homes for people with learning disabilities who present significant challenges*. London: National Care Standards Commission.

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? *Journal of Intellectual Disability Research, 53*, 644-653.

MAHI - STM - 118 - 2425

MMcG-271

Muckamore Abbey Hospital HSC Response – Draft Governance Structure



Health and Social Care Board

Terms of Reference

Regional Learning Disability Operational Delivery Group

FINAL VERSION 16 October 2019

Final Version as at 16/10/19

REGIONAL LEARNING DISABILITY OPERATIONAL DELIVERY GROUP: TERMS OF REFERENCE

1. Introduction

1.1 This paper sets out the Terms of Reference (ToR) for the Regional Learning Disability Operational Delivery Group (RLDODG).

1.2 The introduction to the draft Health and Social Care HSC (HSC) Action Plan initiated in response to the Independent SAI Review of Muckamore Abbey Hospital indicated that 'the first but critical step will be to develop and deliver enhanced services in the community to source, support and sustain people in the places where they live'. This will be one of the key roles of the RLDODG.

2. Aims

2.1 The RLDODG has been established to provide the DOH, through the Health and Social care Board (HSCB), with assurance regarding the HSC's actions, following 'A Way to Go' (Review into Safeguarding at MAH as well as to provide oversight regarding the Permanent Secretary's commitment on resettlement made in December 2018.

2.2 Additionally this group will work to support the development of enhanced and regionally consistent community services for people with a learning disability and their carers which are designed to support and sustain people in their communities; avoid the need for inappropriate inpatient admission; and assist with timely discharge. Where admission is essential, it should be for facilitated for the shortest period necessary.

Timely discharges

3. Objectives

3.1 The objectives of the RLDODG group are to deliver the HSC Action Plan:

FINAL VERSION 15 October 2019

i. To ensure the commitment given by the Permanent Secretary to resettle the primary target list of patients is met;
ii. To address the regional issue of delayed discharges for those patients who are encountering obstacles in their return to the community;
iii. To share the lessons learned from MAH (including the SAI report) and influence the transformation of Learning Disability services across NI which are consistent;
iv. To support the Trusts to develop regional admissions criteria, a regional bed management protocol and a regionally agreed acute care pathway thus ensuring necessary hospital admissions are planned and discharges expedited in a timely manner;
v. To review and develop the training needs and capacity of the multidisciplinary workforce designed to deliver improved intensive home treatment and crisis response interventions in the community;
vi. To improve the skills for the multi –disciplinary workforce and their capacity to provide safe and effective person centred care in all community settings when people experience episodic mental ill health or exhibit distressed behaviours;
vii. To review current forensic LD services and identify service development needs required to improve support in the community as well as inpatients services;
viii. To engage with the NI Housing Executive and provider organisations with a view to the identification of barriers to meeting housing needs and enable the development of innovative approaches to accommodation in the short, medium and longer term;
ix. To improve the capability of current providers of supported living, housing, residential, nursing care, domiciliary care to meet the needs of people with complex needs and by doing so support family carers to prevent placement breakdown.

FINAL VERSION 16 October 2019

4. Membership & Frequency of Meetings

4.1 It is anticipated that the RLDODG will meet at least once a month, but the frequency of meeting will be kept under review, and frequency will be determined by progress being made.

4.2 The group will be chaired by the HSCB and PHA. Membership will include:

i. DOH LD Policy Lead plus Professional Advisers -Nursing, Social Work and Medicine;
ii. Assistant Directors in LD within each of the 5 HSCTs;
iii. HSCB Performance Lead;
iv. PHA Assistant Director for LD (in the interim- Public Health Nurse Consultant will attend)
v. HSCB Social Care Lead for LD and Mental Health
vi. Representative from MAH Management Team, BHSCT
vii. HSCB Social Care Lead for Children's Disability

**Colleagues from NIHE will be in attendance*

5. Operating Arrangements:

5.1 The Regional group will meet monthly.

5.2 A quorum of five members, which includes representation from five organisations, must be present before a meeting can proceed.

5.3 If members cannot attend they are requested to send a suitable nominee of sufficient seniority to represent them. E.g. Senior Service Manager or Co-Director.

5.4 Internal or external persons may be invited to attend a designated part of the meetings at the request of the Chair/Co-chair on behalf of the Group to provide advice and assistance where necessary.

5.5 Members will be mindful to protect the confidentiality of service users in any discussions or papers produced.

FINAL VERSION 16 October 2019

6. Accountability arrangements:

6.1 The Regional group will be convened by the HSCB and will be responsible to the Muckamore Abbey Assurance Group (MDAG) through the MH and LD Improvement Board.

6.2 The HSCTs will provide an update report on discharge plans in advance of the regional meetings to the HSCB which will identify strategic issues impacting on the resettlement of patients which will inform part of the agenda for the regional meetings.

6.3 Regional group members will be expected to provide feedback to and from their own organisations on issues of strategic relevance.

6.4 Regional members will be expected to contribute to the agenda and assist with the work plan and its associated tasks.

6.5 Action points from meetings will be collated by HSCB and circulated to members.

7. Outcomes

7.1 The RLDODG will strive to ensure that the following outcomes are achieved:

i. all delayed patients have been resettled in line with the strategic direction;

ii. the recommendations of the independent investigation have been delivered on and the learning is disseminated regionally where appropriate;

iii. regional issues regarding services, systems and processes with respect to LD services are discussed and solutions agreed and delivered consistently in line with future needs.

iv. BHSCT will have delivered the specific improvements required in Muckamore Abbey Hospital.

i. HSCTs continue to deliver services that are safe, effective and fully Human Rights compliant;

FINAL VERSION 16 October 2019

8. Review & Duration

8.1 The effectiveness of these ToRs and the membership of RLDODG will be reviewed at the first meeting and as necessary with a view to ensuring an enhanced focus on broader service delivery and emerging issues into the future.

8.2 It is intended that RLDODG will form part of the regional operational structure of LD services; ensure oversight and governance arrangements between HSCB and Trusts in NI into the future and provide ongoing advice and guidance to DOH on LD needs and service requirements in light of the new LD service model.

FINAL VERSION 16 October 2019

Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

Draft Terms of Reference

draft

1. TITLE

1.1. Regional Oversight Board for Learning Disability Resettlement – Terms of Reference.

2. PURPOSE

The purpose of the Oversight Board is to provide:

2.1. Policy advice on matters relating to the learning disability resettlement programme.

2.2. Assurance to the Department on the progress of the resettlement programme for the betterment of residents/ patients.

2.3. Effective performance management, monitoring and challenge, as part of the accountability process, for those responsible for providing resettlement services, using a detailed tracker tool for each individual undergoing resettlement.

2.4. Identify, resolve and/or escalate issues of concern in the resettlement process.

2.5. Identify and escalate any issues relating to the management of risk or governance.

2.6. Ensure that resettlement is expedited and the resettlement programme is brought to a successful conclusion for individuals and their families.

3. SCOPE

3.1. The Oversight Board will limit its scope to the overview of the resettlement process and not engage in wider issues in the policy development or provision of learning disability services unless specifically tasked with doing so.

3.2. Existing organisational responsibility for resettlement remains with HSC organisations as before.

3.3. The term of the Oversight Board is one year in the first instance.

3.4. The scope of the Oversight Board will be subject to ongoing review.

4. REPORTING

4.1. The Oversight Board will report directly to the DoH Permanent Secretary.

4.2. Through the SPPG membership the Oversight Board will provide regular progress reports to other interested stakeholder groups.

4 STRUCTURE and MEMBERSHIP[1]

The proposed membership will include, but is not limited to:

4.1 An independent chair.

4.2 Senior representatives from DoH Learning Disability policy branch, Nursing, Social Work and the Allied Health Professions.

[1] Proposed membership is set out in Appendix 1

draft

4.3 Senior representative from the Strategic Policy and Performance Group (SPPG)

4.4 Representatives from HSC Trusts and NIHE (to be agreed).

5 SECRETARIAT

5.1 Secretariat support will be provided from within the SPPG.

draft

Appendix 1 Regional Learning Disability Resettlement Oversight Board

Membership:

Patricia Donnelly	Chair	Independent - HSC Leadership Centre
Mark McGuickian	Director	Disability and Older Peoples Services DoH
Brendan Whittle	Director	SPPG DoH
Maria McIlgorm		Chief Nursing Officer
Aine Morrison		Acting Chief Social Work Officer
Suzanne Martin		Chief AHP Officer

Trust Representation (Director Level):

Belfast HSC Trust – Moira Kearney
Northern HSC Trust – Petra Corr
South Eastern HSC Trust – Margaret O'Kane
Southern HSC Trust – Jan McCall
Western HSC Trust – Karen O'Brien.

draft

Regional LD Operational Delivery Group (RLDODG)

16 September 2019 The Boardroom, HSC Leadership Centre, Hampton Manor Drive, Belfast

Action Points

In attendance: Lorna Conn (chair) HSCB, Miceal Crilly SHSCT, Siobhan Rogan DOH, Donna Morgan NHSCT, Laura O'Neill NIHE, Margaret O'Kane SEHSCT, Marian Hall HSCB, Anne Sweeney NIHE, Ian McMaster DOH, Jerome Dawson DOH, Aisling Curran BHSCT, Maire Redmond DOH, Elma Newberry NIHE, Linus McLaughlin HSCB

Via Tele link: Patrice Curran WHSCT, Maureen McGeehan WHSCT

Apologies: Aine Morrison DOH, Christine McLaughlin WHSCT, Deirdre McNamee PHA, Kieran McShane HSCB, Alyson Dunn NHSCT, Marie Heaney BHSCT, Alison McCaffrey DOH, Sean Scullion DOH

Agenda item	Discussion points	Actions agreed	By Whom	By when
1. Welcome, introductions & and apologies	LC welcomed all to the meeting, noted apologies and a round of introductions took place.			
2. Context for the meeting	LC explained remit of the meeting as regionalising the issues arising from the draft HSC action plan which is in a response to Permanent Secretary commitment and the recommendations of the SAI Review of MAH. This meeting has a strategic focus and reports through the MH & LD Improvement Board to the Muckamore Abbey Departmental Assurance Group chaired by Sean Holland and Charlotte McArdle.			
3. Discussion of TOR & membership of RLDODG	Revisions noted: 2.1 separate into 2 points and add in timely discharges and admissions to be short lived; 3.1 v. insert develop; 3.1 vi inserted MD and remove social care workforce; 3.1 vii extend to consideration of forensic inpatient support and links to other services; 4.2 vii- most appropriate nominee from NIHE to be considered ; 7.1 outcomes needs clear timescales (this will be reflected in the associated action plans and not TOR); 6.2 to clarify that report is an	TOR to be revised and circulated for sign off at next meeting Amended TOR to be forwarded to MDAG meeting Housing Executive to advise of most appropriate person to attend and sign off on TOR	LC/Members of group LC AS; LO'N & EN	**16 October 2019** **30 October 2019** **ASAP**

Agenda item	Discussion points	Actions agreed	By Whom	By when
	update on discharge plans and Statement regarding confidentiality should be included. Children and YP are reflected in HSC Action plan actions and in group membership. The need for carer and service user representation was raised. TOR are closely based on HSC Action Plan which is still in draft. TOR needs to be approved asap.	Consideration to be given to how best to involve carers and service users.	LC/MH/LD Improvement Board/DOH	**30 October 2019**
4. Update on current position in acute Hospitals - PTL; CD & DD; Active treatment	It was hoped that an update on the current position within all the 5 Trusts could have been presented at this meeting. However, 2 returns were late and this impeded analysis in time for sharing. The need for a consistent single template for returns was discussed. This information will now be required for the monthly MDAG meetings and this meeting will require receipt of this information well in advance to allow it to be quality assured by ADs and Director before being presented to MDAG. Where no planned date is indicated it's necessary to provide context in terms of plans which had been unsuccessful; reasons for the delay etc.	Existing template developed by Valerie McConnell to be revised to become one consistent monthly method for reporting. Trusts will complete as requested monthly and the next one will reflect figures as at 1 September 2019.	LC LMCL BHSCT; NHSCT; SEHSCT; WHSCT & SHSCT	**Completed and circulated** **ASAP- 27 September 2019**
5. Update - Seclusion Policy Review and adoption	AC advised that this was in place in BHSCT from 1 September 2019 with associated training being provided to	All Trusts to remain involved with the development and	BHSCT; NHSCT; SEHSCT; WHSCT & SHSCT	**Ongoing**

Agenda item	Discussion points	Actions agreed	By Whom	By when
	staff. It is being piloted for 3 months. It has been shared with other Trusts for comment. LC suggested that it would be helpful for a regionally consistent approach to the policy and its adoption.	adoption of a seclusion policy.		
6. Update - Acute Pathway and criteria update on progress	The need for a regional approach was reiterated and clear criteria/thresholds to be developed. All Trusts had attended some meetings regarding this but further work is required. The need for enhanced community services was identified as critical for the success of any pathway as often this is no alternative at the moment.	Draft criteria to be shared**.**	AC	**ASAP**
7. Regional Bed Management	HSCB has secured funding for a regional temporary 7 months 8A bed manager post until March 2020. This post holder will be located within BHSCT and will assist with development of a care pathway and criteria as well as facilitate essential admissions across and between all 3 LD hospitals.	Follow up required regarding progress on this appointment by BHSCT.		**ASAP**
8. Provider Engagement re: capacity	The need for increased provider development and support to maintain people in the community is critical in the development of community infrastructure and avoiding inappropriate admissions. The BHSCT, SEHCST & NHSCT had hosted a workshop in June 2019 to begin this process. The plan had been to follow up on this work in	Collated feedback from providers will need to be sought from Heather McFarlane, HSCB. Item to be placed on agenda of meeting for further discussion and	LC LC	**By next meeting** **At next meeting**

Agenda item	Discussion points	Actions agreed	By Whom	By when
	September but the focus had needed to shift to the LD service model, given timescales for consultation. Another workshop is being considered for November 2019 after all the feedback to date has been collated. This will need to extend to all 5 Trusts to maximise impact. The need for feedback from the Review of Acute Care was considered necessary to inform this work. How to progress this regionally will be discussed further at the next meeting. The issue of security of tenure was discussed. It was felt that this wasn't an issue for any people with LD.	planning. All Trusts to confirm numbers of people with LD who have tenancy agreements and those with licences to occupy.	BHSCT; NHSCT; SEHSCT; WHSCT & SHSCT	**15 October 2019**
9. Forensic Needs and Scoping	Under a transformation project in HSCB, which is funded until March 2020, Noel McDonald is currently conducting a scoping of need including those with LD. This will be very helpful in planning for services for this group of people. 3 Trusts have provided information and 2 are currently working on this. AD LD did not appear to be aware of this or the Trust colleagues assisting Noel with this.	Noel is to be invited to the next meeting.	LC	**Completed**

Agenda item	Discussion points	Actions agreed	By Whom	By when
	The 2 current business cases for forensic patients to be resettled from Muckamore were referred to and the process to proceed to full business cases was described.			
10. AOB	Housing issues were noted - private landlords and the caps on housing benefit and how this and universal credit were impacting on placements. Additionally, the inability to access supporting people monies and housing benefit when Trust provides accommodation rather than housing associations. A piece of work was conducted 4 or 5 years ago to draft a service specification for supported living accommodation. This could be useful to understand the interface/relationships/responsibilities between HE/Trusts and BSO. However, the progression of this was halted due to legislative change being required.	Trusts to quantify the issues in order that conversations can occur to explore what solutions could be sought across departments. To be circulated.	BHSCT; NHSCT; SEHSCT; WHSCT & SHSCT DM	**Completed**
11. Date of next meeting –	Venues were discussed and Antrim was suggested as suitable for next meeting. 16 October 2019 2-4 pm suits most people and a list for possible dates up until March 2020 has been circulated to check availability. Tele link facilities are helpful for	AC to check if Muckamore is available. LC to circulate list of suggested dates to those who haven't been able to indicate availability and to	AC LC	**Completed** **Completed**

Agenda item	Discussion points	Actions agreed	By Whom	By when
	those with far to travel although those on today's link advised they had difficulty hearing conversation with the result that they had to abandon the meeting after a short while.	circulate dates to all.		

NB *Date and Venue of next meeting is confirmed as: The Boardroom, Admin Building at MAH is booked for the Regional LD Operational Delivery Group (RLDODG) meeting for 16th October at 2pm, with tea/coffee on arrival for 16 people.

Regional LD Operational Delivery Group (RLDODG)

24th February 2022 at 10:30am via zoom

Action Notes

Present:	**Apologies:**
Caroline McGonigle, HSCB (Chair) Lyn Preece, SEHSCT Darren McCaw, DoH Ian McMaster, DoH Siobhan Rogan, DoH Marion Fisher, Supporting People, NIHE Ann Stevenson, BHSCT Bria Mongan, Independent Reviewer Tracy Kennedy, BHSCT Christine McLaughlin, WHSCT Roy Baille, NIHE Deirdre McNamee, PHA Ian Sutherland, Independent Reviewer Kelly Hillock Supporting People (Rep Liam O'Hanlon) Gareth Farmer NHSCT	Catherine McCrisken, BHSCT Liam O'Hanlon NIHE replacing Laura O'Neill Mary Bell, Service User representative John McEntee, SHSCT Maire Redmond, DoH

In attendance: Andriana Alkiviadou, HSCB (note taker)

Agenda Item	Discussion Points	Actions Agreed	By Whom
1. Welcome, introductions and apologies	Caroline welcomed all on the call and introductions were facilitated. Apologies noted.		
2. Action Points from January 2022 meeting	Notes accepted as a true record. Matters arising to be discussed as agenda items.	No more comments were made.	
3. Update re Resettlement Review (BM/IS)	Bria advised that the Review will be completed March end 2022. Bria and Ian have met relevant stakeholders (e.g. IAHCP, Mencap, RQIA, NISCC, ARC, PCC etc. Next steps include engagement with families. Bria noted some positive developments since last meeting, notably that the Directors of BHSCT, SEHSCT and NHSCT held a workshop last week. Directors will meet Bria and Ian to provide them with a plan to support resettlement. Bria noted the importance of planning and contingency planning by Trusts is recognised. Bria also noted positively, providers are keen to work with Trusts to support effective resettlement. Bria and Ian issued a template to Trusts seeking additional information, return date today.	Trusts to ensure the template is returned to Bria and Ian S.	All Trusts

Agenda Item	Discussion Points	Actions Agreed	By Whom
	Bria shared updates re relevant schemes. 5 individuals from BHSCT awaiting Minnowburn scheme, expected to discharge by 2024. Onsite and Forensic Schemes haven't really moved forward. Re Onsite, Feasibility Study to determine if new build/refurb still outstanding. Consideration required re Forensic Scheme, following meeting with Directors, update will be provided at next meeting. Ian S clarified that he and Bria have commenced development of a Supply Map to detail services available within the region for individuals with a learning disability, Currently 143 Supported Living Schemes. 21 Learning Disability Nursing Homes, total of 606 places/beds. 2/3 of those places sit in Trust areas. Largest number of these located in NHSCT (40%) and SHSCT areas. WHSCT only have 5% of this range. Some of those homes have significant number of vacancies. Ian S noted that exploration of what capacity there is within the system is essential in the first instance. Total of 48 Registered Residential Care Homes with 546 places/beds. 1/3 of these homes run by Trusts. 143 schemes. Currently SEHSCT has 43 schemes - 38 of them by Independent Provider and 5 by the Trust. NHSCT has 34 schemes - 27 run by Independent Provider and 6 by the		

Agenda Item	Discussion Points	Actions Agreed	By Whom
	Trust. WHSCT has 17 schemes - 15 by Independent Provider and 2 by Trust. SHSCT has 24 schemes – 11 run by an Independent Provider and 13 by Trust. Triangle noted as a substantial provider within Trusts, Positive Futures also working with all Trusts. It was noted that many individuals with learning disabilities require accommodation, support and care provision. Deidre McNamee noted the importance of MAH inpatient's needs being reassessed as needs change over years. Importance of strategic needs assessment to inform strategic commissioning discussed. Meeting attendees noted the Supply MAP needs to be client focused and dynamic. Need to work with the market to provide appropriate services. Co-commissioning noted as a potential way forward. Second phase of external engagement started in January and is due to conclude end February 2022 .Voids noted in system, Trusts need to explore voids to enquire if services could meet the needs of service users or if these services need decommissioned if no longer effective. Kelly H noted this is particularly important to support strategic commissioning. From chat Ian McAllister: We are scheduling to go to some of the schemes and see the lived	Bria and Ian S to share any outcomes/updates at next scheduled meeting.	BM/IS

Agenda Item	Discussion Points	Actions Agreed	By Whom
	experience for some of the individuals who are being supported, and meeting a number of families too, which will give us an richer picture on the quality. Also from Chat Siobhan R: Also important to consider how to mitigate against the harmful effects of long term segregation for those living in single occupancy dwellings. However individuals with an intellectual disability should be able to choose to live on their own in the same way as all of us have that choice. Ian S reiterated information needs to be analysed to determine if any vacancies are suitable in terms of meeting MAH inpatient resettlement requirements. Regional dashboard with updated data/Supply Map will be a suggestion moving forward to support ongoing resettlement. Gareth F commented that regional information regarding available services would be extremely useful and that this information would also inform strategic planning and commissioning moving forward. The importance of a collaborative approach to procurement etc. was noted moving forward.	When Supply Information available Trusts to facilitate reassessment of individuals, without a plan or where there is delay to ensure existing services/voids are fully explored to determine if appropriate to effectively meet the needs of individuals in MAH requiring resettlement.	All Trusts
4. Updates on Business Cases (Belfast	Tracy K was initially unable to join the zoom call due to technical issues but was listening to the conversation via phone with Caroline	Business Case update to be shared at next meeting by BHSCT.	TK

Agenda Item	Discussion Points	Actions Agreed	By Whom
Trust/NIHE)	McGonigle. No further update re business cases therefore available.		
5. Update on current position in acute hospitals- PTL CD &DD ; Active treatment (Trusts)	**NHSCT** - 16 delays with no individuals receiving active treatment in Muckamore. 2 individuals in transition, 1 to Cherryhill and the other Magherafelt, Another individual expected to discharge to Cloggrennan Trust Supported Living Facility, equating to 3 individuals expected to be discharged by end of March 2022. 5 individuals identified for Braefields scheme. First discharge planned end of April. Aiming to facilitate discharges in pairs where feasible. Mallusk scheme much slower pace. No discharges to scheme since end of last year. Trust holding regular meetings with provider, staffing primary issue, Trust explored MAH/Trust staff being used to facilitate discharges. Discussions remain ongoing with the provider to progress discharges. 1 identified for forensic, 1 confirmed onsite, Twin track for next discharge to Braefields, onsite back up plan. 1 individual without a plan, Trust Resettlement Co-ordinator engaging with providers to progress a plan. Remaining space in Braefields has interest from NHSCT and another Trust. 1 Individual in Dorsy, Fairways still	All Trusts to provide resettlements at next meeting.	ADs

Agenda Item	Discussion Points	Actions Agreed	By Whom
	experiencing staffing issues. Aiming for discharge mid April. Individual in Lakeview still aiming for discharge in May. **SEHSCT**– 8 individuals (7inpatient, one on extended home leave). Trust trying to facilitate discharge for Individual on home leave, anticipating formal discharge 28/02/22. However, JR now being progressed re this decision. 1 individual in Dorsy, discharge planned for 28/03/22. 1 individual, ECR application submitted to panel. Aiming to facilitate discharge to an alternative hospital, awaiting outcome of panel. Two potential options pending assessment outcomes. Onsite provision, 2 individuals confirmed, 1 has nursing needs the other assessed as supported living needs. 1X Mallusk anticipated discharge July 2023. Given discussions re Supply Map will consider other options. 1 individual, Praxis service is not available until late 2023, scoping other options. – Four Synergy Group are keen to develop a new supported Living facility in Lisburn and meeting has been scheduled for 4 March to include NT and BT Roy B advised capital		

Agenda Item	Discussion Points	Actions Agreed	By Whom
	funding would not be available if this company is not NI based. Kelly H also commented that self-funded individuals may choose to apply for a private housing instead of the scheme. **BHSCT**– 16 Total, 14 in MAH and 2 on trial leave) 2 of the 14 recently admitted in October & November and in active treatment. 1 identified for Mallusk, issues in relation to staffing causing delay 5 identified for Minnowburn 2024 discharge date anticipated. 2 identified for the forensic site. 1X on site proposal no date yet. 2x trial leave 1x under the article 15 leave not able to release, currently waiting of a court trial decision. 1x under article 15 leave, recall by DoJ – resettlement options require consideration. No discharges confirmed at the moment by March end. SHSCT 1 individual refusing to leave MAH. MDT met with him and formal complaint recently received. Bria noted the importance of a plan being agreed in respect of this individual. Bria requested Tracy to send an action plan to	Tracy to send an action plan to Caroline McGonigle outlining actions required and steps	TK

Agenda Item	Discussion Points	Actions Agreed	By Whom
	support resettlement for this individual to Caroline McGonigle. Total numbers of inpatients in MAH=38 14 BHSCT 16 NHSCT (2 of these individuals have started transitioning during day but still inpatients in MAH) 7 SEHSCT 1 SHSCT An additional 3 individuals are on trial leave and not currently residing in MAH (2 BHSCT, 1 WHSCT) and 1 other individual from SEHSCT on extended home leave but planned to be formerly discharged by 28/02/22.	taken to support resettlement for this individual.	
6. HSC MAH Action Plan &Muckamore Abbey Departmental Assurance Group (MDAG)	Darren noted the importance of recording agreed timelines and Responsible Officers in respect of actions.		
7. AOB	None recorded		

Agenda Item	Discussion Points	Actions Agreed	By Whom
8. Date of Next Meeting	10.30 am 31st March.https://hscni-net.zoom.us/j/85468269493?pwd=ODdxZVppenE5QUpTQUpqcGRWN0Z2Zz09	**Please note this meeting is to be rearranged at the request of some attendees. Heather Gibson will be in touch to convene an alternative date in March.**	HG