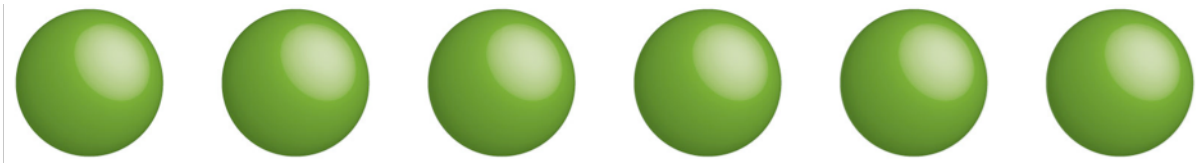
National Development Team for inclusion

Final Report

A REVIEW OF SPECIALIST LEARNING DISABILITY HEALTH SERVICES IN STAFFORDSHIRE AND STOKE



IMPORTANT COVERING NOTE

It should be noted that this report, although only being formally presented to senior Commissioners in April 2012 was first drafted in December 2011, based on fieldwork undertaken primarily around November 2011 and presented to commissioners in draft form in January 2012. We are aware that since that date the learning disability commissioners have, along with the provider NHS Trusts, been working on some of the issues identified in this report. As the report reflects our findings as a team over that earlier review period, it is possible that the current position has evolved beyond our data and evidence.

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1. Background

1.1 The National Development Team for inclusion (NDTi) was commissioned by NHS and local government commissioners for Staffordshire and Stoke to review specialist learning disability health services across the two areas. The commissioners recognised the need for a review of the strategic approach to these services. The brief was to review current services against policy and best practice models and provide recommendations to the PCT commissioners for future services.

The commissioners requested that the review had a particular focus upon services to people labelled as challenging and/or who have complex needs – i.e. those in greatest need of specialist NHS input and who are likely to prove most costly to services. A separate note has been provided to the commissioners, outlining some of our conclusions in relation to the brief look we took at how specialist learning disability health services are supporting people to access mainstream health services.

2. The National Development Team for Inclusion

2.1 The NDTi is a not for profit organisation that promotes equal and inclusive lives for people in their communities, particularly where ageing or disability are issues. The organisation does this by taking action at local and national levels: advising policy makers, encouraging public debate, carrying out research & evaluation, and providing change management support to local and national organisations to help them achieve better outcomes.

2.2 The NDTi Team for this work was lead by its Chief Executive, Rob Greig, who was previously the Government's National Director for Learning Disabilities. The other team members were Sue Turner, NDTI Project Lead for the Learning Disability Public Health Observatory, and Bill Love, then Head of Learning Disability for NDTi but now NDTi's Head of Development Support and Training.

3. Process

3.1 In order to undertake this work, the NDTi team reviewed all available documentation and met and spoke with a wide range of stakeholders, including:

- Commissioners from both PCT/CCGs (including prison health commissioners), and local authorities
- Managers and clinicians from both NHS provider Trusts and the provider arm of the PCT
- Managers, care managers[1] and front line staff from both local authorities
- A small sample of social care provider organisations that were identified to us as having a particular role or interest in supporting people with more complex needs
- Representatives of the Learning Disability Partnership Boards across both areas including Mencap and family voices

3.2 The vast majority of meetings were face to face, though for reasons of people's availability and in order to deliver the contract within budget, a small number were conducted by telephone interviews. A number of relevant services were also briefly visited in the course of the work.

3.4 The scope of this review has been quite time and resource limited. Nonetheless, an extremely wide range of issues were raised with the NDTi by people interviewed. This report will not cover all of those issues, for three reasons (i) some were outside the scope of the brief (ii) there was insufficient time in the contract to explore every issue raised (iii) in order to maintain a reasonable length to this report with a focus upon what appear to be the key issues.

3.5 Given the request to focus significantly upon people who challenge and have the most complex needs, it was decided to use the published commissioning good practice guidance as an analytical tool to support this work. This framework was developed by the NDTi for the Department of Health. Based upon evidence from localities that have made some progress in commissioning evidence based supports for people who challenge, it identifies seven main areas and details what should be in place locally to maximize the chances of effective services being commissioned and delivered. It was the initial analysis against this that led to the change in focus of the work outlined in paragraphs 3.3 – 3.4.

This report will not be structured purely along the lines of that guidance given that our brief goes

[1] A significant gap was that the Stoke care managers did not attend the set meeting and so this important perspective was missing and knowledge on matters relating to the care management of people with significant health needs in Stoke had to be extrapolated from information provided from other sources.

wider than people who challenge. However, reference to that Guidance will provide additional information about the thought process and analysis that has been undertaken in this work.

The full framework can be found at

www.ndti.org.uk/uploads/files/Challenging_behaviour_report_final.pdf

3.6 As the work progressed, it became clear to the NDTi team that the likely recommendations arising from the review were going to be far more wide-ranging than originally anticipated in the commission for the work. The brief implied a need for recommendations that would focus upon changing elements of service design and model. Whilst the review concludes that such changes are needed, its core conclusion is that the system as a whole is in need of change – without which any changes with elements of service delivery will have no discernable long term impact.

3.7 Discussions were therefore held with the learning disability commissioners representing the four commissioning bodies and agreement reached to amend the second part of the original proposed process - in order to seek to engage with more senior officers who could commit to consider the likely proposed strategic change agenda. (Telephone conversations were also held with the Chief Executives of both NHS Trusts). This change also led to a delay in the production of the final report for commissioners in order to tie in with availability of key local personnel.

3.8 This document is that final report. We will also produce an 'easier to read' headlines document for self-advocate use.

4. Executive Summary of Conclusions

4.1 There are a number of individuals and staff teams working in both Staffordshire and Stoke that are clearly committed to the delivery of healthcare services (and related social care) to people with learning disabilities. However, there are significant shortcomings in the current commissioning and delivery of important elements of specialist health care that lead us to believe that the experience of people with learning disabilities and their families is, in many cases, not what it should be. Thus, there is a need for a substantial short and medium term programme of organisational change, led by the commissioners that also involves significant services changes by NHS providers.

4.2 Our clear conclusion is that the current arrangements and services are not delivering what is expected by national policy, nor are they achieving value for money. A substantial and medium term programme of organisational change is essential if local services are to deliver policy expectations and also to avoid perpetuating a continuing escalation of expenditure levels without any commensurate increase in the quality of services provided to people. Such a programme of change needs to be led by the commissioners, with a view to shifting both the prevailing culture and the service models.

4.3 In summary, our reasons for this conclusion are that:

- There is a lack of strategic direction from the commissioning authorities. This has enabled and/or resulted in service developments by the NHS Trusts have been somewhat ad hoc i.e. not part of a strategic plan to address identified needs within an overall strategy
- There is a lack of understanding, across the whole system, of how specialist health services could and should be interacting with the social care services in order to provide 'whole life' supports – particularly for people who are labelled as challenging
- As a result of the two previous points, there are some outdated and inappropriate service models in place – significantly because structures and processes do not exist to effectively review and change services based upon evidence of performance
- This is resulting in people not receiving the supports that could and should offer them the opportunity to live better lives - instead, a significant number of people are being 'trapped' in inappropriate and probably unnecessarily expensive services
- As a result opportunities are being lost to achieve one or both of (i) better outcomes for the same investment (ii) financial savings

The text in subsequent sections of this report will describe the more detailed reasons and evidence behind this summary. It concludes with an outline of components of a service model and recommendations for action.

4.4 Amongst the most important changes to be delivered are:

- A joint approach by health and social care commissioners that incorporates specialist health services and continuing care in order to create shared financial and outcome incentives that improve the competence and capacity of local services to support people with learning disabilities with health needs, including as they relate to behaviour that challenges services
- As part of this, a commissioner led strategy that guides what NHS providers and other commissioned services seek to deliver
- The engagement by NHS providers in the delivery of that strategy as their strategic priority
- A refocusing of NHS resources away from bed based services into more preventative, responsive and joined up community based supports that operate in partnership with social care providers
- The creation of staff and system resources to lead effective person centred life planning and service development for people with the most complex needs in order to help develop local resources and services
- New, partnership based working arrangements for health and social care professionals across both authority areas
- Effective and informed strategic oversight of the improvement process and service delivery by Learning Disability Partnership Boards and senior managers.
- The development of robust mechanisms to ensure the continuing engagement and ownership of this significant change agenda from within the Clinical Commissioning Groups

4.5 The resources currently being invested should be sufficient to achieve different and better outcomes if invested in different ways. The crucial components in this will be the development of a shared agenda between the NHS and local government that encourages a sharing of risk and potential benefit and provider investment in evidence based services that reflect the joint strategy.

4.6 These conclusions are particularly important in the light of the issues raised by the Panorama programme on abuse at Winterbourne View and the resultant DH action. The service shortcomings identified in this report are almost identical to those that are widely understood and accepted as having led to the Winterbourne View failures. There is no reason to believe that Winterbourne View, and the circumstances that surrounded it, were any different to those around any other private assessment and treatment hospital. Staffordshire and Stoke are making significant use of such facilities – use demanded primarily by the inability of local services to support people in appropriate local housing and support with NHS back-up and support. Unless these shortcomings are addressed, people who challenge and have complex needs will continue to be sent out of area and/or the local health and social care system and the risk of a repetition of abuse – this time involving people from Stoke and Staffordshire – will continue.

4.7 As already noted, we are clear that many individuals working in services are personally

very committed to delivering better outcomes for people with learning disabilities. This commitment has led to a number of specific initiatives that have had a positive impact upon people and their lives, for example people moving from outdated campus provision to individually tailored and supported homes within local communities and some individualised care packages for people who previously lived in long stay institutions that appear to be achieving better outcomes with reduced staffing levels.

4.8 However, our conclusion in that these have happened despite the organisational mechanisms that surround people and services rather than because of them. What we have identified is a problem with the whole-system as well as with specialist learning disability health services in the County and City.

4.9 There are three major issues that the review has indicated need to be addressed as a matter of priority, namely:

- Strategic Vision and Direction
- Evidence based practice
- The service model

4.10 Underpinning these are two other significant factors that will both facilitate the addressing of the major issues and also flow from them being addressed:

- Leadership and inter-personal relationships and partnership working
- The availability of appropriately skilled services

This report details how and why actions are needed in relation to these five major issues

4.11 We wish to emphasise that, whilst the PCT/CCG commissioners need to take a lead on specific action in response to these recommendations, achieving effective and sustainable change will only be possible by concerted action in partnership with the two local authorities – action that will also involve changes in oversight and practice by both local authorities. Additionally, it will require strong clinical and managerial leadership from within provider NHS Trusts.

4.12 Unless specifically stated, all comments apply across both Staffordshire and Stoke and across both the north and the south of the area.

5. Strategic Vision and Direction

5.1 This report was initiated by commissioners to inform the development of a strategic approach to the future provision of specialist learning disability health services. The decision to commission the work thus implied a recognition that an agreed strategic vision was lacking. It is therefore not surprising that we agree with that and state that it requires attention as a priority. Such a strategy cannot be written by outside consultants – though its development can be supported externally – strategies have to be locally produced and owned if they are to succeed.

5.2 Beyond the lack of a written strategy, we were unable to identify any 'informal' understanding across key players and organisations as to what the role of specialist health services should be. Such an understanding can partially compensate for the lack of a formal strategy as it enables individuals to work together towards shared end points, even if they do not have a written strategy to refer to. However, we heard radically different views from people in key places about what specialist health services should be doing. These varied from the view (expressed within both heath and social care structures) that the role of the NHS was to 'fix'[2] challenging behaviour and complex needs, through to (a minority view) that the role of the NHS was to contribute specialist expertise to enable people to live ordinary lives with social care support[3].

5.3 Agreement about the role of the NHS in supporting people is crucial. The belief system of some people that challenging behaviour is the NHS's business is wrong – in terms of policy, good practice and evidence. Supports for people who challenge (and indeed have other complex needs) are best provided through a partnership between local government and the NHS - with specialist health services providing input to and supporting care managers and skilled housing and support services in order to help people maintain a positive (and cost effective) lifestyle that minimises the challenges faced by services. NHS bed based services are then a small back-up for occasions when community supports are not working as planned.

5.4 Linked to this, we are concerned that there does not appear to be a widespread knowledge about, and belief in, the evidence base about how best to support people who challenge and have complex needs. With a small number of exceptions, the people we met were unable to describe and/or misrepresented and/or seemed to be unaware of the research and policy evidence. In

[2] The word 'fix' is our interpretation of what people were saying to us rather than that used by local people. The essential principle was that when people displayed behaviour that challenged or had complex support needs, they were sent to the NHS to deal with prior to (hopefully) being returned to other services. Such an approach and belief system is at odds with both evidence and policy.

[3] This second description is what national policy, such as described in the Mansell Report, would expect to be the case

addition to views we received from people, the evidence of services that exist suggests that national policy is not being actively pursued by services. For example:

- The apparent gaps in provision in local, personalised community based services for people labelled as challenging
- The large number of NHS funded beds for people who challenge and/or have complex needs, be those within the NHS Trusts, through CHC funding or the use of private hospital provision.

5.5 This lack of either a formal strategy or an informal consensus about what the NHS should be doing has meant that some service development and innovation (statutory and third sector) appears to have been ad hoc. Some developments appear to have taken place because of personal or organisational initiative, rather than there being an understanding about how it fitted into the wider service system and helped to deliver an overall strategy. For example:

- At a service wide level, the decision by SSSFT to develop a new assessment and treatment unit (see section 8.11 for further comments on this) and its intention to turn this into a male only facility without these decisions being in response to a local commissioning strategy
- The Staffordshire care managers and the in-patient staff at Combined Trust could each identify one or two (different) examples of creative individual planning around individuals with complex needs that had enabled people to move on from NHS bed based services. However, these resulted from individual staff initiative rather than a system that then replicated this learning for other people in similar situations

5.6 It is therefore a priority that work is undertaken to develop a shared strategic vision that describes the role of the specialist health services within the context of the whole service system – a vision that is informed by the needs and aspirations of people with learning disabilities and their families and shared by the local authorities as well as the NHS commissioners, providers and others. The Partnership Boards would be the appropriate vehicle through which this work should be done and agreed. This work should be underpinned by action to help key people locally understand the policy and evidence base in order to generate the leadership for change that is essential within each part of the system.

6. Evidence Based Practice

6.1 Linked to the previous point, one of the most striking features of the review was the difficulty we experienced in obtaining evidence of service performance, in particular evidence of outcomes for people who use services. We asked everyone we met with to furnish us with evidence around the outcomes from their work. We received very little beyond some process data[4]. For example, senior managers in both NHS trusts asserted that they were responsible for 'successful' services but they and their staff were only able to provide limited evidence to underpin this claim. Meanwhile, social care managers expressed significant concerns about the difficulty they sometimes experienced in engaging specialist health services to address urgent crises in the community.

6.2 We are not stating that there are no successful services – we were anecdotally told of some examples, such as:

- The movement of people from outdated campus provision into individually focused accommodation in communities around Staffordshire,
- A sustained reduction in behaviours that challenge by people who had moved from long stay institutions,
- The design and delivery of person centred supports by a small third sector residential care provider,
- The specialist day service in South Staffordshire using person centred approaches to support someone with complex needs into employment, with evidence of positive family feedback.
- Action in the north of the County to bring people placed in CHC funded services to local, in-County services
- We were also told of people who had been moved on successfully from Assessment and Treatment services in South and North Staffordshire, and were shown some good examples of person centred planning at the A&T Unit, Harplands.

6.3 Shortly before completion of this report we received some data from SSSFT. This included a description of a review of the implementation of Patient Related outcome Measures (PROMs) in

[4]It should be noted that this is not necessarily just a local problem. Learning Disability health services nationally collect very little outcome evidence - in part because it has never been a collection requirement of the DH or NHS centrally, and this lack of national data makes it difficult for this review to cite norms against which local services should be performing. A current initiative by the NDTi in partnership with the Learning Disability Public Health Observatory (IHaL) is seeking to develop a short suite of service-wide outcome measures by the late summer of 2012.

the Trust's services. It described how a review of this process showed it was being widely used and produced evidence of the impact of peoples' voice on the determination of content of their care plans. This is to be welcomed, but we have not had access to the detail of how this influenced care plans (e.g. was it in relation to significant life-influencing factors), the types of changes it resulted in nor evidence of how this related to wider life outcomes and so cannot comment on its wider helpfulness beyond elements of clinical practice.

6.4 However, the general lack of outcome evidence must question the basis on which the services are being commissioned and delivered. Information we received in less structured ways adds to this concern, for example:

- Documentary evidence that there are a number of people that specialist health services in both the north and south have been unable to support and, as a result are now in expensive out of County or in County private sector provision but with little known about the quality of their lives or service in those places. (We note that renewed action by commissioners to review such services has taken place since the recent Panorama programme).

- Statements from all the commissioners and senior managers in both NHS Trusts that they found it difficult to identify any social care providers that they had confidence in supporting people labelled as challenging. If this is the case, why are people who may present challenges being placed with these providers? (We note that moves to introduce an approved provider list of organisations skilled at supporting people who challenge may help to address this).

- Local authority managers in both authorities expressed their belief that there was often little discernable change in people's behaviour and needs between when they entered assessment and treatment (and related) beds and when people were deemed ready to leave – what had been the 'added value' of that service input? The lack of outcomes data from the Trusts makes it difficult to respond to this question.

- A previous report commissioned locally to consider the specialist healthcare needs of people with learning disabilities within prison settings did offer expert opinion and use of a recognised evidence base - however most of the proposed actions have not been progressed.

6.5 Financial information was also weak. We were provided with some financial data by the commissioners and some more by the two main NHS Trusts. This was of insufficient detail for us to be able to fully understand how financial resources were being applied and certainly insufficient to be able to then commence a value for money review – particularly when the lack of outcomes information is considered. The commissioners shared this belief with us.

6.6 Linked to this, the service specifications we were shown do not, in our opinion, provide the basis for enabling the commissioners either to specify the service being delivered or obtain evidence on performance in ways that will enable them to take informed commissioning decisions. The structure of the documents appears to be a mix of policy summaries, service specification and operational policy – possibly adapted from documentation not designed for learning disability

services. There would perhaps be benefit developing an overarching service specification with each service element having its own sub-specification.

7. The Service Model

7.1 Whilst there is no definitive national model for the detail of what specialist learning disability health services should contain, there is a clear policy steer[5] of what could be expected. Table 1 below summarises the key elements of this, alongside a note of what we found was missing or different in Staffordshire and Stoke.

Table 1

Service Element	What is Expected	What the Review Found that Differs from Expectation
Multi-professional community based health staff	A range of professionals working in integrated ways with social work/care management colleagues	A range of professionals working in separate teams with some informal links with social work colleagues, without shared leadership or objectives and with previous co-location having ended for (apparently) financial reasons. Some comments from social care services on problems in obtaining timely support.
Specialist teams	Specialist team(s) linked into multi agency working with a focus on people needing additional support e.g. people who challenge	No such teams other than a small 'outreach team' in the South linked to one bed in the Assessment and Treatment Unit. We were told that the day assessment and outreach team described in North Staffordshire paperwork submitted to the SHA was now a community team.
General health needs	Strategic Health facilitation and link workers for both primary and acute care mainstream services, connected to specialist learning disability services.	Not covered in this report
Inpatient services	At most a "handful" of assessment and treatment beds, with some possibly being in partnership with	More beds than expected, with evidence that (i) some people stay in them for a long time and (ii) some people cannot be 'coped with' and so there is also a use of private sector

[5]Commissioning Learning Disability Specialist Health Service" Good Practice Guidance. DH 2007

	neighbouring areas to gain 'critical mass'. No campus style NHS beds	assessment and treatment services, both in and out of area. NHS Campus provision still in place in the north and people being in other NHS beds in both north and south for periods of time that means they meet the DH definition of 'campus'
Forensic Services	Community focused resource, linked into both learning disability and mental health services as well as the CJS, potentially delivered on a cross authority basis.	A lack of shared understanding of what specialist health supports are commissioned to go into CJS settings (secure and non secure units) and, as a result, limited specialist health input. People generally leaving prison units with no specialist heath care delivery/support plan.
Continuing Healthcare	100% NHS commissioned beds only where "highly complicated or unpredictable health needs" prevail" - with most CHC resources providing specialist support for people in ordinary housing and support. People who challenge not automatically being seen as NHS responsibility.	A high number of people being funded through CHC. A positive willingness to utilise part funding for people, but often in traditional rather than person centred services. Challenging behaviour being widely seen as an NHS responsibility and thus a call on CHC.

7.2 As can be seen there are some significant differences between what we expected to find and what exists. In addition to what exists, there are also some important discrepancies between what the guidance says about how services should be operating and what the review found, as summarised in Table 2.

Table 2

Service Element	What is Expected	What the Review Found that Differed.
Multi-professional community based health staff	In addition to clinical role, also undertaking: • Health promotion • Health facilitation • Teaching and training • Service development	Some health promotion, health facilitation and teaching and training work, but all teams were struggling to gather evidence of effectiveness. Health professionals not obviously engaged in much service development work.
Care Pathways	Regular reviews, with local authority, of people out of area and/or in NHS and independent sector NHS funded beds to prevent them getting 'stuck'	A worrying lack of clarity about where responsibility rests for reviewing services for people funding by the NHS – almost certainly resulting in people staying in inappropriate services for too long (see paragraph 8.2).
In patient services	Assessment and treatment beds having a clear purpose and be linked into local services	No clear articulation of role of some beds in the south. Some North beds being effectively long term not assessment focussed. Private sector beds disconnected from local system.
Mental Health Services	Delivered primarily through mainstream mental health provision	Some joint working between learning disability and mental health services evident e.g. mental health liaison nurse in S. Staffordshire. The scope of this review meant it was unable to verify the persistent high ratings within the green light for mental health and LD action plan self-assessment.

There are a number of specific comments we wish to make in response to elements of the service model:

Community Teams

7.3 There are clearly some good working relationships and positive work being undertaken by individual health professionals and groups of professionals working together in their inter-actions with and support for people with learning disabilities. This encompasses people living in the family home and in supported housing and residential care. We heard positive comments both about clinical input and other support such as training and advice to social care staff. Whilst several NHS community based staff and social workers/care managers described how they sought to maintain

informal contact with one another, most people we met with described the down-side of not having health and social care professionals based together. It reduces the opportunity for informal information exchange, mutual learning and – perhaps most importantly – the opportunity to work together around the services of individuals with the more complex needs. Different stories were shared about why the teams were separate – the most common being it having happened to save a small amount of rental budget to one party or the other. Most people said that the teams should be back together, but it did not seem to be on anyone's agenda (other than the people commissioning this review) to make it happen.

7.4 Co-location is only part of the issue though. Working towards shared objectives and shared priorities enhances the benefits of collocation – but can only be done when there is a clear understanding of the respective roles of each set of professionals. Policy is clear that integrated teams should work to local authority led strategies to deliver Valuing People Now. In some localities, this has wrongly been interpreted as a local authority 'takeover' that denies the expertise and contribution of NHS staff. The joint strategy and integrated commissioning described elsewhere in this review report should include the bringing together of health and social care professionals, towards agreed shared objectives, whilst recognising the specific contribution of each.

7.5 One specific issue that this bringing together of health and social care professionals will help to address is the concern noted elsewhere about a lack of clarity around planning service change for people with the most complex needs (see section8.2)

7.6 Finally, this is not a call for an 'old fashioned' community team. In responding to the Valuing People agenda, integrated health and social care teams must also be outwards looking to encompass mainstream resources and practitioners that can help deliver the full policy agenda i.e. including those responsible for employment, housing, primary care and so on. However, the detail of this is getting beyond the brief for this work and so will not be described in this report.

NHS Bed-based Services

7.7 Two inter-connected elements give us particular cause for concern – namely the very large number of NHS beds and the significant use of private sector hospital or nursing home provision (both in and out of County). Local NHS services should, by working with social care commissioners and providers, be able to support almost everyone within a locality if the services are well designed, comprehensive and have the appropriate skills. This is clearly not happening.

7.8 In our opinion, there are far too many NHS beds in the locality. We have sought to understand why the demand for these exists, but it has been difficult to get a clear and specific answer in the time available. However, from information provided by a variety of people, two consistent themes emerged:

- Beds are used as an early point of intervention – at least in part because of a lack of staff and systems to prevent admissions being necessary. (see para 9.3 below). Our view is that this does not represent a good use of available financial resources.
- There are inadequate systems to ensure that once someone is in an NHS bed (or indeed a

private sector bed) service planning takes place to get them into a person centred service that then better meets their needs (see para 8.2)

7.9 There is limited evidence (see also para 9.6) about the impact of work undertaken in any of the assessment and treatment units. We note elsewhere in this report that this concern was expressed to us by Social Services managers in both authorities. The lack of outcomes data makes it difficult for us to comment on this, but we did gain access to summaries of some numerical data about admissions to bed based services and this is commented on in paragraph 9.6.

7.10 We were also informed that, in general, admissions to assessment beds are not undertaken in partnership with social workers/care managers. This immediately removes any local authority 'stake' in getting the person back out again and the principle of starting to plan discharge form the day of admission risks being compromised.

7.11 We are concerned about the model that is being adopted for the linked assessment and treatment service and rehabilitation unit in the south. This is for two reasons:

- We have been unable to obtain any clarity from people we have spoken to about the specific role of the one assessment bed that is part of a pilot in the south. Staff from other services similarly reported a lack of understanding about its purpose. Also the reasons why a person would be referred to the outreach team rather than the community team was unclear both to us and other community staff we spoke with. This service does not seem to have a clear place and purpose in terms of overall care pathways.

- The physical service design of the new Milford unit is extremely institutional – both in terms of the internal layout and the high fencing that surrounds it. It is more akin to a secure facility than an 'open' assessment and treatment facility.

7.12 The assessment and treatment unit in the north was able to demonstrate positive approaches to person centred planning, but sometimes struggled to discharge people (one individual had been in an assessment and treatment bed for 5 years). The majority of admissions were unplanned/crisis admissions, despite most of individuals being known to the community teams. We were told this was because the community teams were stretched. The precise role of the Telford Unit would also benefit from further consideration. For example, in the medium term, is there really a role for it if there is an effective assessment and treatment unit work alongside strong community services. Might it be better considered as part of a cross-authority secure service provision linked to the developing forensic agenda?

7.13 Chebsy Close is clearly an NHS campus and should have been included in the list of NHS campuses returned to the DH as part of the Valuing People campus closure policy. We are informed that the West Midlands Valuing People lead agreed with senior managers at Combined Healthcare in 2008/9 to this not being the case and are at a loss to understand why that happened. The consequence is that the local services have lost the opportunity to access national resources to assist with the closure of the facility. The development of a plan to enable the people living there to move to more appropriate services and for Chebsy Close to be closed should be a priority. We understand that there is broad support for this amongst key people within the Combined Trust.

Given that support, we will not detail in this report the reasons why this change should be progressed.

Continuing Healthcare (CHC)

7.14 For both the north and south of the area, a fairly traditional approach is used for CHC of referrals into a CHC Team, and then referral onto a panel for agreement. The national Diagnostic Support Tool is used and there is expected (and we saw evidence of this) to have been full involvement of health professionals, social workers and families. Across both north and south, there appears to be a positive willingness to develop funding packages that are shared between the local authority and NHS – which would be in line with national expectations and good practice. We were informed that there has been some good progress in recent years in the north in terms of bringing people back to local services from out of district private hospital CHC funded services.

7.15 However, we are concerned that the operation of the (CHC) funding processes may be achieving neither the best outcomes for people not the best value for money. There are four issues:

- The numbers of people considered appropriate for CHC appears to be high– over 150 across the whole area. In particular, 68 of these are fully funded by the NHS. We are told that this number, which represents people for whom it has been decided that their health needs are the overwhelming factor that should determine how their support is designed and funded, is significantly driven by the numbers of people that are described as challenging services and a perception that this makes people the NHS's responsibility (see paras 5.2 and 9.9 for further comment on this). Once people become fully CHC funded, this can limit the potential to design individualised, community based services that meet their need – though the introduction of personal health budgets may begin to change this situation.

- There is a lack of clarity and/or action about where responsibility rests for reviewing placements of people funded by CHC and considering whether those services still meet their needs and instigating action to redesign services when needed. (See para 9.2). For example, in the north, we were informed that no examples could be identified of anyone in CHC funded services having been proposed to positively move onto a different service over the last six years. We find this surprising and suggest a lack of such pro-active review contributes to the high numbers of people being funded. We are aware that the CHC lead for the north wishes to address this, and emphasise it needs to be done by using the type of systems we outline in our recommendations

- The predominant service models to which CHC funding is used are nursing/residential care provision along with some funding of intensive support to someone in the family home. There are few examples of flexible health support within individualised service design led by local authority commissioning – though it is good to note there are two personal health budgets in place in the south and one being planned in the north

- There is a lack of integration between the continuing healthcare processes and the joint commissioning arrangements.

Other Issues

7.16 Day Services. The SSSFT provides an element of day service provision for people with complex needs. It is unusual for the NHS to still be in the business of day service type of services. However, the review team were pleasantly surprised to see that some good outcomes appear to be being achieved for some individuals. We are aware that a wider review of day services is taking place across Staffordshire and so did not explore this element of service delivery any further as it was beyond our brief. However, we would comment that if this service provision is to be incorporated into a wider local authority day service review, then it would be important to retain the positive outcomes for some individuals with complex needs, including a focus on employment opportunities for them.

7.17 Person centred working. A number of places are using mechanisms for individual planning based upon person centred planning. Both local authorities have identified personnel who lead on person centred planning – though the brief for this work did not encompass a review of that and so we have not explicitly looked at how those local authority led systems are working for people with significant needs for support from the NHS. Instead, we have focused on information developed within and coming into the NHS services. Both NHS Trusts use person centred planning systems, with elements of Combined Trust utilising recent training from Helen Sanderson Associates (a training agency with a positive reputation for this work) and the SSSFT appearing to base its systems on training provided several years ago by one of NDTi's predecessor organisations – the NDT.

7.18 However, it does seem that across a significant proportion of services, it is the paperwork that is being followed rather than the spirit or intent of person centred working. For example, in reviewing referrals to CHC funding, whilst forms existed with headings taken from recognised person centred systems, we could identify little or no person centred planning documentation that had followed and utilised genuine person centred approaches. More generally, documentation existed, but was either incomplete or else its contents reflected very basic day-to-day goals rather than more creative life planning. This means that there is less likelihood that outcomes for individuals will drive decision making about there is a greater risk that perceived 'clinical condition' rather than life domains will drive service design. There appears to be little consistent oversight of the person centred planning and implementation used by provider partners with a resulting variation in quality and impact. There are exceptions to this, for example the Combined NHS Trust's Assessment and treatment unit did appear to be implementing thoughtful person centred planning. We are also aware that Staffordshire local authority has a system for reviewing person centred plans. As noted above, our brief did not enable us to explore this but it appears that this does not extend to reviewing plans for people that are substantially supported by NHS providers or CHC funding.

8. Partnership working and Leadership

8.1 A major concern of the review team was that, whilst there are a number of good individual inter-personal relationships, there was a lack of a cogent approach to partnership working across the whole area. This applies at a number of levels:

- Whilst both Staffordshire and Stoke have Joint Commissioning Units, commissioning of learning disability services is not what we would recognise as joint i.e. the commissioning of specialist and mainstream health services is not undertaken in an integrated way with social care services and there are no mutual incentives (financial or service) to encourage this to be the case. A common observation made to the review team by people from all organisations was that there was little sense of over-arching strategic direction and leadership to learning disability services within which people could play their part.

- There was limited evidence of mutual trust and confidence between people in different services (with the exception of relationships between the learning disability commissioners themselves). Almost all people that we met placed responsibility for problems and difficulties with other people and organisations, with limited recognition that they or their organisation had any ownership of current service difficulties (if, indeed, such difficulties were even acknowledged). We would, however, note there was a clear recognition of a need to change and modernise services from the learning disability management in Combined Trust.

- There is a lack of integration in how the service is delivered – for example (a) between health and social care professionals and (b) between CHC purchasing and other elements of commissioning. A greater sense of all people and organisations being 'in it together' is a key development need in the area.

8.2 A particular concern arising from the review, as has been noted earlier, is the lack of clarity about where responsibility rests for individual service design once a person has been identified as having significant health needs and in particular if someone is labelled as challenging and/or is funded in whole or in part through CHC. Whilst for most of the local population of people with a learning disability there is clear care management leadership for this, we were told, and saw evidence, that this become less clear in some situations across both local authority areas. For example:

- Once people are in an NHS long-term bed, care management input appears to largely cease until the NHS Trust states that a person is ready to leave. The Combined Trust asserted that, even when this is requested, they experience some difficulty in obtaining care management action to move someone on and that there are difficulties in relation to

funding responsibility.

- We heard conflicting evidence about where responsibility rests between care managers and NHS Trust staff when people enter an in-area NHS assessment and treatment bed

- When people become funded through CHC, the responsibility generally appears to move to the CHC Team in the NHS when people are 100% NHS funded, and we again received conflicting stories about what happens when services are jointly funded. Either way, the CHC team are neither resourced nor expert in individualised person centred service design. Therefore, by definition, what is happening is primarily periodic review about whether people meet the criteria for CHC with the prime source of information coming from the service provider – who has a vested interest in maintaining the status quo.

8.3 There are two reasons why this situation should change.

- National policy is that, as part of the duties under S47 of the NHS and Community Care Act, the local authority should continue to provide assessment and review to all people who might be eligible for social care services, which includes people currently in receipt of NHS funded services. This point was clarified by the DH in a letter to all Directors of Social Services following the abuse of people with learning disabilities in NHS funded services in Cornwall and Merton and Sutton a few years ago.

- People whose behaviour challenges and people with complex health needs are generally those whose personal situation can change most over time. They are also the people who, arguably, are most at risk (witness Winterbourne View) and thus have the greatest need for external scrutiny and review by public services. In order to ensure best outcomes for people and the best use of public resources, active involvement from one or both of care management and specialist health professionals is therefore important – with that input linked to a continuing question of 'would this person benefit from an alternative or redesigned service?'

8.4 By not undertaking such reviews, services in Stoke and Staffordshire are effectively committing themselves to an ongoing and open-ended financial cost. Effective person centred review and service design can result in both better outcomes and financial savings. For example, the SLOT service in Birmingham was established to review people in expensive and CHC funded out of area services. It's funding costs around £450k per year. It is generating recurring savings of around £900k per year – based on the previous cost of individual services prior to the team's involvement.

8.5 The profile and involvement of the two Partnership Boards in setting the future agenda for specialist learning disability health services appears to have been low. We met with representatives from both Partnership Boards who informed us that they had not discussed specialist health services. Given the proportion of local spend that specialist services takes up this is surprising. There had been discussion about access to mainstream health services and, as previously noted, self-advocate linked/led initiatives to improve information and knowledge around access to primary care. The commissioners advised us that, in addition to the discussions about mainstream healthcare, there had been discussions about issues such as changes/reductions to

community learning disability teams at the Partnership Boards. We have not been able to identify how Partnership Board discussions have led directly to any changes in either commissioning direction or provision style of specialist health services and we would have expected the Board to be playing a significant role in planning and receiving this review. The Partnership Board should be central to the strategic development and direction of health services and we urge that they become more central players over the coming months.

8.6 Throughout this work, we were not conscious of a prevailing culture of seeking to engage with families and self-advocates. There are mechanisms at a strategic level to engage with families and self-advocates. Also, many health professionals see partnership with families and people with learning disabilities as central to their individual practice. However, these things do not seem to have influenced the day-to-day culture of decision making. It was difficult to identify how people's voice was influencing decisions around specialist health care planning and delivery - either at a strategic level (the previous point about Partnership Boards is relevant to this) or around individual service design (where comments in paragraphs 7.17 and 7.18 on person centred working are relevant). Our limited level of direct engagement with families and self-advocates in this work makes it difficult to draw definitive conclusions on these points, but we suggest that a Partnership Board led review of how people's voice is heard in the development and delivery of all health services would be a constructive step.

8.7 We were made aware of issues some substantial time ago in and around the service at Chebsey Close that had led to the suspension of (primarily) management staff in the learning disability service within the Combined Trust. As is often the case with staff suspensions and investigations, the rumour mill takes over and we were told about these incidents from a number of sources and received at least three different explanations as to what it was about – including patient abuse.

We were advised by Trust Management that thorough investigations had concluded there was no abuse and the issue was purely one around management style and culture. We fully understand the obstacles to public statements during staff disciplinary processes, but would encourage the Trust to be public at the first available opportunity about the detail of these incidents in the interests of all concerned – including themselves as an organisation.

9. The availability of appropriately skilled services

Service Gaps

9.1 As has already been noted, we are concerned that there are a number of appropriate services that we would expect to find but which do not appear to be in place. This review was neither set up nor resourced to review the competence of individual services and certainly not of individual staff and managers, and therefore we will limit our conclusions to those based on two main sets of evidence, namely (i) evidence that services are not working by reference to service usage and client 'journeys' and (ii) services that are missing.

9.2 We will look at this from two angles – reactive and proactive. The two have to work together for a service to be effective i.e. there should be good services in place so that when people enter a time of crisis or high level need, they can be supported locally in ways that help them either sustain their living arrangements or else be supported through intensive input elsewhere for a short period and then return and/or move on to live as independently as possible. However, there should also be services in place (health and social care) that support people with complex health needs in positive ways so that such periods and occasions of 'crisis' are kept to a minimum. The evidence both in terms of numbers of people receiving different types of service and anecdotal stories from people we met suggest that there are significant gaps in relation to both proactive and reactive services, and a reliance on bed based services to fill the gap.

9.3 We sought data in relation to people placed in CHC funded services and also people currently in NHS Directly provided beds in order to try and understand the reasons why people were admitted to those beds. The responses received did not enable us to undertake a thorough analysis as they were very broad-brush in nature – a typical reason given for admission/referral was 'local services not available to meet needs'. There was little or no explanation forthcoming about what it was about existing services that was absent or deficient. In other cases, we saw documentation where (for example) the healthcare professionals involved had recommended 'nursing home' as the required service – without any explanation of what support was needed, to achieve defined outcomes and thus why a nursing home was the proposed solution. Nonetheless – a nursing home was then provided.

9.4 Similarly, we asked what services needed to be in place to enable people to move on – but responses were equally broad and non-specific. Our conclusion from this is that, on the whole, there is not a culture of seeking to understand the role that services (i) have played in someone's needs escalating and the service breaking down and (ii) they could play in helping people into a new future.

9.5 Within this general picture, some staff did articulate specific service development needs – for example we received a number of comments about the needs for more skilled services around

autism, dementia, prison in-reach and people with very high support needs. However, despite this there was (i) no collated evidence to show the scale of demand (ii) no discernable process to turn this into service development action that would fill the stated gap, and (iii) a tendency to turn this into a stated requirement for a registered service for these labels rather than a question about developing pro-active skills to meet needs, e.g. "(we need a) … service registered to manage patients with learning disability, dementia and challenging behaviour".

Bed Based Services

9.6 We have already commented on the use of assessment and treatment beds and their impact on medium/long term service usage. Summary data from both Trusts is informative. The expectation would be that assessment and treatment beds provide added value to people's lives, helping them address times of crisis and then either return to their previous living situation or else move on to a more appropriate 'ordinary life' setting with support. Clearly there may be occasions where a person's home life was a contributing factor to presenting issues, so change on discharge is something that could be expected. If we view a person's own home, the family home, supported housing and residential care as being broadly 'ordinary life' and NHS hospital, private hospital and nursing care as 'institutional' life, the data in Table 4 shows the following (numbers of all as a percentage of total as Stonefield data was presented to us in that form and Harplands/Telford as numbers which we converted):

Table 4

	A & T Harplands (since 2006)	**Telford Unit (since 2006)**	**Stonefield House (since 2000) as a %**
Admitted from 'ordinary life'	61%	37%	50%
Discharged to 'ordinary Life'	50%	38%	67%
No data	2%		
Admitted from institutional life	37%	63%	44%
Discharged to institutional life	39%	50%	33%
Still in A & T/No data	11%	12%	6%

These data suggest that the assessment and treatment services are having little if any impact in supporting people to 'move on' in their lives to live in less restrictive environments. Although the data presented by SSSFT for Stonehouse does show a trend in that direction, their definition on admission include 25% of admissions coming from their acute mental health beds - which we have thus included in 'institutional'. We have sought information on where people were living prior to admission to the Trust's acute mental health beds and length of stay in those beds. Although we were informed this data was not available, we were also informed it was likely that most were from

home or residential care. Thus, these people should arguably be included in the data for the 'ordinary life' category as that is where they were living prior to the Trusts' involvement. This would present a different and opposite picture.

9.7 Other information contained within this data is also illuminating:

- At Stonefield, 19% of people were admitted from private hospital or secure provision (including prisons) whilst 33% of people were discharged to such services
- Significant proportions of admissions and discharges to the Combined Trust's bed based services were between its own units
- 2 people were admitted to the Harplands A & T unit from private hospital or similar whilst 10 were discharged to such facilities
- The average length of stay in Harplands A & T was under six months with a longest stay of two years, compared to Stonefield which is described as 'within the optimum two years limit'. (This presumably means that a significant proportion of stays are of over two years duration). Also, calculations for Stonefield include people still resident in the Unit, so the mean length of stay and recent reduction in length of stay over the last two years are probably different if these people are not included in the calculation.
- 32% of people were admitted to Stonefield as informal patients – the remainder under a section of the Mental Health Act 1983. On discharge this had increased to 70% being informal, which indicates an improvement in factors considered relevant to detention under the Act.

9.8 It would be risky to conclude too much from this data, given the limited detail available and the differing timeframes over which it was collected. However, we suggest that:

- The limited and possibly negative change between 'admission' and 'destination' accommodation suggests that one or more of systems, culture or skills are not sufficiently focused on ordinary life outcomes
- The significant proportion of people discharged to private hospitals begs the question of what those hospitals could provide that the local NHS could not – be that around skills, client group focus, environment, or other factors. As noted earlier in the report, we have not been able to obtain a clear picture of this from information provided.
- The length of stay data for Stonefield begs further investigation

9.9 Finally in relation to these issues, given the difficulty we experienced in gaining clear pictures and details of service gaps for individuals and service performance, we asked the commissioners to provide examples of cases where they felt a service response had been inadequate. As this was at the end of the work, we have not had the time or capacity to explore or verify the detail behind them, but from the commissioners notes provided, the following issues would appear to be important and also corroborate concerns we have already outlined:

- A lack of a flexible response team that could provide early intervention and design

strategies for improving the position 'in situ'

- Lack of clarity about where responsibility for leading a response should rest
- Services not being available because a person was the 'wrong gender'
- Access to an NHS bed being seen as an early response strategy
- A strategy to assess challenging behaviour away from the environment that could be a major causal factor of that behaviour
- Delays in action whilst discussions took place about availability of funding, including in situations where abuse had been suggested

Social Care Support

9.10 As noted at the outset, long-term health needs can only be effectively met through a partnership with social care services. Our brief was not to review social care services but, in order to gain a perspective on this, we briefly met with a small number of social care providers that were identified as working particularly with people with complex health needs and/or who challenged services. Prior to this we asked all the commissioners and senior NHS provider managers whether there were social care providers with whom they had confidence in providing supports to people who challenge. Whilst names were offered of some 'better' providers, the overwhelming response was that there were no social care providers who were perceived as strong and skilled partners in supporting people with complex need and behaviour that challenges. Our subsequent meetings with these identified providers suggested a mixed picture from traditional service orientated group homes to the potential for highly individualised support packages.

9.11 This is a fundamental challenge for services. Without such skilled social care providers there is little or no possibility of being able to deliver services that are cost and quality effective from the perspectives of either the local authority or the NHS – to say nothing of outcomes for the person. We are aware that Staffordshire is developing a new approved provider list that it is hoped will help to address this, and that Stoke already has a list that could assist. However, the DH commissioning guidance emphasises that the usual tendering and approved provider list approaches will not, on their own, help develop partnerships with skilled providers - a more targeted and flexible approach is needed. We would suggest that there is potential to work with some current providers to develop a skilled person centred service base through skilled market facilitation[6].

Perception of Demand

9.12 We believe that the factors outlined in this report, taken together, are leading to two inter-connected outcomes. (i) a disproportionately high number of people presenting challenges to services and/or (ii) local services having a low tolerance of behaviour that challenges and so labelling people unnecessarily. Key managers and clinicians were asked how many people were

[6] TLAP have just commisisoned NDTi to develop guidance on market facilitation around services for people with coplex needs.

considered to be presenting significant challenges to services – whilst numbers varied significantly, those numbers suggested ranged from two to eight times the number that national data would suggest to be the case. (National indicators would suggest around 180 for Staffordshire and around 60 for Stoke. This number describes people who may, at some point over a prolonged period present such challenges and thus need to be on the service 'radar', rather than a number that are likely to be presenting challenges at the same point in time). Also, whilst national data is not available on the numbers of people funded through CHC, we noted earlier that we were surprised at the comparatively high numbers (which reflect either a perception or a reality of the extent to which health needs dominate a person's service needs). For example, we have recently been working in a County of only slightly smaller area and with similar socio-economic profile, and they have less than half the number of people on fully funded CHC compared to Staffordshire and Stoke.

10. A Note on Achieving Change

10.1 This report concludes that a major change agenda is essential across both Staffordshire and Stoke. Above all else, this is concerned with cultural change – including new approaches to partnership working and beliefs about how to support people that require significant input from specialist healthcare professionals. That cultural change will lead to service change, but cannot be achieved overnight. There are places in the country where services are much more closely aligned to the national good practice guidance, having achieved this in part by working over time to achieve ways of delivering support that is not over-dependent upon bed based care. We are not suggesting that Staffordshire and Stoke can move to this position immediately – but it should be a goal to be achieved over the next five years.

10.2 In considering the recommendations in paragraph 12, we therefore emphasise two particularly important components:

- Phasing of actions. For example, whilst it might be attractive to immediately progress the movement of people out of Chebsey Close, if this is done before action is taken to ensure (i) effective person centred service design for people who challenge, (ii) the availability of skilled social care providers and (iii) the availability of skilled specialist healthcare support to work alongside those social care providers, there is a risk that the new services will at best not provide the potential outcomes for the individuals or, at worst, fail.

- The availability of leadership, in terms of capacity and belief systems, to take this agenda forward on behalf of all agencies and individuals and within all agencies/organisations. There clearly are a number of individuals that are committed to better lives, including better healthcare, for people with learning disabilities in Staffordshire and Stoke. What appears largely absent is the existence of collective leadership, with the systems and structures behind it to drive values based change as described by a shared vision and set of goals. This leadership should encompass everything from the most senior levels through to front line practitioners.

11. Outline Service Model

11.1 In many ways it is difficult to be prescriptive about an exact service model that should be adopted across the area. In part this is because of the limitations of the specific evidence base, and in part because of the previous point about pace of change. What is about to be described in a position to be worked towards. Some elements should be put in place immediately whilst others will be worked to over a period of time as the local service culture is ready and the resources available.

11.2 We recommend that the future service model across Staffordshire and Stoke should aim to consist of the following. In citing examples to consider, we are not necessarily saying that everything about those examples is positive – but rather that there are things to learn from what has been done elsewhere:

A joint commissioning structure that through either pooled or aligned NHS and social care budgets creates incentives for joint working rather than passing responsibility for individuals between authorities
Integrated social work and specialist health teams in place to inform commissioners in relation to person centred individual service design for people who challenge and/or have complex needs
A small team of expert practitioners (mix of health and social care) with a brief to bring people back home from expensive, long term out of area placements, with the team having direct links into commissioners and being part of the integrated health and social work team structures.
An intensive support team, possibly the same team or potentially a related team also connected to CLDT structures, with a brief to work with people with the most complex needs to support them in ordinary housing and support (including the family home). This would include intensive support in times of crisis to both support the person (and family if appropriate) and assess/plan service change if needed.
A very small number of short break beds. Working from the principle of supporting people at home wherever possible, some people will sometimes need a 'short break' from their living environment (be that home, supported housing or residential care). Such a facility should be defined as 'social care' with intensive input from NHS staff as needed.
Access to mainstream mental health beds wherever possible for people with a diagnosed mental illness

A very small number of in-patient assessment and treatment beds for people whose psychiatric care cannot be provided in mainstream mental health services. Use of these beds for non-psychiatric purposes should be a rare exception.
Partnerships with a small number of skilled social care support providers, operating from a preferred provider list, who are contracted to support people locally.
Access to low and medium secure beds where required because of Mental Health Act or Court requirements
In addition (supportive text not covered in this report) specialist health staff to support and promote good general health including: • Nurse consultant or similar to lead strategic health facilitation • Primary care liaison nurses or facilitators to promote access through primary care • Acute liaison nurses or similar to promote access to general hospitals
This model to be underpinned by investment in system supports (in partnership with the local authorities) including: • An understanding of the evidence base through education, learning and external visits • A real understanding of person centred practice and service design • Investment in family and self-advocate support and working practices that promote listening to people's voice

11.3 The commissioners of this work have asked us to point them towards examples of good practice. In doing so, we wish to emphasise that the current changes taking place in the NHS (in particular) are creating great uncertainty if not turmoil in some locations to learning disability services with changes occurring at a rapid pace and in some cases what were perceived as positive services changing in nature. The examples offered are based upon some of our knowledge over the past twelve months.

- Oxfordshire have a solid track record of integrated commissioning. They also continue to have, as part of that, integrated community learning disability teams. They are also part of a cross-authority medium secure service approach that appears to be well linked into local services
- Westminster is also an example of a positive and apparently successful approach to NHS commissioning – contact Mary Dalton, learning disability commissioner.
- Somerset Council have a long history of effective integrated health and social care teams. Additionally, a number of years ago they took the decision (at the initiative of their Consultant Psychiatrist) to remove all specialist learning disability NHS beds, accessing

generic mental health services instead. They have no long term NHS beds. Contact David Dick, Commissioning Manager, Somerset Council

- The SLOT Team in Birmingham (referenced already in the report) have for a number of years successfully brought people with complex needs back from out of area placements at a significant financial saving. A weakness is that the team is not that well connected to commissioners and we have recently heard that new commissioners, apparently unaware of the Team's track record, are considering cutting it. Contact Martin Ayres, South Birmingham PCT – provider arm

- Plymouth PCT is taking an interesting approach to people in expensive placements, by commissioning in an external voluntary organisation to do intensive planning with individuals and set up individualised services. Contact Sam Sly, Director of Beyond Limits

- Gloucestershire PCT/local authority who have a small learning disability nurse team attached to the PCT with attached social worker input that has been bringing people back into local services and achieving significant financial savings. Contact Kevin Elliott – NHS Gloucestershire

- There are a number of intensive support teams that appear to be doing good work – for example there are some examples in Wales (suggest speaking with Dr. Sandy Toogood from Bangor). Although we do not have current information, the team in Dudley was playing an important role in helping to close their former NHS campus (contact Anne Parkes)

- In Lewisham, there is a long standing arrangement of a small number of 'challenging behaviour' expert staff that work as a resource alongside social care providers, advising and modelling how to continue to support people with complex needs in their own home. Also, in Lewisham and associated London boroughs, there is a cross-borough in-patient facility, the Estia Centre, which appears to operate within a model that (comparatively) minimises the use of in-patient beds

- Services in Tower Hamlets have an explicit intent to avoid use of in-patient beds and have a remarkably low usage level – in part through partnership with 'social care' short break resources. Contact Dr. Ian Hall, Consultant Psychiatrist

- The learning disability service in Islington won an award a short while ago for the way in which their generic mental health services worked in partnership with and provided access to people with learning disabilities

- There are examples dotted all over the country of skilled social care providers working well with people who are complex. An interesting new example is in the north-east where a number of authorities have contracted with Positive Support in Tees CIC (contact Dave Barrass) to develop individualised services for people who challenge. More generally, there are long track records of partnerships with providers in places like Glasgow and Hackney.

- In relation to primary care, acute hospital and general health services (not explicitly covered in this report) there are a range of good examples across the country. Sue Turner, IHaL Project lead at NDTi can advise.

12. Recommendations

This review recommends that to work towards this service model, the following actions are necessary:

i. The senior managers in Staffordshire PCT, Stoke CCG, Staffordshire County Council and Stoke City Council make a shared and public commitment to take action to ensure that specialist learning disability health services across the area are (a) modernised and (b) developed in an integrated way with local authority commissioning and provision. Consideration should be given to using the Challenging Behaviour National Steering Group Charter as a framework for this commitment.

ii. As part of this, a clear statement is made that people who challenge services and people with the most complex needs, will be supported through integrated health and social care pathways

iii. As part of this, whilst recognising the financial pressures each authority is under at present, a commitment is made to utilise resources freed up in this redesign to commission modernised services rather than unilaterally withdraw funding – aiming for a medium term financial saving to both authorities as the performance of services improves over time

iv. A rapid piece of work is undertaken to write a strategy for the future development of specialist and mainstream learning disability health services across the area. This should be developed (a) in full consultation with all relevant stakeholders, using the Learning Disability Partnership Boards as a key mechanisms and (b) using external expertise to promote greater understanding of recognised best practice

v. The NHS provider Trusts make a commitment to work in partnership with the commissioners to deliver on this new strategy and pursue the resultant service design and delivery changes that are required by it.

vi. Linked to supporting the Partnership Board's engagement with this new strategy, a review of how the voice and people with learning disabilities and families is heard in decision making around healthcare should be instigated

vii. This learning disability health strategy should form part of moves towards genuine integrated commissioning that enable financial resources across the health and social care sectors to be considered in tandem with one another in order to create financial incentives to work together and thus produce person centred outcomes for people.

viii. The strategy should include plans to introduce genuinely integrated working between specialist learning disability health staff and social work/care management staff. This

should not, however, be the old fashioned CLDT framework, but should be developed in a way that will promote new relationships with mainstream health, social care and community resources.

ix. As part of this, the strategy should provide clarity about where responsibility rests for reviewing individual services for all people funded by the health and social care system and provide clarity about who leads on individual planning for people with the most complex needs to ensure their services can develop and evolve over time as their needs change.

x. This should be linked to a strategic review of how person centred planning is delivered for people with significant health needs, including the effective involvement of family members and independent advocates, and how this is integrated into wider person centred service design

xi. To assist this, a new resource should be established, probably through freeing up resources currently locked into NHS in-County beds, to work with people that are labelled as challenging and/or have the most complex needs, in pro-active and person centred ways with a view to (i) preventing admissions to hospital (ii) designing and then supporting person centred, community based services that will better meet peoples' needs (iii) embarking on a programme of review and service redesign for all people currently either out of District and/or in private hospital provision and/or in CHC funded services. This resource should be accountable into revised, integrated commissioning structures.

xii. Plans should be put in place to enable people currently living in NHS beds (such as Chebsy Close) to move to more appropriate community supports and thus enable those facilities to close and the resources be deployed in more effective ways

xiii. In reviewing NHS beds, the strategy should develop commissioner-led clarity about the purpose of all assessment and treatment and related beds, along with how they fit into care pathways.

xiv. NHS providers should instigate a review on internal knowledge and learning in relation to evidence and best practice in working with people with the most complex needs and implement the findings

xv. The strategy should include a shared local authority/NHS approach to identifying and nurturing relationships with local providers that have the culture and skills to support people in order housing whilst presenting significant challenges to services.

xvi. A suite of outcome measures should be developed by the commissioners and providers working together as part of a review of contracting methodologies for learning disability services, possibly by linking into the proposed IHaL initiative on this

xvii. Consideration should be given to whether it would be beneficial to commission specialist learning disability health services from one provider across all of Staffordshire and Stoke.

13 Conclusion

13.1 We wish to conclude by re-iterating our statement from the start of this report that doing nothing and continuing as at present is not an option.

13.2 One of the problems with a local 'economy of care' responding to nationally driven priorities is that this can sometimes take over the focus of attention from other issues. We suspect this may have been the case in the progression of the NHS campus closure agenda. The commissioners were, themselves, aware of a number of short-comings and so sought this review to help pinpoint and articulate them. The issues that this review has identified cover a number of underpinning problems that need to be addressed if services for individuals are to be able to reflect national best practice and achieve the outcomes that people with learning disabilities and their families rightly expect – even in a time of financial austerity.

13.3 The Mansell report provides a typology of authorities in relation to how people who challenge are supported. Those typologies are:

- Removers – places that send people away because they cannot be coped with and so those people are 'out of sight, out of mind'
- Containers – places that have local services to support people, but with those services having low aspirations and people achieving little progress of chance of success in their lives
- Developers - places that use person centred service development to achieve services that help address individuals particular need and thus enable them to achieve better outcomes within the same, or less resources

13.4 This review concludes that Staffordshire and Stoke are generally a mix between being removers and containers. The recommendations from this review are designed to point the Authorities on a route towards them becoming Developers. Whilst this analogy is specifically about one element of the role of specialist health services (i.e. supporting people that challenge services), that is a major role and one that, we would suggest, is the most central in determining the effectiveness of the NHS and its partners. By addressing the systemic issues that can effect this change to 'Developer', a resultant impact will also be felt in relation to access to general health care and community-based interventions to people with less complex needs.