Guide for commissioners of services for people with learning disabilities who challenge services

learning
disability

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.

December 2010

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[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.

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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.

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[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 <u>not</u> just reduced demands

> **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.

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).

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.

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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

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.

(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'.

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

> **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.

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.

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.

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[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 <u>or</u> 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.

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[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"

Guide for Commissioners: Challenging Behaviour

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.

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

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.

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

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.

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.

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

> **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.

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.

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.

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[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

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

> **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.

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.

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[8] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103329.pdf

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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

> **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.

'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.

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 <u>skilled</u> 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 <u>not</u> 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.