

Innovation and Development  
in Community Care

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# Developing better commissioning for individuals with behaviour that challenges services – a scoping exercise

Peter McGill, Vivien Cooper and Gemma Honeyman



“The Tizard Centre is one of the leading UK academic groups specialising in learning disability and community care”

### **The Tizard Centre**

The Tizard Centre is one of the leading academic groups in the UK working in learning disability and community care.

The Centre's primary aims are, through research, teaching and consultancy, to:

- find out more about how to support and work with people effectively
- help carers, managers and professionals develop the values, knowledge and skills that enable better services
- help policy-makers, planners, managers and practitioners organise and provide better services.

### **The Challenging Behaviour Foundation**

The Challenging Behaviour Foundation is a charity supporting families, professionals and other stakeholders through education, information, research and partnership working.

It aims to:

- provide information and support to parents and professionals caring for individuals with severe learning disabilities and challenging behaviour
- demonstrate how local service provision for individuals with severe learning disabilities and challenging behaviour can be improved, and actively facilitate such provision on a national basis
- highlight the needs of those with challenging behaviour and influence policy on their behalf
- promote research into challenging behaviour associated with severe learning disabilities and disseminate the results of such research so that practical benefits are gained.

### **The authors**

Peter McGill is Reader in the Clinical Psychology of Learning Disability in the Tizard Centre at the University of Kent. Vivien Cooper is Chair of the Challenging Behaviour Foundation and the parent of a young man with learning disability and challenging behaviour. Gemma Honeyman is Family Support Policy Officer at the Challenging Behaviour Foundation.

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# **1 Summary**

## **1.1 Background**

- The revised Mansell Report (Department of Health, 2007) identified a number of continuing problems faced by people with learning disabilities whose behaviour presents a challenge:
  - Break down of community placements,
  - Increasing use of out-of-area placements,
  - Persistence of poor quality institutional solutions;
- The Valuing People Now delivery plan included a commitment to a “scoping exercise to develop better commissioning for individuals with behaviour that challenges services” (Department of Health, 2009b).

## **1.2 Aims and Methods**

- In-depth consultations with the families of six individuals with behaviour that challenges services aimed to provide an up-to-date picture of the outcomes of services for individuals and their families;
- Extended interviews with eight local authority and health commissioners sought to both identify obstacles to progress and consider the kinds of supports that might help in the process of local service development;
- As a scoping exercise the overall aim was to map out the issues “from a distance” and determine where future work was likely to be most useful.

## **1.3 Family Consultation**

- Families reported a lack of expertise and capability in understanding and responding to challenging behaviour in local services. This was seen as an important factor in the use of out-of-area placements;
- Access to services was reported to be extremely difficult by families other than at times of crisis. As a result opportunities for crisis prevention were missed;
- Families reported a lack of support and training for themselves in their roles as carers, with often detrimental effects on their physical and mental health;

- A lack of information and training hampered the extent to which families could plan realistically, and hopefully, for the future;
- Families consistently reported not being included as essential partners in planning for their relatives;
- It was noted that all of the experiences reported by families have been commonly reported in the past and are well-documented in the professional and academic literature.

#### **1.4 Commissioner Interviewers**

- There was no evidence of significant, ongoing local work to implement the recommendations of the revised Mansell report;
- Commissioners reported continuing difficulties around the development of local services for people labelled as challenging;
- Discussions with commissioners identified a range of barriers to local service development:
  - Lack of coordination between adult and child services;
  - Lack of a systematic commissioning framework based on good quality information about the quantity and nature of local need;
  - Lack of confidence in the ability of locally available providers to deliver high quality supports to people labelled as challenging;
  - Wide variation in the application of NHS continuing care criteria and associated inter-agency perverse incentives;
  - (with exceptions) continuing difficulties between local authorities and the NHS in coordinated and integrated working;
  - Lack of specification of the commissioner role so that wide variation in the nature and quality of commissioning practice;
  - Family preferences (sometimes) for specialist, out-of-area placements perhaps in the context of earlier, local placement failures;
  - Lack of collaboration and understanding (in some areas) between commissioners and clinical support services;

- Commissioners considered and commented on a range of possible supports for their local practice.

## **1.5 Recommendations**

- National action:
  - The Challenging Behaviour National Strategy Group (CB-NSG) should coordinate and drive the process of improving the quality of outcomes for individuals whose behaviour challenges and their families;
  - The Office of the National Director should encourage care providers to review and enhance their capacity to work collaboratively with local commissioners in the development and delivery of personalised supports for individuals whose behaviour challenges;
  - The CB-NSG should, in collaboration with the Care Quality Commission, Skills for Health and Skills for Care, explore the possibility of establishing nationally accepted standards around the training and qualification of staff supporting individuals;
  - The Office of the National Director should encourage the use of existing mechanisms (such as the Big Health Check and Partnership Board annual reports) to monitor and hold to account commissioners for their performance in developing better, more local provision;
  - The Department of Health should review the application of continuing care criteria in order to clarify the reasons for the wide variation in numbers between areas and with a view to reducing perverse incentives;
  - The Learning Disability Public Health Observatory should be asked to support commissioners to gather and use local information on need;
  - The Department of Education should be asked to review policy on the use of out-of-area placements for children and young people with learning disabilities, with a view to the need for continued data collection and the development of prevention and early intervention efforts;
- Support for commissioners:

- A programme of nationally-coordinated work should be developed to support a number of local commissioners (in every Region) to implement existing guidance. This programme should include attention both to the development/redevelopment of personalised supports and the more systematic commissioning of provision which has the capacity to prevent and intervene earlier with challenging behaviour and mental health problems;
- A programme of dissemination activities centred on a new website should be developed to share lessons with all commissioners, collate evidence and examples of good practice in a manner accessible to commissioners, and encourage the development of specialist networks within the commissioning community.

## **2 Introduction**

This report, and the work it describes, were commissioned by the Department of Health as a “scoping exercise to develop better commissioning for individuals with behaviour that challenges services” as part of the delivery plan for the Government’s strategy for people with learning disabilities (Department of Health, 2009b, p.31).

The report draws on three sources which are introduced below.

### **2.1 Family consultation**

The involvement of family carers has been a key element of the Valuing People Now strategy. Their reports of their experiences provide a very direct picture of the effectiveness of provider and commissioner practices. In the absence, as yet, of more comprehensive evidence on need, consultation with families is one way of finding out about the extent to which currently commissioned services meet need.

The Challenging Behaviour Foundation drew on its extensive experience of supporting families and consulted in depth with 6 families. These families were selected from those who had received information and support from the CBF and who were willing to be interviewed about their family experience. While inevitably repetitive of previous work it was hoped this would provide a very up-to-date picture of the outcomes of services for individuals with behaviour that challenges and their families.

### **2.2 Interviews with commissioners of learning disability services**

Commissioning is seen as a key element of changing and developing services. There is limited evidence, however, that the extensive guidance that has been provided has led to significant changes in the nature and quality of the services provided for individuals with behaviour that challenges. It seemed useful, therefore, to talk to a number of commissioners about their local experiences and their perceptions of both the factors influencing their current practices and potential drivers of changed practice in the future.

Eight commissioners were interviewed. Interviews lasted, on average, just under 2 hours. All commissioners were from the London or South East Regions. Some were from local authorities, some from health, some were joint. Local authority commissioners came from a mixture of metropolitan and county authorities.

By scoping commissioner experiences and perceptions it was hoped that:

- Issues (such as obstacles to development) requiring more detailed investigation would be identified;
- a better informed range of supports for commissioners could be provided.

### **2.3 The literature**

The report is informed throughout by the professional and academic literature on both challenging behaviour and commissioning.

There have been many reports on commissioning and many on challenging behaviour. While reference will be made to these, it would be foolish to repeat their contents at length. The report's intention is to take a slightly different approach to the issues which acknowledges the difficulties of producing change in this area. The report will focus on understanding some of the reasons why change has proved difficult. It is, however, only a "scoping" report, intended to map out the issues "from a distance" and without, necessarily, being able to detect the detailed nature and generality of each issue.

### 3 The Problems

The revised Mansell Report (Department of Health, 2007) identified three central problems faced by people with learning disabilities whose behaviour presents challenges:

- Community placements break down;
- Out-of-area placements increasingly used;
- Poor quality institutional solutions persist.

These problems are, of course, closely linked. Placements competent to meet the needs of people who present a challenge are often not available in peoples' local areas despite continued guidance that they should be made available (Department of Health, 2004). Over 1/3<sup>rd</sup> of people with learning disabilities supported by local authorities are placed out of area and there was a slight rise in the percentage between 2006 and 2008 (Whelton, 2009). While there is no definitive evidence concerning the comparative quality of out of area placements it is clear that they are inadequately monitored (Beadle-Brown, Mansell, Whelton, Hutchinson, & Skidmore, 2006; Emerson & Robertson, 2008) and that the quality of at least some is dubious (Beadle-Brown, et al., 2006; Becker, 2006; Emerson & Robertson, 2008).

People placed out of area are by no means exclusively people presenting challenging behaviour but are more likely to be so (Emerson & Robertson, 2008). While the current report starts from a consideration of the commissioning of services for adults who present challenging behaviour, it is important to note that the process of exclusion underlying these problems often starts in childhood. Children whose behaviour presents a challenge are frequently excluded both from school (including from special school) and from other local services such as short breaks. As a result, out of area residential placement is relatively common (McGill, 2008). Such placements are, from the point of view of the commissioners of adult services, literally 'out of sight and out of mind'. As a result, substantial numbers of those placed in residential schools continue in out of area placements, often in services provided by the same provider<sup>1</sup>. Others, having remained with their families throughout childhood, leave their local areas at 18 or 19 when it becomes apparent that

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<sup>1</sup> In a recent evaluation by Peter McGill of a residential care provider, 2/3rds of the residents (average age 24 years, almost all in out of area placements) had previously been placed in a residential school, many in schools run by the same provider.

there is no local college at which they can continue their education and no local process for developing the personalised, supported accommodation and employment opportunities that they need. Others, either during childhood or adulthood, in the wake of a mental health crisis and their typical exclusion from local mental health services, go off to an out of area private psychiatric hospital. Once out-of-area, a return to a local community placement is relatively difficult. Typical transition protocols are challenged by the difficulty of including people now living some distance away (Heslop & Abbott, 2007). The whole process of developing a local service, relying as it does on a good understanding of the person's needs and wishes, is made more difficult. Families, experienced in the failures of local services and used to the apparent safety of the out-of-area provider, may oppose any move. Providers, often relying on economies of scale and based in areas of the country where property and land are cheaper, have a vested interest in maintaining the status quo.

Many out-of-area placements are relatively institutional, e.g. in "village" or "campus" or "hospital" settings. Concern about their quality inevitably arises given the increased difficulty for local authorities of monitoring outcomes for individuals. The very nature of the settings often reinforces the view (amongst commissioners, providers and/or families) that the individual could not succeed in a local, more inclusive placement. But there is considerable evidence that this is not true. First, studies of the resettlement of people from the long-stay hospitals demonstrate very clearly that individuals whose behaviour is challenging are able, when supports are tailored to their needs, to live in ordinary, local community settings (Mansell, McGill, & Emerson, 2001). Second, there are practice examples of individuals returning successfully from out-of-area residential school placements as children to local life (Emerson & Robertson, 2008). Third, there is considerable variation in the use of out-of-area placements suggesting that some areas are much more successful than others at including people in local service developments (Whelton, 2009).

## **4 Family consultation**

There is a well documented history of families of people with learning disabilities leading and driving change in support and services for their relatives (Brown, Orłowska, & Mansell, 1996). Most children with learning disabilities and a majority of adults live with their families. Even when individuals leave the family home, they do not leave the family and relatives often continue to provide considerable support. Families are therefore important partners, often providing lifelong support and care to their relative and it is essential to engage them appropriately and to recognise and value their experiences and knowledge.

In 2009 the Challenging Behaviour Foundation invited a number of families to share details of their experiences. Six families from across England took part in in-depth interviews about their experiences of caring for a son/daughter with learning disabilities and behaviour described as challenging and about the support they received.

Several key themes emerged from the interviews:

- a lack of local expertise and capable local services,
- a crisis management approach to accessing services,
- a lack of support for family carers,
- a lack of information and training,
- a lack of working in partnership with families to plan and deliver good outcomes.

These experiences are not unique to the six families interviewed and are consistently raised by family carers who contact the Challenging Behaviour Foundation, often in crisis, for information and support.

### **4.1 Lack of local expertise and capable local services**

Families consistently identified a lack of local expertise in understanding challenging behaviour and a lack of capable local services. For some families this has led to an out of area placement for their son/daughter. This placement has occurred not as a positive choice but because it was the only option in the face of inadequate local services.

*“My daughter was permanently excluded from our local special needs school aged 13 years. She now lives in a residential school 200 miles away, it takes about three and a half hours each way. We have to travel to that once every six weeks, I think it’s terrible really, there should be something in the local borough, but that is the situation unfortunately.”*  
(Mother)

Families often identify what local support mechanisms they would find helpful, but these are not available or offered:

*“If we had respite there is no way we would have put Adam in residential. If we were guaranteed respite every weekend, if we had a bit more support within the home, if I could phone social services and say this is the areas we are having difficulties with.... Just support me to help me take my son out, until my husband came in and respite, that would be my top. Our local authority... have got no respite facilities for autistic children or young adults, ...it’s always been ‘it’s in the pipeline’ but how long this pipeline is and where it ends nobody knows.”* (Mother)

Most families acknowledge that many of the professionals who support their children are not equipped with the skills and knowledge to manage behaviour perceived as challenging:

*“At my daughter’s local special needs school the strategy was to isolate her in her buggy every time she lashed out. So this poor teacher was constantly taking my daughter, putting her in her buggy outside the classroom door and then a few moments later bringing her back in again, where my daughter would do it again. So she was in and out of the classroom door. After a couple of years of this her behaviour was dire because she actually preferred to be isolated...eventually the local educational psychologist said the school’s not coping, they don’t want her anymore, she’s going to have to go to...a residential school”* (Mother)

Interestingly, many families, despite the fact that they are the ones providing the majority of care without training or support themselves, indicate that the decision regarding out of area and/ residential placement is made when the support services are no longer able to cope.

#### **4.2 Crisis management approach**

Families consistently identified a crisis management approach to accessing services. Families identified and requested support and services early, yet it was only when they had reached crisis point that adequate services were offered.

*“I just wanted to say I’ve had a very difficult time over the years. For years I’ve been asking social services to help with support during the holidays and it was refused and I knew something was going to happen. At the beginning of this year my son got arrested for smacking a baby....The police had no understanding, and it was only because he was arrested that social services were involved and I’ve been given support. It makes me so sad and cross that things have to get to that point before you are given the help you need. It shouldn’t have to take a child being arrested to get someone to listen to you, it shouldn’t.”*  
(Mother)

The impact on family members is often significant and substantial:

*“I had a breakdown in February and this is when everything changed for my son...and this is the reason why at the moment he is in residential care. If we were getting the help that we needed earlier things might have been different but we find it so frustrating that every step of Adam’s life we have had to fight.”* (Father)

#### **4.3 Lack of support for family carers**

Families consistently identified a lack of support for themselves in their role as a carer. The impact of not receiving adequate support had varying consequences affecting families financially, emotionally and physically.

*“I wouldn’t be able to count on two hands with spare fingers how many jobs*

*I have lost because I have put my son first” (Father)*

The experiences of families demonstrate double standards when it comes to appropriate training – those who are trained and paid to provide support can exclude an individual and the responsibility for that individual rests solely with the family, who are untrained and unsupported:

*“The last couple of times it has happened has really scared me as I have been unable to defend myself, that’s frightening. And he hurts you know, he’s big and strong and he hurts. ...Domiciliary care was stopped because of health and safety, this is the underlying theme, health and safety, health and safety, but nobody thinks about my health and safety, it’s like as a parent you don’t count” (Mother)*

The additional burden of trying to access appropriate support via the system, in addition to pressures of supporting an individual with behaviour that is challenging, can be unsustainable:

*“I mean last summer I was at the point of suicide really because when you are trying to deal with social services and the frustration that’s there is just unbelievable. So it’s just to get that point across really.”(Mother)*

#### **4.4 Lack of Information & Training**

Negotiating the systems that are in place which are meant to support families was identified as a problem by the majority of those interviewed. It is difficult for families to find good practical information that will help them to get the support and services that their family member requires.

Over the last ten years the Challenging Behaviour Foundation has received a high number of requests for information on transition from family carers.

*“I don’t know where to start, who to contact. I think all this information should be put into a booklet for people with special needs kids to say, you know, when they are young you*

*are entitled to this and that and when they are older and transition you know, you need to contact this person or your local social services to just give people an idea of what they need to do, because they don't know, they really don't know. And I don't think this borough is much different to any other borough really.” (Mother)*

Poor experience of accessing support and services over extended time clearly has a negative impact on the expectations of families – they have no experience of services being able to meet the needs of their relative:

*“Because over the years we've been rejected and, you know, you can't come here, we can't work with him, we don't want him, we can't meet his needs, that you think residential is the only option.” (Mother)*

*“My son is in an out of area emergency placement and I am worried he will end up in an out of area adult service, out of our reach/input and very likely not suitable for him, as has been the case to date.” (Father)*

In order to meet the needs of family carers caring for a relative with severe learning disabilities and behaviour described as challenging an information pack “Planning for the Future” was developed. A version is available for: England, Wales (Welsh language & English language), Northern Ireland and Scotland.

Since publishing these information packs in 2007, family carers have highlighted that, when they request individualised support for their son/daughter, there are many barriers. One of the main barriers that families identified was a lack of local commissioning in response to need. They are offered “what is currently available” (usually an out of area residential care home), rather than what is possible:

*“what I actually wanted for my son was a local support service designed around his needs. What I was offered was an out of area residential care home, because that just involved a few phone calls and negotiating the price. A local individual service would have*

*to be set up from scratch – somewhere to live and staff to support him - and no one seemed to be able to do it.” (Mother)*

To empower families to engage positively with their local commissioner and overcome one of the barriers to local support the Challenging Behaviour Foundation has created two new resources:

- Planning your house;
- Getting your house.

#### **4.5 Lack of working in partnership with families to plan and deliver good outcomes**

Families consistently report that they are not regarded as essential partners in planning support and services. Most families have a wealth of knowledge and expertise about how to support their relative well, and what works and what doesn't, and this is not recognised or utilised:

*“No-one’s ever asked me what I want. Never. Never, ever. And I have had to fight...I’ve never been asked. I’ve just been told. Scrapping for the most basic of help.” (Mother)*

*“Now my son has a good multi-disciplinary team so everybody works together and we all make sure that we’re singing from the same hymn sheet before we implement anything. But that didn’t happen in the past. So we could have had a speech and language therapist telling us to do one thing. A social worker telling us to do another thing. School doing completely something separate. And maybe not even have a psychologist. What’s had the greatest impact is working as a team. We all know that we are all doing the same thing and consistency has had a huge impact on the way that we manage our son, in all the environments that he is exposed to.” (Mother)*

While the experiences described above are those of only six families they are common amongst families both of children and adults (e.g., Allen, Hawkins, & Cooper, 2006;

McGill, Papachristoforou, & Cooper, 2006; McGill, Tennyson, & Cooper, 2006; McIntyre, Blacher, & Baker, 2002; Wodehouse & McGill, 2009).

## **5 Commissioner interviews**

All interviews addressed the question of the extent to which work was being done locally to implement the recommendations of the revised Mansell report (Department of Health, 2007). No commissioners reported significant, ongoing local work. Indeed, most noted that the report had not been discussed either by the authority/PCT or the Partnership Board. This seemed to be to do with its being guidance rather than setting out mandatory requirements. There was also some feeling that its highly specific focus on relatively small numbers of people led to its being marginalised.

At the same time all interviewees noted that there were continuing problems around the development of effective, local services for people labelled as challenging with many people still in, or being placed in out-of-area placements. Interviewees generally identified two groups, members of which were more likely to be placed out of area. These were, firstly, people with severe learning disabilities and challenging behaviour, often also with a diagnosis of Autism or Autistic Spectrum Disorder and secondly, people with mild/borderline learning disability and forensic/mental health issues. A recent survey of high cost placements (most of which were out of area) made by local authorities in the South East region was consistent with this, finding that the largest group was people with (severe) learning disability/autism and challenging behaviour, with a significant minority having mild learning disability and forensic/mental health needs.<sup>2</sup>

### **5.1 Barriers to local service development**

In the course of interviews commissioners were asked to comment on a range of possible barriers to local service development. They also identified additional barriers themselves. The barriers discussed in some detail below were all endorsed by at least half the interviewees as being significant concerns. In addition, at the end of this section, a number of other barriers (mentioned by less than half the interviewees) are discussed in less detail.

#### **5.1.1 Lack of coordination between adult and child services**

Most commissioners were aware that children placed in residential schools constituted a significant source of future out of area adult placements. While initiatives were being taken

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<sup>2</sup> This survey was carried out in 2009/10 by Jo Poynter and Peter McGill on behalf of the Challenging Behaviour - National Strategy Group. 14 out of 19 local authorities responded.

to address this in some areas, most commissioners reported a lack of joint working with the commissioners of children's services. For example,

*"I can tell you who my children's commissioner is but I don't see him very often... when I do I don't understand what he is talking about because we use completely different sets of language and data and jargon".*

The concern with data, in particular, was widespread. One commissioner reported two cases in the last year where (s)he only found out about the person 3 months before adult provision was required. More generally, there remained problems about identifying the number and needs of individuals far enough in advance, in part because of the different databases involved (see also Emerson & Robertson, 2008):

*"So what I have got is from 8 different teams including education, leaving care, learn to live team, children with disabilities team, out of borough education, respite, carers and the learning disability team is a whole cohort that I've have had to bring together and double check against one and other and come up with what I believe is a definitive list and it's ever changing".*

Even where approximate numbers were known there was concern about the validity of the information available with some feeling that it was not always possible to rely upon children's services needs assessments:

*"I think it is very difficult is to get a handle on what their needs are because they are so subjective so...you know this young man is on £4,500 per week placement and children's services are really promoting that this is somebody with incredibly high needs ... but we have learnt that you can't assume that he does have that level of needs. In fact we have got quite a few examples of individuals who were getting 2 to 1 input as children and we've assessed them and come out with our packages and they are managing absolutely fine with much, much less support".*

Some commissioners noted the potential for preventative, early intervention at a younger age to reduce the likelihood of residential school placement but recognised that there were limited incentives for children's services to carry out such work as the costs during childhood were often shared across agencies and savings might primarily affect adult services. This prompted discussion of the value of a "whole of life" perspective:

*"we start seeing people, stop seeing children or adults. You start to see somebody who has, if you like, 'a career of need'"*.

It was noted that such an approach could be associated with a funding mechanism in which money stayed with the person as they moved from children's to adult services.

The transition period was also associated with placement in out of area residential colleges. Such placements were often in the financial interest of adult services who, because of LSC funding, only had to

*"Top up with the residential placement allowance - that's somebody that you're saving thousands of quid on because the top up is 23K for a residential placement and the LSC pays for the rest so for 3 years you get them off your books essentially for what you could pay for them in one year in residential home"*.

Placement in residential college was also driven by the lack of suitable local college provision and there was concern that, although it was early days, the transfer of LSC funding to the local authority was not making an obvious difference.

A couple of commissioners noted particular concern about future provision for young people with autism. In part there was some evidence of more people coming through to adult services than anticipated. In part, it was often difficult to identify suitable local providers who could continue the autism-specific approaches (such as TEACCH) used in residential schools/colleges.

### **5.1.2 Lack of a systematic commissioning framework**

Commissioners generally welcomed the world class commissioning framework (DH Commissioning and System Management Directorate, 2009) but it was clear that most were labouring under a severe lack of, or difficulty in accessing, good quality information (see also Commission for Social Care Inspection, Healthcare Commission, & Mental Health Act Commission, 2009; Pritchard & Roy, 2006). Joint strategic needs assessments often contained only extrapolations from national data so that it was very difficult, for example, to establish the number of people displaying challenging behaviour in the local area. As a result services have been “*commissioned on the basis of demand rather than on need*”.

Many opportunities were missed to use existing processes to accumulate information that would assist in strategic commissioning. For example, amalgamated information from such things as person-centred planning or annual health checks could be useful. While it was clear these problems were recognised only one commissioner reported a concrete plan to improve the quality of information specifically related to challenging behaviour – the establishment of a short-term, jointly funded post to pull together information.

Another commissioner noted their use of the Person Centred Commissioning Now pathway (Fulton & Winfield, 2008) to help develop local services for individuals. While not a strategic framework this helped to offset the frequently reported difficulties facing care managers who were described as

*“usually looking for placements in crisis which means that you don’t have time to plan properly. You just place in what’s available and hope. And what’s available? Residential care is available”.*

### **5.1.3 Quality of provision**

In line with previous reports (e.g., Royal College of Psychiatrists, British Psychological Society, & Royal College of Speech and Language Therapists, 2007), most commissioners reported difficulties in finding suitable local providers for people whose behaviour was challenging and might otherwise be placed out of area. While many providers described themselves as ‘specialist’ this was often mistrusted:

*“on their lovely glossy website they have challenging behaviour specialist and autism and you name it, they’re specialists in it...there must be a very, very, very small percentage of providers who are actually able to do what they say they can do”.*

Even where relatively sophisticated tendering and procurement processes had been used to identify the provider of a specific service there was concern about staff competence (see also Commission for Social Care Inspection, et al., 2009) and the extent to which extensive support from clinicians was required. Sometimes such support was delivered with mixed feelings as it was felt that such providers should really be able to sort themselves out. Commissioners reported beginning to invest more effort in service specifications and contracts which would include the training/qualifications that staff would be expected to hold and some commissioners were willing to consider financially supporting providers willing to train up their staff to meet such criteria. Some commissioners saw provider networks as being a useful (albeit long-term) way of sharing provider expertise over time.

The perceived limitations of providers were linked to commissioner difficulties in judging the quality of provision. It was widely accepted that standard judgements (such as CQC ratings) were not sufficient for such specialist services and that a much more detailed focus on, for example, the quality of staff support was required. But commissioners, themselves, usually had very limited direct knowledge of specific clients or services and relied on contract monitoring processes which did not always focus on outcomes and were, inevitably, much more difficult to operate with out of area placements.

Judging the quality of NHS provision was also difficult as the relationship between commissioner and provider was sometimes rather ‘blunt’ e.g.,

*“I would be saying hang on a minute we haven’t agreed that you should be doing that and that of course is the other side of the coin - the trust doing what it wants to”.*

Such providers also sometimes had a history of leading the service development process and were operating in an environment in which service specifications were absent or unclear.

#### **5.1.4 Continuing care**

Some commissioners reported “*that we have an awful lot of continuing care and that’s where our money is going*” while another said “*there aren’t big numbers*”. Figures published by the Department of Health suggest very wide variation across PCTs in the number of people classified as eligible for continuing healthcare – from 2 to 26 per 10,000 population in the 4<sup>th</sup> quarter of 2009-10 (see [www.adass.org.uk](http://www.adass.org.uk)).

Commissioners reported a number of problems associated with continuing care. First, many people so funded were placed out of area and there was little resource to support bringing them back to the local area. Second, care manager input from the local authority was difficult to obtain. Third, some commissioners reported concerns regarding the continuing care assessment arrangements with long waiting lists, and assessors requiring additional support to properly assess people with learning disabilities.

One commissioner felt that continuing care arrangements created a significant incentive (see also Allen, 2008; Mansell, Beadle-Brown, Skidmore, Whelton, & Hutchinson, 2006) for the local authority to

*“allow behaviour to escalate because it will bring people within the round of continuing care and full payment by the health service”.*

Once receiving continuing care it appears to be difficult (though not technically impossible) to return to local authority funded care and there is a danger that the service provided is more restrictive (Emerson & Robertson, 2008) and monitored by a regime which stresses health outcomes. At the same time the continuing care regulations clearly support personalisation and one commissioner felt it should not have a significant impact on the nature of the person’s placement.

#### **5.1.5 Inter agency issues**

The majority of commissioners reported problems between the local authority and the PCT regarding commissioning both generally and for people displaying challenging behaviour in particular. Pooled budgets were in the minority and there was “*no appetite for joint commissioning*”. In some areas this had clearly led to a ‘bunker’ mentality (“*I concentrate on health*”) with each agency seeing the other as having a “*different view of the world*”.

More specifically, the local authority was sometimes perceived to not be willing to take the lead on issues relating to challenging behaviour and there was a perceived danger of the NHS forgetting that *“there was still a job to be done”* in learning disability. On the ground, clinical teams in some areas were not integrated (Commission for Social Care Inspection, et al., 2009) and there were communication problems and possible duplication of function (e.g. between care manager and clinician). This problem sometimes became salient when the clinical team was attempting, perhaps with limited success, to support a local provider of residential support for one or more people who displayed challenging behaviour without jointly agreeing the aim of the work with the care manager responsible for contracting the service.

#### **5.1.6 The Commissioner role**

Commissioning of services for people with behaviour that challenges might reasonably be regarded as a problematic activity when compared with the commissioning of many other sorts of provision. Commissioners must focus much more on individuals since, unlike in, say, the medical context, challenging behaviour cannot be considered as a ‘disease’ and must be managed in a holistic way that takes account of the rest of the person’s life. But demand for, and the effectiveness of, services remains difficult to predict and the evidence base is somewhat limited and poorly disseminated. Commissioners must, therefore, work with considerable uncertainty and also have to allow for the substantially greater role played by carers and the frequently limited capacity of service users to say what they want and to take decisions.

It is perhaps not surprising, therefore, that the interviews showed up a very wide variation in the ways in which commissioners fulfilled their responsibilities. Some worked closely with individuals and their families, clearly being driven by a concern for how their lives worked out – *“for me it’s about getting to know them all really”*. Others saw their role as being much more strategic and *“commercial”*, focused on getting better outcomes and value for money from providers.

Although, in part, such variation is the result of different agency structures and responsibilities, it appears to also reflect a degree of uncertainty in the nature of commissioning itself. In a sense there is no ‘job description’ and in a few areas (not those where interviews took place) it remains difficult even for those closely involved to identify who is the commissioner.

This variation means that it is relatively easy to identify weaknesses in commissioning though the nature of the weaknesses will vary substantially from area to area. Some of these weaknesses may be inherent in the way in which the role is set up in particular authorities, some will reflect the varying backgrounds from which commissioners come:

- Tendency to attend to some issues more than others in a relatively reactive and random manner;
- Lack of profile, links, partnership and influence within the larger organisation(s);
- Lack of motivation for, or belief in the possibility of changing things;
- Lack of knowledge of learning disability and/or challenging behaviour;
- Lack of skill in overcoming financial and organisational obstacles within their own agency.

Commissioning arrangements in local authorities (as well as the NHS) are currently going through significant changes. There were different views about the impact of these changes. Some saw them as very positive:

*“taking commissioning out of learning disability services and separating from providers...is a good thing...in the past commissioning has been driven by social workers, care managers, internal providers”.*

Others saw these kinds of changes as being problematic in that they might limit the extent to which commissioners could promote whole systems change and would confine them to the ‘carrots and sticks’ contained in the contracting process.

Inevitably, changes in commissioning arrangements (both in local authorities and the NHS) create additional turbulence and uncertainty both within the system and for individual commissioners. Consequently, the risks of inaction increase.

### **5.1.7 Families and service users**

A number of the commissioners noted that families were sometimes happy with out of area placements and resisted suggestions that their son/daughter might return to the local area -

*“his mum and dad would hunt me down and shoot me because he’s settled”*. Such views were understood by commissioners and considered to reflect the earlier failure (perhaps many years ago) to prevent the out of area placement. Commissioners also noted similar views amongst families of younger people and felt that they had to manage parental expectations, especially when the service user had lived in a residential school/college:

*“often the residential colleges will have a nice unit in the grounds and they will then talk to families about finance... It’s really difficult to shift all that”*.

More generally, commissioners felt that families had to be prepared for the *“change in the level of resource from child to adult services”*.

Some families, and individuals, will express a preference for out of area placements, perhaps especially if the local area offers less housing space and, arguably, a more dangerous environment for their son/daughter.

No commissioners (except in reference to short breaks) described services specifically aimed at family carers.

### **5.1.8 Clinical support services**

As well as one or more multidisciplinary community learning disability teams, all areas had, or were developing, some kind of specialist behaviour support service. There is growing evidence of the effectiveness of the behaviour support team model (e.g., Hassiotis, et al., 2009).

There was a contrast between commissioners’ perceptions of these services. In some areas they were clearly highly valued:

*“staff work at putting hours to support that model [local provider] and in quite an intensive way that I have not come across in other areas and it is literally about supporting people with those challenging and complex needs”*.

Where such positive perceptions existed it was clear that the commissioner worked closely with the clinical support provider:

*“I can then go to him [psychologist] for advice about...the specification and go to some providers and he provides the clinical support to the provider.”*

In other areas commissioner perceptions were rather less positive:

*“we are not totally sure about this service as commissioners and we are actually starting to look at it very closely in terms of whether we want to continue with it in this way ... we are convinced about function, but in terms of the structure, and the way that it is delivered, we are not really sure about it.”*

### **5.1.9 Other barriers**

A range of other barriers were noted by a minority of the commissioners. These included: a lack of emergency support that might help to prevent out of area placements; funding/finance issues such as the difficulty of securing money to ‘double fund’ the transition between an out of area and in area placement; and difficulties around the provision of services for people with mild/borderline learning disability which was often a source of dispute.

## **5.2 Support to commissioners**

Commissioners were asked their views on a range of possible supports.

### **5.2.1 A learning set for commissioners from a number of authorities with ongoing individualised support**

Response to this ranged from *“this would be good”* to *“been there and done that”*. Generally there was no great enthusiasm and a feeling that it would be difficult to match with local demands and any change would be hard to sustain.

### **5.2.2 A national programme board to drive the development of local services**

Most commissioners thought this would be a good idea but there was also a general view that any such initiative should be ‘mainstreamed’ as much as possible within existing performance management arrangements.

### **5.2.3 Technical assistance to local commissioners/providers around the development and initial operation of services for specific individuals**

Most commissioners were relatively positive about this. It was suggested by one commissioner that it would be particularly useful if could help manage finance, tendering and estates issues within his own organisation and by another that it could be linked to meeting the PSA 16 target on increasing the percentage of people with learning disabilities living in settled accommodation.

### **5.2.4 Technical assistance to local commissioners to engage in local strategic planning including attention to prevention and early intervention**

Most commissioners were positive about this though it was suggested that the child/adult barrier would be difficult to bridge and it could perhaps be combined with individual-level technical assistance.

### **5.2.5 More training and support for provider organisations**

Most commissioners were positive about this though with some concern about its targeting and how it would be financed. One commissioner suggested that it would be useful to have a nationally recognised module for care staff.

### **5.2.6 Other supports**

Commissioners suggested a range of other possible supports though there was considerable variation and all of these suggestions were endorsed only by a minority of those interviewed:

- A network that could provide peer support around the development of bespoke provision. Such a network might be real or virtual, the latter possibly linked to a website or similar where materials, procedures and experiences could be shared;
- The collation of evidence on the effects, including the preventive effects, of different kinds of services;
- A national focus on mainstreaming learning disability (including challenging behaviour) into the equalities agenda;
- Clear guidance on what individuals and families should be able to expect locally;

- Support to incorporate an outcomes focus much more explicitly in contracting and monitoring.

### **5.3 Commentary**

In the light of the interviews conducted with commissioners it is perhaps easier to understand the continuing high numbers of people living in out of area placements. In the absence of any significant attempt to prevent/intervene early around challenging behaviour and mental health problems, demand (especially from residential school and college leavers) may seem unremitting and remains somewhat unpredictable. Commissioners faced with difficulties in finding suitable local providers, and with variable clinical support available, use established, out of area providers even though this makes it more difficult to monitor and judge the quality of provision. Once so placed many service users and their families are reluctant to consider a more local placement and will resist, often with the assistance of existing providers, any attempt to move back to the local area. The problem is exacerbated in some areas by poor inter-agency relationships and the use of continuing care criteria to fund placements which create an incentive for local authorities to avoid supporting local competence in the absence of closer partnership working across the health and social care economy. Given the frequent lack of systematic commissioning frameworks and a clearly defined commissioner role such processes operate piecemeal and prevent the identification or strategic tackling of the issues.

A similar analysis is possible in respect of people with mild/borderline learning disabilities and mental health/forensic issues. For somewhat different reasons there is similarly unpredictable demand and a lack of clear local pathways.

## **6 Recommendations**

The complex problem of the persistence of out of area provision for people who present challenging behaviour will not yield to a single, simple solution. In what follows a range of recommendations are made for action at different levels, with different groups, of different kinds, to try and match some of the complexities of the issues.

### **6.1 National action**

#### **6.1.1 Coordination by the National Strategy Group (CB-NSG)**

The CB-NSG was developed in response to the perception of a lack of coordination and coherence in national and local strategy and policy around challenging behaviour. In five meetings during 2008-10, the Group drew together senior stakeholders from a range of national and local organisations and a range of backgrounds. It has sought to both identify obstacles and barriers and to initiate coordinated action to overcome these. It has developed a Charter laying out clearly the rights and values of individuals whose behaviour presents a challenge and their families and the practical action required. So far, nearly 60 organisations have signed up to the Charter including a number of large, national service providers and national professional organisations.

It is clear that this group has already served a useful function in raising awareness and triggering both local and national action. It is particularly significant that it is one of the few groups, nationally or locally, that bridges the child-adult divide, one of the major barriers to the development of better, more local services. This aspect of its work might usefully be further emphasised. The CB-NSG might also contribute to the task of collating evidence on the effects of services, develop its charter as the basis for the kind of ‘offer’ that should be available to individuals and families locally and the kinds of outcomes that should be measured locally, and, building on the human rights approach it has taken to date, use the equalities agenda as a driver for service improvement.

#### **6.1.2 Provider development**

Another of the major barriers identified by commissioners was the recruitment of providers (especially of residential support) who could deliver effective, local services without requiring extensive, local clinical support. While the development work described below should contribute to overcoming this barrier it also seems appropriate to focus on national

capacity in this area. It may be that the work already being done by the National Director with large private providers on the wider housing agenda will contribute to this. It may also be useful to consider broadening this work to large, national providers (across the third sector) who may be encouraged to review their own capacity and the extent to which they can develop in-house training and support services that would enhance the capacity of their own locally-provided services.

### **6.1.3 Workforce development**

One aspect of the problem of recruiting providers is the extent to which care staff have limited skills and understanding of challenging behaviour. In part this may be tackled by more explicit contracts and specifications but it remains the case that anyone can establish a service and call it ‘specialist’ without any particular experience or qualification. It would be useful, therefore, to explore the possibilities of establishing nationally accepted standards around training and qualification. A previous attempt was made on this by the National Care Standards Commission (Wing & O'Connor, 2004) and it would be useful to revisit this in collaboration with the CQC, Skills for Health and Skills for Care, perhaps building on the recent work on knowledge sets by the latter. This stream of work might also play a part in the CB-NSG.

### **6.1.4 Prompting and monitoring better performance**

At present commissioners are not held to account for their performance in respect of the development of better, local services. A number noted the value of such accounting but argued for its inclusion in existing mechanisms. Therefore, it is recommended that the use of existing mechanisms (such as the ‘Big Health Check’ and the Partnership Board annual report requirement) be reviewed with this in mind.

### **6.1.5 Reviewing NHS provision and continuing care arrangements**

There has, of course, been extensive recent review of NHS and private hospital provision (Care Quality Commission, 2009) and this is not what is proposed here. Rather, given the apparently limited progress made between the two CQC audits coupled with the findings reported above, consideration should be given to whether the current pattern of NHS provided and/or commissioned care is likely to improve sufficiently to contribute to future personalised support arrangements. It is clear that learning disability is an increasingly marginal issue within the NHS other than in the entirely appropriate efforts to make

healthcare more accessible and equitable. The extent of variation in continuing care arrangements and the broader continued difficulties between PCTs and local authorities suggest severe commissioning problems. At the very least some kind of inspection of the implementation of continuing care criteria with people with learning disabilities is required but the risks associated with a separate system of funding support for a minority of people with learning disabilities should also be considered.

#### **6.1.6 Prompting examination of the role, training and support needs of commissioners**

Given the variation in backgrounds, experience and qualifications of commissioners it would be useful to examine the scope for a programme of commissioner development. Previous approaches to commissioner development have been well-received (Cornes, et al., 2010) but have not typically incorporated more specialist knowledge of learning disability. More specifically, the general absence of good quality, local information on need might prompt consideration of how to support commissioners to gather and use such information. The new Learning Disability Public Health Observatory might usefully be asked to consider providing such support.

#### **6.1.7 Prompting greater collaboration between the Department of Health and the Department for Education**

The problem of the extensive use of residential school placements has been recognised nationally for some time. From 2003 to 2008 the Special Educational Needs Regional Partnerships collected annual data on out of authority educational (and, latterly, social care) placements (South Central Regional Inclusion Partnership, 2003, 2004, 2005, 2006; The Regional Partnerships, 2007, 2008). This data contributed to two reports (Department for Education and Skills/Department of Health, 2004; Pinney, 2005) identifying a number of concerns about such placements and promoting a strategy of “redeploying resources towards sustainable local provision” (Pinney, 2005, p.51). Unfortunately, annual data are no longer gathered following the reorganisation of the Regional Partnerships, and there is now no visible national policy. Given the impact of such placements on adult social care (leaving aside their impact on children) it would seem appropriate to raise these issues with the DfE and seek the further development of policy and action in this area.

## **6.2 Support for commissioners**

### **6.2.1 Development work to support personalisation**

While there are examples of excellent initiatives in a number of areas, it is clear that the overall pattern remains one of the frequent out of area placement of people with learning disabilities who present challenging behaviour. This is a particular problem for young people who have already spent some of their lives in out of area residential schools or colleges. If this pattern does not change we can look forward to continued growth of out of area placements since it is much harder to ‘repatriate’ (Allen, 2008) people once so placed. Yet there is considerable evidence that the development of personalised services for this group is perfectly possible (e.g., Mansell, et al., 2001) and clear guidance has been provided to support the process (e.g., Fulton & Winfield, 2008). Development work should, therefore, focus on supporting a number of local authorities (and their partners including families, providers and health staff) to implement this guidance locally. Such work will only be effective if it gains commitment from local authorities so it is important that they contribute to the funding of the work and ‘sign up’ to it at the highest level. It would also be appropriate to use the process to encourage local authorities to focus more systemically on the potential for developing services which effectively prevent and intervene earlier with challenging behaviour and mental health problems. This would be consistent with the move, in health and social care policy more generally, towards an emphasis on prevention and the promotion of well-being (Department of Health, 2008, 2009a). Such a focus should attend to the experiences of families described earlier in this report by commissioning (or prompting the commissioning of) skilled family-centred support services. Such services would be likely to reduce preferences for out of area placements by providing good quality, local support.

### **6.2.2 Dissemination and networking**

Not all areas can participate in the above development work and, indeed, many would not want to. It seems important, therefore, to also provide support in a way that provides greater coverage and creates more opportunities for good practice to be shared and innovative practice encouraged and supported. One cost-effective way to do this might be the establishment of a website. Such a website could have a number of different functions:

- Collation of evidence about the effects of services;

- Collation of examples of good practice (such as those identified by the current NDTi project on commissioning);
- Provision of opportunity for the development of virtual, ad hoc networks of commissioners around specific issues;
- Broader dissemination of lessons from the development work on personalisation.

The website would draw on examples such as that established by Research Autism ([www.researchautism.net](http://www.researchautism.net)) and that for the Commissioning Support Programme ([www.commissioningsupport.org.uk](http://www.commissioningsupport.org.uk)). It would be important that it was as interactive as possible to encourage active commissioner involvement.

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