



Facing the commissioning challenge: responding effectively to people whose behaviour is challenging

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Abstract

Securing better health and better care outcomes for people by effective use of public resources is at the heart of the commissioning agenda. Commissioning should ensure that the needs and wishes of people are well understood, and the market managed, so there are a range of local supports and provision available at a reasonable price. This is particularly important for people with intellectual disability whose behaviour is challenging, where effective clinically informed leadership is essential. Although models of good practice have been demonstrated for more than 20 years, making this happen on a wider scale remains the real challenge. Common wisdom about positive practice is not common practice in meeting identified needs. This paper aims to demystify the 'commissioning' role, and highlights the case for change in current practice, exploring some of the key barriers that must be addressed and suggesting ways to achieve better outcomes.

Key words

learning disabilities; intellectual disability; challenging behaviour; commissioning; positive behavioural support

Introduction

Securing better health and better care outcomes for people by effective use of public resources is at the heart of the commissioning agenda. As a result, good commissioners are able to understand both individual and local service needs over time. They should be able to shape services that are fair and of good quality, and that change to match individuals' assessed needs and wishes. They should also be able to use the resources they have in the most effective ways to ensure that each locality has the capacity to respond flexibly, including ensuring effective support for those who are seen as challenging. The Mansell Report (DH, 1993) noted that:

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

The commissioning task requires effective and informed leadership to ensure that such conditions exist.

Even though models of good practice have been demonstrated for more than 20 years, making such conditions happen on a wider scale remains a challenge. Evidence of what works in commissioning positive behavioural practice has not kept pace with identified need. Placement breakdowns continue to be too common a problem; many people remain excluded from services; clinically informed

recommendations are ignored; assessment and treatment facilities too often become blocked as individuals are not able to move back home; many placements eventually found are of high cost and low value in meeting identified needs. The Cornwall Inquiry (Healthcare Commission, 2007) traced reported abuse of people with intellectual disability, including of people whose behaviour was challenging, to lack of focus and commitment by commissioners to act in informed ways.

Given this recognised challenge, why has commissioning practice so often failed? Why has there too often been a preoccupation with passive, reactive and/or short-term orientated 'fixes', and failure to ensure clear, effective, early interventions? Commissioning actions appear to have been preoccupied with immediate costs and activity targets, with too little attention to strategic long-term outcomes, even though guidance such as the Commissioning Framework for Health and Wellbeing (DH, 2007b) sets an alternative clear direction for a shift to personalised services, a strategic reorientation to promoting health and well-being, investing early and in childhood to reduce future ill-health and disability costs, and a stronger focus on results with better partnership working promoting social inclusion and tackling health inequalities.

More recently this required shift has been captured in the vision for World Class Commissioning, summarised as 'adding life to years and years to life within a better value for money framework'. This ambitious programme is based on

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an examination of best practice in the UK and other systems around the world, and aims to transform commissioning practice in public services with resulting improved quality, effectiveness and efficiency of services (DH, 2009b). Ensuring better strategic and operational commissioning for people with intellectual disability exemplifies this vision, and making it happen for people whose behaviour is challenging has been regarded as a critical 'acid' test (IDeA, 2008). This has been reinforced by a variety of key reports and policy guidance over the past decade.

This paper aims to demystify the elements of effective 'commissioning' roles, processes and the relationship of this work to positive outcomes in intellectual disability services, and to challenging behaviours. It highlights the case for a change in current common practice, explores some of the key barriers that must be addressed, and suggests key ways to achieve better outcomes.

Commissioning in line with *An Ordinary Life* and the Mansell reports

More than 20 years ago, a key publication from the King's Fund set out a framework for developing high-quality services for people with challenging behaviour, *Facing the Challenge: An Ordinary Life for People with Learning Difficulties and Challenging Behaviour* (Blunden & Allen, 1987), followed by the supporting report *Meeting the Challenge* (Allen et al, 1991). Both demonstrated examples in a UK context of success, with all key necessary elements identified in line with international research findings:

- ▶ clear informed commissioning and clinical leadership with a focus, commitment and enthusiasm across local systems to a shared positive value base recognising that people with challenging behaviour have equal value, rights and need to live and participate fully in their local communities with access to effective support

- ▶ responsibility taken by lead commissioners, managers and clinicians to support people locally and design well co-ordinated person-centred supported home and day services, grasping 'local windows of development opportunity' with careful calculated risk taking and flexible supports, avoiding the 'easy ways out' of placing people presenting complex support needs with someone else or somewhere else away from their local communities
- ▶ use of positive clinical technical assistance including behavioural approaches adapted to the social context (Lovett, 1985), communication-enhancement interventions (Reichle & Wacker, 1993) and rapid access to skilled clinical advice and intensive practical change and crises management programmes (Emerson et al, 1987).

Box 1, below, sets out the key points about challenging behaviour with which commissioners should be familiar.

The Department of Health published the findings of a project group chaired by Professor Jim Mansell, *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* (DH, 1993). This built on the King's Fund reports by identifying critical issues in effective local service developments, including the following.

- ▶ Improved understanding of the needs of children (and adults) with reputations for challenging behaviour placed out of area, and a focus on clear strategies enabling a return locally.
- ▶ Implementing programmes in early intervention and detection of emerging problem in childhood and at transitions.
- ▶ Services structured around individual needs, minimising the occurrence of challenging behaviour and with the resilience to cope with severe presenting challenges, including those related to mental health difficulties and

Box 1: The key things commissioners should know about challenging behaviour

- It is relatively common, present for 5–15% of service users and varied in presentation
- Some people are at greater risk so need targeted interventions
- It is damaging to people themselves, relationships, families/carers, services and society
- It often emerges in early childhood, persists over decades with 70–80% persistence over seven years, and so needs early effective intervention and understanding. Personal histories matter
- The factors causing and maintaining challenging behaviour are varied and complex, and include various mixes of biological-psychological-social factors and as such require responses from confident, skilled teams informed by comprehensive assessments and formulations that take into account individual disabilities and personal history and acknowledge that they may be expressions of desired ordinary life experiences, control communication, relationships and chronic negative behaviour patterns/habits
- Positive behaviour support strategies do work when delivered within coherent comprehensive support systems backed by competent, confident and capable staff, rather than naïve reliance on staff to react 'naturally' with little training
- Most people do not receive effective interventions, and many continue to receive no, ineffective or potentially damaging 'treatment', and also are excluded from local valued opportunities that then damage individuals further by over-reliance on medication, control and punishment
- Setting up challenging behaviour home/day units or just moving people does not work





offending behaviours, rather than 'place and hope' strategies that result in mis-matches.

- ▶ Careful design, provision and maintenance of local placements, recognising the impact of social context on challenging behaviour presentations since behaviours are a product of interactions between individual factors and the circumstances in which people live, rather than isolated pathological acts.
- ▶ Using the wide-ranging evidence base and knowledge about effective positive behavioural support strategies and programmes, and targeting prevention activities with enriched environments and able staff supported to promote adaptive behaviours.
- ▶ Organising long-term flexible support packages and accepting the need for complex multi-component intervention and support plans that need adjusting and review at regular intervals.
- ▶ Ensuring access to skilled, experienced clinical practitioners in local community support teams that support confident, committed, capable and competent social providers, avoiding artificial distinctions between health and social care, and able to provide high levels of practical, technical, clinical and regular emotional/de-briefing support for carers, avoiding exploitation of commitment and dedication.
- ▶ People generally feel more secure with fewer people to relate to, and have a greater sense of control over their environment and life, so grouping people with challenging behaviour together tends to create additional problems and should be avoided.
- ▶ Developing services that enable staff to connect with individuals whose behaviour is challenging, and then continue direct involvement, thereby developing a real sense of personal responsibility and commitment.
- ▶ Accepting that changing challenging behaviours takes time and effort and no one answer works for individuals at all times.
- ▶ Changing the continued 'reactive' focus dominant in supporting individuals to manage crises.
- ▶ Responding to emerging danger signs with crisis management and support, with rapid deployment of 'hands on' staff support, accessible on-call services, contingency relapse planning, respite/break options, access to alternative homes and jobs, training in managing physical interventions, skilled specialist interventions and, last resort, access to emergency beds.
- ▶ Completing regular structured service review and development programmes.
- ▶ Effective contracting for improved services by specifying service models shown to achieve good results such as supported homes, employment, education and leisure packages, what services will achieve, and key elements of the required models of care, including amount

and quality of staff support, and external validation strategies of care quality and options for raising safeguarding concerns.

- ▶ Adopting comprehensive investment frameworks that recognise hidden costs such as responding to placement breakdowns, crises and other carer costs, and using joint funding approaches to emphasise inter-dependency between services, and strategies to strengthen local 'mainstream' services.

Mansell identified the way forward as that of strengthened commissioning combined with provision of effective clinical expertise (Allen *et al*, 2005; Carr *et al*, 1999; Donnellan *et al*, 1988; Emerson *et al*, 1999; Horner *et al*, 1990).

Although all this work has subsequently underpinned both the *Valuing People* (DH, 2001) and *Valuing People Now* (DH, 2009c) strategy commissioning and delivery programmes, there has been limited specific guidance on what clinicians and commissioners should do. Following recognition of continuing problems in designing, developing and delivering effective supports for people whose behaviour is challenging, the Mansell report was revised and brought up to date by the lead author (DH, 2007c). He confirmed that the recommendations of the original report remained relevant more than a decade later. Although good progress had been reported on many fronts since the publication of *Valuing People*, progress on challenging behaviour lagged behind. Failure to commission and develop appropriate services is continuing to lead to damaging outcomes for individuals, and is a serious cost to society. Mansell noted that the main reason for this concerned poor, and at times ill-informed, commissioning leadership, together with a general failure to introduce positive behavioural support practices.

In terms of challenging behaviour, the agenda is clear: commissioning should follow the recommendations of *Facing the Challenge* and the Mansell report.

Commissioning principles

The central challenge for all commissioners remains balancing effective and efficient service delivery, improved outcomes for users of services, higher quality and cost-effectiveness. Commissioning should ensure that the needs and wishes of people from the local area are well understood and the market managed so there are a range of local supports and provision available at a reasonable price. This requires a connection between commissioning plans and operational micro-commissioning, decision-making practice where individual care packages are agreed and reviewed.

In its simplest form, commissioning is an on-going cyclical process to understand the needs and wishes of individuals, using assessments and research to detail priorities and choices which lead to determining how best to deliver the support and to allocate the funds it requires. Plans are then developed, monitored and evaluated to ensure the





quality of the service. To be effective, this process needs to be inclusive. However, beneath those words lies a more complex agenda and a continuous process that has been summarised as the eight-step commissioning cycle (DH, 2007b) – **Figure 1**, below.

The process, done well, includes a range of activities, such as knowing what services people need to live a good life, using this knowledge to plan changes for localities, taking action to change services where they are not good enough, funding services to meet individual needs, checking that outcomes from services are of good quality, and changing services and plans if needed. This then requires a clear, articulated vision and commitment to achieving meaningful long-term outcomes that connect with the needs and aspirations of local people (a strategic commissioning plan), understanding needs, demand and supply over varying time-frames, effective and efficient use and deployment of resource, and financial planning linked to service development and changes in delivery patterns.

A detailed intellectual disability commissioning assessment framework was developed by the Care Quality Commission (and its three predecessor regulatory bodies, the Healthcare Commission, CSCI and the Mental Health Act Commission, 2008) in response to collective concerns over the quality of commissioning practice and the widely reported negative service experiences of people with intellectual disability and complex needs, including those whose behaviour was challenging. The key elements of the framework enable local review of progress against the priorities implicit in *Valuing People Now* (DH, 2009c), and support the required new World Class Commissioning competencies and roles for commissioners (DH, 2008b). Some of the key elements

of this approach have been captured as a person-centred commissioning pathway approach (IDeA, 2008).

The CQC (2009) has now recognised that commissioning plays a key part in ensuring that outdated care and support are sustained. Key strategic development priorities have now been identified to enhance the quality of outcomes for people with intellectual disability who use services: ensuring that care is centred on people’s needs and protects their rights, championing joined-up care so that health and social care are more co-ordinated, acting swiftly to help eliminate poor care, ensuring and promoting high-quality care, and regulating effectively in partnership.

Commissioning for challenging behaviour – key challenges

In February 2009 the Parliamentary and Health Service Ombudsman and Local Government Ombudsmen reported on the six individual cases highlighted in *Death by Indifference* (Mencap, 2007) of people with intellectual disability who died prematurely while in the care of the NHS. In addition to their conclusions on these individual cases, the report recommended that all NHS and social care organisations should:

- ▶ urgently review the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of local needs
- ▶ urgently review the capacity and capability of the services they provide and/or commission to meet the additional and often complex needs of people with intellectual disability, including those who present challenging behaviours
- ▶ report accordingly to their Boards by March 2010.

Figure 1: The eight-step commissioning cycle

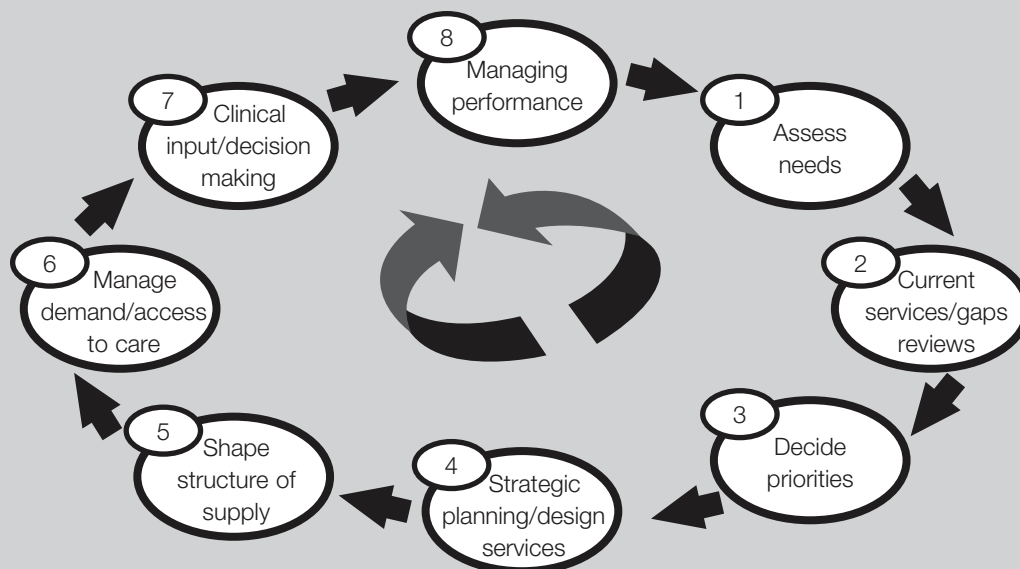
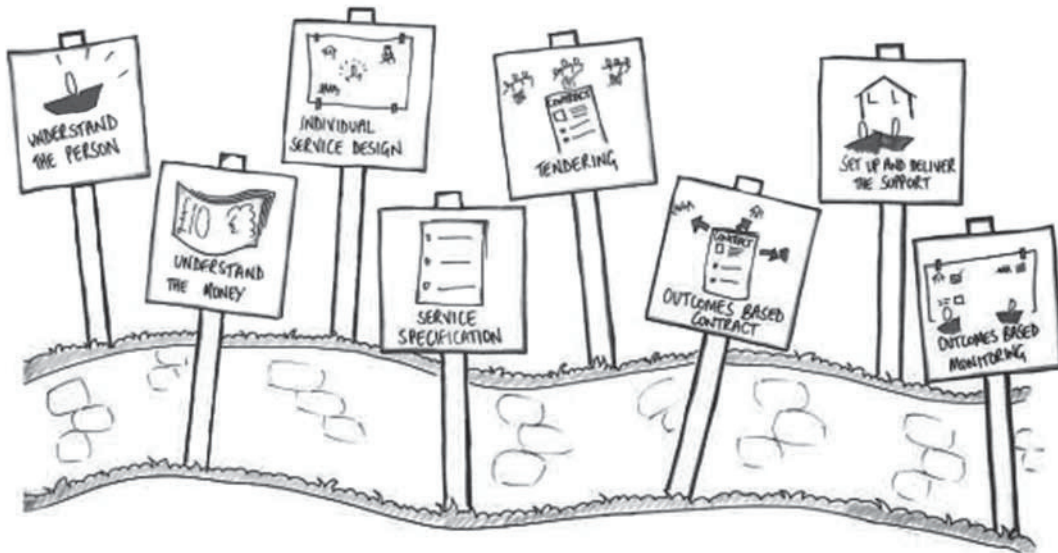




Figure 2: A person-centred commissioning pathway approach



The findings of the Joint Commissioning Review for People with Learning Disabilities and Complex Needs (2009), carried out by the Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission, highlighted:

- ▶ concerns about broader commissioning skills and practice
- ▶ continued negative professional values and attitudes
- ▶ poor forward planning for people with intellectual disability to prevent crisis
- ▶ lack of person-centred care plans, poor care planning and care
- ▶ over-reliance on poor-quality out-of-area placements with limited local services
- ▶ negative treatment of people whose behaviour challenges
- ▶ concerns about excessive physical interventions and restraint rather than proactive strategies involving antecedent control and ecological changes
- ▶ growth of large traditional service models in the private sector
- ▶ lack of regular monitoring of placements and support for quality outcomes
- ▶ poor practice in capacity, consent and deprivation of liberty issues
- ▶ increased burden on family carers
- ▶ very few people getting annual health checks and support in primary care
- ▶ people and their families having bad experiences while in general hospitals

- ▶ limited progress in securing positive support from mental health services
- ▶ lack of involvement of people in delivery, training and development of services.

Other distinct commissioning challenges have been confirmed by the recent World Class Commissioning Guidance on Commissioning for People with Learning Disabilities (DH, 2009b), including managing the challenges of lead social care commissioner arrangements, legal requirements, person-centred care, information sharing, promoting access to services, consent and capacity issues, effective communication, diagnostic overshadowing, knowledge and skills, and resettlement and campus closure plans.

The recent transfer to local authorities of responsibility for past PCT-led social care commissioning and funding (DH, 2009b) for people with intellectual disability has been designed to enable PCTs to focus better on meeting the health needs of people with intellectual disability (now defined as responsibility for health care, including specialist and mainstream services, forensic support and continuing health care).

This action has been complemented by the guidance on *Commissioning Specialist Health Services* (DH, 2007d), which requires an effective and identifiable strategic presence within PCTs to inform and support the commissioning and delivery of services in ways that address the needs of people with intellectual disability. It also confirmed the particular need to enhance local specialist support for people, to reduce the number of poor-quality, high-cost out-of-area placements.





Nevertheless, too little attention and value have been focused on enabling the availability of well-functioning community learning disability teams in line with *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance* (DH, 2007d) and professional practice guidelines such as *Challenging Behaviour: A unified approach* (RCPsych et al, 2007).

Many non-clinical experienced and social-orientated commissioners lack experience in commissioning person-centred support for complex needs, which has too often resulted in support for risk-averse cultures. This has then appeared to pressure local services into being unwilling to sign off risk assessments that would enable local placement of people who challenge. As a result, too often choice and normalisation principles have been confused with the need for balance with effective structure, boundaries and clinical support involving known, successful, positive behavioural technologies (Emerson & McGill, 1989; LaVigna & Willis, 2005) and person-centred essential planning principles (Lovett, 1985; Smull, 1995), thereby really 'learning to listen' to the 'message value' underpinning challenging behaviour presentations (Lovett, 1996).

The lead commissioning role of local authorities should not be mistaken for the removal of any continuing responsibility and effective involvement of PCT commissioners and other clinicians in informing necessary local service responses to challenging behaviours and health needs. However, too often commissioning remains primary-led by social care practitioners ill-equipped and unsupported in terms of clinical confidence, knowledge and experience of managing and changing challenging behaviours. High on the agenda to respond to this, local commissioners need to think and act both strategically and pragmatically, overcoming the tension between various priorities and competing targets that sometimes conspires to create boundaries to effective partnership at the social-health commissioning interface.

The separation of commissioner and provider roles has also stopped many skilled intellectual disability professionals and other key stakeholders, able to provide important information at a number of points in the commissioning cycle, from doing so. In fact, at times lack of clinical engagement may well have contributed to some ineffective commissioning decisions with respect to challenging behaviours, when well-presented, high-cost but ineffective services with a lot of window dressing have become confused with effective positive behavioural supports.

The emergence of the personalisation agenda in health and social care will also bring new challenges for commissioners, as it requires commissioners to think about care and support services in a different way by challenging all existing systems, processes, staff and services to put people first (DH, 2007a), together with more effective market management and the stimulation of competition that has grown in recent years. The principle factor in managing the local market should be

for commissioners to procure services from providers who are best placed to deliver the needs of patients. As part of this process, commissioners now need to develop better specifications for contracts for individual support and care pathways, and then place greater emphasis on effective outcome-based contract management.

Finally, over the coming years, it is clear that commissioners will be operating in a intensely cold financial climate, with reduced budget allocations, increasing focus on achieving savings, and a need to prioritise investment on the essential clinically- and cost-effective services (NHS Confederation, 2009). New developments will be scrutinised even more closely, to ensure that they are evidence-based and will be of direct benefit to users of services and the wider community. Commissioners will need to employ new approaches and create opportunities to engage service users and carer experts by experience in developing pragmatic solutions.

Putting the jigsaw together: commissioning for challenging behaviour

I am fortunate in having been afforded a range of experiences over the past 25 years as an assistant/support worker, clinician, manager and commissioner that have endorsed the value of each of the pieces of the emerging commissioning jigsaw.

For example, experience suggests that effective commissioning and service delivery rely on the sustained commitment and skills of individuals; negative changes often result from small yet significant changes to the context (such as shifts in leadership, local priorities or team composition). Supporting positive behavioural support programmes requires both strategic attention to system-wide interventions and supporting key anchors, allies and assistants. This latter point is critical, as too often personal factors are down-played, with the good intention of managers to implement mechanistic service systems that reduce reliance on personality factors. Clearly, while such an approach is understandable, it is bound to ensure attainment of only minimum service standards rather than true person-centred, excellent supports.

Based on a review of effective commissioning and clinical practice experience in Birmingham, Sheffield, Liverpool, Cheshire and Trafford the following priorities exist.

- ▶ Establish senior, local, clinically informed strategic commissioning and operational leadership posts, usually focused on enabling positive outcomes for vulnerable people rather than intellectual disability alone.
- ▶ Begin with a local person-centred needs assessment process to identify proactively all known local individuals with severe reputations for presenting challenging behaviours, then develop detailed personal profiles and functional analyses of challenging behaviour. Follow up proactively by combining the evidence on the wider number, health needs and





experiences of people and those presenting complex needs to prioritise investment decisions.

- ▶ Enable an effective, robust, person-centred planning process and formalise links between the outcomes of individual person-centred plans and strategic development decisions for services and local strategic needs analyses.
- ▶ Focus on shaping joint early-intervention programmes with children's services, including enhanced behavioural support and transition support pathways, and providing a range of Aiming High flexible, planned/crisis, short-break options.
- ▶ Identify and share best practice in the creative use of funds to help create cultures that sustain positive support arrangements within budgets.
- ▶ Take stock of current services, looking at costs and effectiveness, deficits in provision and unmet need, and key workforce development needs.
- ▶ Enable regular, reflective, solution-focused dialogue with providers and service users at multiple levels to identify what has worked well and where there have been problems.
- ▶ Shape markets to match local needs, with greater flexibility in tendering and contract processes to ensure they work well for people using the services.
- ▶ Initiate tendering and preferred provider frameworks, and decide on the providers who are best able to meet needs and where appropriate decommissioning may be needed.
- ▶ Complete clear service specifications for individuals, group services and projects.
- ▶ Facilitate regular commissioner-led contract and service development review meetings to monitor effectiveness and tracking of progress for real person-centred outcome changes and positive stories, as well as performance data, by honest communication between commissioners, individuals who use services and support providers.

Box 2: Completing the jigsaw of positive commissioning responses to challenging behaviours

- **Person-centred and clinician-informed commissioning**, focusing on needs assessment, prevention and early identification/intervention and proactive community development, ensuring that interesting options are matched to individuals' needs and personal champions who truly care for people and act as anchors
- **Better support for children and families integrated with children and family services commissioners**, focusing on practical positive family-centred behaviour support plans for young children to disrupt the establishment of negative habits and rituals, effective types of support to prevent or reduce challenging behaviour in childhood, and working with commissioners for children's services to tackle 'upstream' problems and ensure transition is well managed
- **More and effective support for families**, through better access to information, training, support and respite/short breaks, and integrated structured interventions with schools and through the transition process
- **Effective expert care management and resource allocation panels**, with all people with intellectual disability and complex needs having a named care manager, health facilitator or navigator whom they have met, who actively monitors how their needs are being fulfilled and offers support should they wish to raise concerns; wider systems planning ahead, based on clear, accurate, person-centred summary profiles or plans with simple written records of history, key preferences, helpful and unhelpful responses, to inform the design of capacity to cope with changing demands, rather than waiting until crises occur
- **Competent health and social care providers** with effective managers/leaders, and access to supported home, workplace and lifestyle opportunities conducive to learning, joy and experiencing a wide variety of activities and relationships; recognising how challenging behaviour is maintained by environmental processes, interventions should take place in normal settings, with personalised routines and managed expectations of carers to reduce unreasonable pressures and stress
- **Specialist clinical capacity**, competent clinicians and community support teams, skilled and accessible ongoing positive behavioural support, practical emotional support, interventions that work in natural settings, and bio-psycho-social programmes
- **Effective interfaces** with specialist child and adolescent mental health, disability and adult mental health, continuing care, safeguarding services including Aiming High for Disabled Children, early intervention teams, transition, *Mental Capacity Act*, Green Light Toolkit protocols, crisis resolution, assertive outreach and emergency support services, secure services and PCT/locality authority resource allocation panels
- **Long-term resource deployment**, including confident, competent staff to support effective ways of working and sufficient respite break opportunities and supervision and training
- **Funding, procurement and contracting mechanisms**
- **Emergency support options**, providing coping strategies to deal with presenting challenging behaviours, managing them with low-arousal responses, enabling access to psychiatric support and short-term alternative places for support as part of integrated care pathways





- ▶ Ensure links to clinical and corporate governance by appropriate reporting lines, accountability, safeguarding mechanisms, complaints management systems and training/development activities.

Box 2, opposite, summarises how the ‘jigsaw’ can be completed.

Mansell has noted that:

... since cost is sometimes given as a reason why adequate services for this group of people are not developed, it is worth noting at the outset that these services were all developed within the existing resource framework available to their host agencies. Resources are a question of priorities as well as of the amount available (DH, 2007c).

At a time when commissioners are faced with increasing demands and financial constraints, they should not resort to traditional group services, but support personalisation even more, and focus activities to ensure they make a real difference to people. Only then can high-quality commissioning lead to high-quality outcomes for people whose behaviour is challenging.

It is up to effective commissioners to rise to the challenge and make this a reality everywhere, with strategic analyses of need, investments and action involving positive behavioural support strategies.

Summary points

- ▶ Securing better health and better care outcomes for people by effective use of public resources is at the heart of the commissioning agenda.
- ▶ Commissioning should ensure that the needs and wishes of people are well understood and the market managed so there are a range of local supports and provision available at a reasonable price.
- ▶ This is particularly important for people with intellectual disability whose behaviour is challenging, where clinically-informed leadership is essential.
- ▶ Although models of good practice have been demonstrated for more than 20 years, making it happen on a wider scale remains the real challenge.
- ▶ Common wisdom about positive practice is not common practice in meeting identified needs.
- ▶ To respond to this challenge, commissioners will need:
 - to work together more effectively to secure and deploy technical commissioning expertise/capacity and develop effective positive behavioural supports
 - to recognise that effective commissioning requires development of deeply embedded, sustained and trusting relationships with all stakeholders – not just technical skills
 - to ensure there are sufficient incentives for individuals

- and teams of the right calibre to take on the necessary leadership roles across systems
- to invest heavily in preserving and improving relationships with partners, and consider all opportunities to combine resources
- as a result, to respond positively with what we know works in effective commissioning practice as outlined above.

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