Supporting staff working with people who challenge services

Guidance for employers
February 2013
Foreword

Ensuring that our workforce has the right skills, knowledge and experience to work alongside people who may challenge is an important part of any model of care and support.

This guidance has been developed in partnership with people, families, employers and commissioners to help with decision making around workforce development in the context of people who may challenge. It has been designed to provide guidance in relation to supporting people with a broad range of support needs, including people with mental health needs, a learning disability or someone with dementia.

Effective workforce development takes account not only of worker skills knowledge and expertise but how they are recruited, retained, supervised, supported and worker behaviour is monitored and reviewed.

A personalised strategic approach to the needs of workers is as important as understanding and supporting people with care and support needs who may challenge.

By developing this guide to workforce development and people who may challenge we hope that employers and commissioners will have the confidence to work in partnership to promote workforce development solutions that enable workers and the people they support to have confidence in each other and thus reduce the likelihood of people who may challenge being adversely impacted in their opportunity to live independently and as part of their local community.

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Executive summary

This strategic guidance is aimed at adult social care employers and commissioners working specifically with adults with a range of support and care needs such as older people with conditions across the dementia spectrum, people with mental health and personality conditions, and those with learning disabilities who have particularly complex needs and/or are labelled as challenging services. The guide will help employers with developing competency and expertise in providing support to people who challenge, across different groups.

In order to address these challenges, the guide is made up of the following ‘sections’:

- Introduction and purpose of the guide
- Organisational actions
- Building workforce skills and knowledge
- Using learning tools and resources: identifying the best training solutions for your teams
- Specialist approaches: additional considerations for working with different people
- Useful contacts.

This summary provides ‘10 key points’ from the guide to provide an overview of the main areas employers should be concerned with.

What is ‘behaviour that challenges services’?
Whilst Emerson’s definition (1995) was written to describe the behaviour of people with severe learning disabilities, it can apply to people with the conditions set out above. With more people living longer with dementia and enduring mental health problems as well as with learning disabilities, employers working with people who challenge will need to ensure that their teams are well trained and supported in order to ensure the best possible outcomes for the people they support. National policy and good practice guidance has for over a decade stated that people who in the past would have been confined to institutional settings, including people who display behaviour which challenges, should now be supported to live a positive life in the community.

This guidance will address two specific challenges that employers need to consider – no matter what ‘client group’ they are working with. These are:

1. Organisational actions: how to design, recruit and retain a workforce that is equipped to support people who challenge.
2. Workforce skills and knowledge: what competencies and qualities organisations need to recruit and train for when building a workforce with people.
Organisational actions

**Being a person centred organisation**
Adopt person centred approaches in all areas of organisational activity to working with people who challenge in a way that recognises the person behind the behaviours and takes a solution focused attitude.

**Key point 1:** Be flexible, and offer a range of options to enable staff to develop the ability to deal with people who challenge effectively in any scenario or setting, whilst knowing how to manage risk and be clear what to do when things go wrong.

**Positive work with families**
Many people that challenge are being supported for the most part by their family carers, who are the true experts and understand the key skills and competencies that staff need in order to effectively support their relative.

**Key point 2:** A person’s family is often the most important, long-standing connection in their life. Therefore, the ability of staff to work positively and inclusively with families and carers is a core staff skill.

**Develop a culture that focuses on people’s assets and life outcomes**
Policy is clear that people who are labelled as ‘challenging’ have the same rights to life and positive outcomes as everyone else. Not recognising the assets that people have in their life and how they can continue to contribute to their local communities is one of the greatest failings of services.

**Key point 3:** Retain a clear focus on outcomes, and use this evidence to inform staff of the impact of their work. This can create a highly positive feedback loop that encourages renewed staff investment in the success of the services they work in.

**Promote choice and control**
A holistic, personalised approach to supporting people that challenge involves, providing a space for the individual’s voice and preferences to be heard, giving access to independent information, advice and advocacy to support choice and control, and ensures that those choices are well informed, and involving families and other supporters.

**Key point 4:** Ensure staff are confident of their role and of the skills they need to obtain and use in supporting the person to speak out, have their voice heard, and maintain a positive relationship with that person and their family, as well as Independent Mental Capacity Advocates (IMCA).
Partnerships that use one another’s expertise
Across all client groups, there is an expectation of integrated working – with social care providers making use of expertise from friends and families, from people using services, healthcare professionals, social workers/care managers and others.

Key point 5: Bring together a range of different types of knowledge and expertise to support people and their families – no one organisation will have all the answers and should not have to work alone.

Building workforce skills and knowledge
In developing this guide, we have consulted widely to help establish a framework for the key sets of skills that staff need to have in order to work effectively with people who challenge services.

Understanding the nature of behaviour that challenges
The evidence is clear that people are best supported in ordinary community settings and by pursuing individualised and personalised approaches. Services that group people who challenge together in the same setting are not generally as effective as services that are built around the individual.

Key point 6: There is more that is the same than different between individuals whose behaviour challenges and those that do not. Focusing on the commonalities helps to identify what we are aiming to achieve before focusing on the differences.

Understanding positive strategies to support and address behaviour that challenges
Staff need both proactive and reactive strategies to manage the support of people who challenge services. They also need to understand a range of positive approaches that are evidenced to be effective, and have those at their disposal when designing and delivering personalised support.

Key point 7: Understanding the unique nature of the behaviour and life wishes of each individual is a central starting point for effective support.

Using person centred approaches
Both policy and the evidence base are clear that effective services start by listening to the individual, their wishes and aspirations, and planning and designing services around that.

Key Point 8: Effective person centred planning is the best way of achieving success – and thus has to remain at the heart of staff practice – no matter how great the challenges that a person presents.
Communication skills
The most effective starting point for understanding behaviour that challenges is to acknowledge that it is functional – i.e. people’s behaviour is a way of communicating something (whether they are able to speak or not) and staff respond accordingly.

Key point 9: Staff need to have access to a range of approaches to communication that will enable the person’s voice, whether spoken or not, and the voices of their families and carers, to be clearly heard.

Non-aversive interventions
Aversive behaviour intervention can be described as punishing an individual in order to suppress the behaviour that challenges. Over the past two decades the emphasis has been on intervening before the challenge occurs using ‘non-aversive interventions’. Such interventions are essentially how positive behaviour support can be described (McDonnell 2010).

Key point 10: All staff that may work with people who challenge in ways that result in such behaviour need to be trained in appropriate non-aversive techniques – and understand the limits of when and where they should use such approaches.

Using learning tools and resources: how you identify the best training solutions available for your teams

Using internal coaches and mentors
Many organisations make use of experienced staff that are familiar with and use person centred approaches to support newer members that are undergoing induction, or who are in their first role working with people who challenge. Training itself may be useful alongside mentoring/ buddying schemes and the specific art of coaching, but using in-house resources may provide an innovative, effective, and immediate solution to ensuring readiness of teams.

Measuring training outcomes
The effectiveness of training can be measured by way of independent evaluation, comparing staff confidence before and after the training, in supervision and appraisal. People who challenge need to achieve positive outcomes as a result of improvement in practice as a direct result of learning, be that through traditional training, or mentoring and coaching.
Specialist approaches: additional considerations for working with different people

**Learning disability**
Specialists working with people with learning disabilities will find a wide range of resources about people who challenge, with recent policy and guidance, most notably the findings of the review of services following the closure of the Winterbourne View specialist hospital for people with autism and learning disabilities.

The government’s three-year strategy, *Valuing People Now (2009)* and the late Professor Jim Mansell’s report *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* are other important sources of guidance.

**Autism**
People on the autistic spectrum are often categorised together with people with learning disabilities. However, it ought to be remembered that autism is a discrete condition, many people on the autistic spectrum do not have a learning disability and that there are individuals with autism that also have other conditions such as mental health problems.

Skills for Care’s *Autism Skills and Knowledge List* helps employers to enhance staff awareness, with clear guidance on achieving the best outcomes for people with autism.

**Mental health**
Behaviour that challenges is sometimes associated with those with mental health problems when they are unwell. The government has committed to addressing stigma around mental health by signing up to the Time to Change campaign, and has published a national framework for mental health and wellbeing.

The cross government strategy *No health without mental health* sets out six priorities, one of which is related to ‘a positive experience of care and support’. This includes experiencing choice and control over an individual’s own life, and access to the latest interventions that are available.

**Older people**
Older people, particularly those with dementia, have not traditionally been recognised as a group of people who challenge services. Anecdotal evidence suggests that this is because behaviour that challenges in older people is not perceived as such, and therefore responses to it may be inappropriate. Forms of restraint used such as locked doors, and medication (including the inappropriate use of anti-psychotics) may be seen as care and support rather than recognised as a deprivation of liberty and potentially abuse.
Acknowledgements

This guidance was commissioned by Skills for Care and developed by the National Development Team for Inclusion, together with an employer led partnership group.

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The project team is grateful to everyone who read and commented on early drafts of the guide, and for the support of the Skills for Care policy team.
Section one: introduction and purpose of the guide

This strategic guidance is aimed at adult social care employers and commissioners working specifically with adults with a range of support and care needs such as older people with conditions across the Alzheimer’s and dementia spectrum, people with mental health and personality conditions, and those with learning disabilities who have particularly complex needs and/or are labelled as challenging services. The guide will help employers with developing competency and expertise in providing support to people who challenge, across different groups. Appendix one, ‘useful contacts’ gives contacts to the range of organisations that have participated in the preparation of this guidance, and others who can support you and your teams in achieving the required competency and expertise.

This guidance will address two specific challenges that employers need to consider – no matter what ‘client group’ they are working with. These are:

- Organisational actions: how to design, recruit and retain a workforce that is equipped to support people who challenge
- Workforce skills and knowledge: what competencies and qualities organisations need to recruit and train for when building a workforce.

Within each of these two main challenges, a number of specific issues have been identified, based on the experience of other employers that require attention. Each issue is described with a summary of what policy and evidence suggests should be happening and then makes suggestions for employer action – including through pointing employers towards helpful resources.

The guide then offers concluding sections about:

- Using learning tools and resources: how an organisation can identify the best training and development solutions for their teams
- Additional resources to assist in working with different people and people with multiple conditions
- Useful contacts to organisations that are available to build upon what has been recommended in this guide.

What is ‘behaviour that challenges services’?

Eric Emerson (1995) provides the most widely used definition: ‘culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’. (Emerson 1995 in Emerson and Einfield 2011)
Whilst this definition was written to describe the behaviour of people with severe learning disabilities, it can apply to people with the conditions set out in the introduction. With more people living longer, and with a growing number of older people living with dementia, employers working with people who challenge will need to ensure that their teams are well trained and supported in order to ensure the best possible outcomes for the people they support. Social care adult services are themselves also changing. National policy (see below) and good practice guidance has for over a decade stated that people who in the past would have been confined to institutional settings, including people who display behaviour which challenges, should now be supported to live a positive life in the community.

It is important that people supporting those whose behaviour challenges see the behaviour in the context of the person’s disability or impairment. For example, behaviour viewed as challenging seen in someone with a condition such as autism may have a very different function than the exact same behaviour displayed by someone with dementia. Therefore, when developing staff to support people whose behaviour challenges, employers need to find solutions that develop an understanding of the person and their experience of their condition, before it can be understood how best to respond as a service to that behaviour.

**Key recent policies related to adult social care:**

- [Caring for our Future: the Care and Support White Paper](#)
- [Care and Support Draft Bill](#)
- Think Local Act Personal partnership programme
- Prime Minister’s Challenge on Dementia: [progress report](#)
- [Valuing People Now: strategy for people with learning disabilities (2009)](#)
- [A national response to Winterbourne View: final report](#)
- [No health without mental health: the mental health outcomes strategy](#)
Section two: organisational actions

How to design, recruit and retain a workforce that is equipped to support people who challenge

In order to design a workforce with very well developed knowledge and skills to support people who challenge, an employer needs to ensure that their organisational processes and systems enable staff to use their skills effectively. Training staff to a high degree of skill will not, on its own, lead to high quality support. The organisation needs to have the structures and culture in place to support the application of those skills (Institute for Public Care, 2012).

There are often misconceptions regarding the medical and social models of disability when thinking about the best ways to work with people who challenge. It needs to be borne in mind that the social model of disability requires appropriate healthcare support and recognition of specialist interventions, to support behaviour that is deemed inappropriate in a social context.

An employer also needs to prove organisation-wide commitment to working within a positive behaviour support model when supporting people who challenge. This requires commitment at all levels towards working with person centred approaches, and using frameworks such as applied behaviour analysis.

2.1 Being a person centred organisation

What policy and evidence propose
The best starting assumption for understanding challenges that a person is presenting to services, is that their behaviour is a form of communication. They wish (or need) to be heard; for their views to be heard and acted upon. This makes being person centred the most important starting point for an organisation i.e. putting the individual at the centre of their support, and ensuring that their wishes and individual approaches are what shape the support, rather than the person being expected to fit into what the organisation already does.

This approach is core to the Think Local, Act Personal (formerly Putting People First) agenda and should be part and parcel of the organisational culture in your journey towards ensuring that people who challenge, whether they have a learning disability, a mental health problem, or dementia, are able to be supported to live positively in their community.
## Ideas and resources to help make this happen

<table>
<thead>
<tr>
<th>Good practice</th>
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<tbody>
<tr>
<td>Ensure a clear understanding of the nature of personalisation and putting the person at the centre.</td>
<td>SCIE report 47: <em>Personalisation: a rough guide</em></td>
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<td></td>
<td>Think Local, Act Personal <em>Making it Real: marking progress towards personalised, community based support</em></td>
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<td>Department of Health (NMHDU) and NDTi <em>Paths to Personalisation</em> on developing effective personalisation in the mental health field.</td>
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<td>Co-production: ‘Do with’, rather than ‘do to’ so that staff understand this is a core element of how they behave at work. Ensure the user's voice influences every aspect</td>
<td>Department of Health <em>Don’t just do it – co-produce and live it!</em> A guide to co-production for older people and organisations, transferable across groups.</td>
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<td></td>
<td><em>Skills for Care Supporting Me: a guide for Personal Assistants employed by or for someone who may behave in ways that others find challenging</em></td>
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<tr>
<td>Consider how to embed person centred approaches in the structures and management of the organisation and not just place that responsibility on staff working with the people they support. For example, communicate with your team on a regular basis, and make the person centred approach a key aspect of management and supervision.</td>
<td>Richard Williams and Helen Sanderson <em>What are we learning about person centred organisations?</em></td>
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<td></td>
<td>Department of Health <em>Personalisation through Person Centred Planning</em> Putting People First guidance</td>
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</table>
Be clear about what to do when things go wrong. Turn this into a learning process rather than a desire to pin the blame on someone or an organisation. Celebrate when things go right and learn from that.

Ensure staff are clear on where to access both compliment and complaints policies and procedures for families and carers and that these are in an accessible format.

Organisational policies should be person centred in content e.g. client's finance, organisational decision making.

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<th>Care Quality Commission Essential Standards of Quality guidance</th>
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<td>Ensure staff are clear on where to access both compliment and complaints policies and procedures for families and carers and that these are in an accessible format.</td>
<td>Living with risk – guidance in providing choice and control whilst allowing individuals to take informed risks.</td>
</tr>
<tr>
<td>Organisational policies should be person centred in content e.g. client's finance, organisational decision making.</td>
<td>Helen Sanderson Associates Person Centred Thinking and Planning guidance on developing your organisation’s policy.</td>
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2.2 Designing staff structures that work

**What policy and evidence propose**

Working with people who challenge requires particular expertise. Working in social care, supporting people with a wider range of needs requires particular qualities. Expecting people who present the greatest challenges to be supported by any standard staff structure and/or staff who have not been effectively trained and supported will almost certainly result in the service not being effective. Equally, it can be a mistake to ‘over-professionalise’ a service. By making too much of the ‘label’ that a person or a service has been given, there is a risk that staff and others will start to expect behaviour that challenges in all inter-actions – which can be a self-fulfilling prophecy.

The challenge is to ensure that there is the right level of expertise within the organisation – to ‘normalise’ structures as far as possible whilst also ensuring that staff have access to additional expertise as and when they need it. Front line leaders and managers also need to exercise ownership and understanding of the task of supporting people who challenge, in order to maintain the quality of the support.
Ideas and resources to help make this happen

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<tr>
<td>Ensure that basic good practice in staff structure and design is in place to underpin support to people who challenge</td>
<td>Guidance on designing your workforce are set out in the Putting People First set of resources in the framework <em>Workforce planning for social care</em> published by the former Care Services Improvement Partnership (CSIP)</td>
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<td></td>
<td>Registering on the <em>Investors in People</em> website reveals a number of resources that are useful whether or not your organisation is seeking IiP accreditation</td>
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<td></td>
<td><em>The Principles of Workforce Redesign</em> – key principles and practice guidance on how to successfully change the way people work</td>
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<tr>
<td>Build on this by ensuring additional expertise exists within the organisation – both at a senior level to oversee quality and interventions, at the front line level for day to day practice, and include those receiving support so that they are enabled to support themselves.</td>
<td>Establish a core training programme, using external trainers if needed, to ensure key staff are aware of and possess the skills and competencies needed</td>
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<tr>
<td>Skill in working alongside people from other services such as a specialist community team that covers the ‘group’ of people being supported.</td>
<td>Employ and/or develop Behaviour Support Advisors, take a multi-agency approach to ensure cross fertilisation of skills and expertise</td>
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<td>Set up mentoring or ‘buddying schemes’ for new members of staff with more experienced colleagues as part of the induction process. This can be done immediately with minimal outlay and utilises the more subtle skills of your experienced team members</td>
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<td>Consider the use of coaching for individuals that need specific skills. This may involve the use of external coaches or training staff to be coaches themselves.</td>
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2.3 Recruiting the right staff

What policy and evidence propose
Clearly, it is vital that the right staff are recruited to support people who challenge services. Personalisation clearly indicates that people should have choice and control over who the staff are that support them. There are a range of approaches than can help this. This does not just apply to permanent staff, but also to temporary staff, where there is clear evidence of the negative effect on quality that can arise from using agency staff that are not known to the people they support.

This guidance encourages employers to be flexible, offering a range of options to enable staff to develop the ability to deal with people who challenge effectively in any scenario.

There are also some practices that should be put into place for every recruitment round, including the use of agency staff.

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<tr>
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<tr>
<td>Develop tailored person specifications for individual people – seeking to match their interests to those of the staff recruited to support them.</td>
<td>Challenging Behaviour National Strategy Group Pamphlet for Commissioners: services for adults with learning disabilities who display challenging behaviour; well matched and skilled staff</td>
</tr>
<tr>
<td>Involve people that will be supported, and their families in the recruitment of staff that will work with them.</td>
<td>National Council for Voluntary Organisations Workforce Development Good employment Practice case study: recruitment</td>
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<tr>
<td>Look beyond qualifications and consider personal qualities.</td>
<td>Use role specific personality tools to identify the right people, or develop teamwork tests that can be given at interview stage to demonstrate candidates’ values. Employers consulted noted that ‘benevolent’, ‘introverted’ people sometimes made the best support workers, however it should be borne in mind that a person may need different personality ‘types’ to provide holistic support workers.</td>
</tr>
</tbody>
</table>
**Ideas and resources to help make this happen**

| Have rigorous, but flexible approaches to recruitment: | Challenging Behaviour National Strategy Group *Pamphlet for Commissioners: services for adults with learning disabilities who display challenging behaviour: well matched and skilled staff*  
Advertise in diverse media - for disabled and ethnic minority staff:  
www.disabledworkers.org.uk  
The Voice www.voice-online.co.uk  
Use a competency approach to core skills and interviews-assessing people on their past behaviour rather than how they think they might respond in the future.  
Finders Keepers, the adult social care recruitment and retention toolkit |
| --- | --- |
| - Offer trials and/or assessment prior to appointment.  
- Aim for diversity – reach more people of different ages and ethnicities, and both genders.  
- Discuss ‘behaviour that challenges’ and its role as communicating during process to establish the nature of the work early on.  
- Involve people being supported and their families and carers in the entire recruitment cycle, in meaningful ways that they are comfortable with e.g. writing job descriptions, sitting on interview panels. | **Be clear with applicants at selection stage about the person centred culture of your organisation. Test the extent to which applicants understand the concept and are able to ‘live it’.**  
**Ensure effective induction that enables people to realise from the outset what the work entails and if it is for them.**  
**Ensure that safeguarding and whistleblowing policies and channels are understood and available to people right from the start.** |
| **Helen Sanderson Associates** *Person Centred Thinking and Planning* guidance | The [Chartered Institute for Personnel Development](https://www.cipd.co.uk/) provides guidance on developing inductions.  
Use Skills for Care’s [Common Induction Standards](https://www.skillsforcare.org.uk/) and [Management Induction Standards](https://www.skillsforcare.org.uk/)  
CQC guidance *Whistleblowing: Guidance for providers registered with the Care Quality Commission* |
2.4 **Effective support to staff and so ensure good retention levels**

Continuity of good staff in the life of the person they support is known to be an important indicator of a person’s likely satisfaction with a service. The loss of important relationships with staff can and does create tension in a person’s life that can be detrimental to their wellbeing. Whilst many advocate staff rotation as good practice for supporting some groups, consistency is needed for people who challenge, and so this may not be the best approach to take. Concurrently, organisations need to recognise the need for robust systems to prevent and spot abuse. Also, bear in mind that some members of staff may need a break to work elsewhere if they are at risk of burnout. These issues should all be aspects of staff supervision.

From the organisation’s perspective, having staff leave is a costly and disruptive occurrence – so it is in everyone’s interests to promote appropriate staff retention. However, there are also benefits from enabling ‘new blood’ to enter organisations. This helps to challenge and question existing work practices that may have become stale – and can also be an important safeguard against abusive cultures developing.

**Ideas and resources to help make this happen**

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<tr>
<td>You should have clear work/life balance policies for all staff, throughout the organisation.</td>
<td>Managers to lead by example, and encourage their teams to set clear work boundaries to avoid staff burnout and maintain efficiency and high quality. Staff should feel free to speak to their line manager if they feel they are unable to manage their allocated tasks. Managers should seek to reprioritise work or support the employee to achieve the tasks where possible.</td>
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<td>Provide clear management lines and clarity about responsibilities.</td>
<td>Provide guidance that staff can refer to, with effective supervision and appraisal to ensure clarity and feedback</td>
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<td>Keep records of retention rates and see poor retention in individual teams as an indicator of a problem needing to be addressed.</td>
<td>Use exit interviews to gather information and set up a system for taking learning forward, particularly if there is a high staff turnover</td>
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<td>Set up robust internal systems for feedback to staff and updates to policies and procedures.</td>
<td>Effective supervision, appraisal, and use of in house media such as intranet and newsletters. Good quality debriefing is important as part of a culture of reflection.</td>
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<td>Provide shadowing, buddying and mentoring opportunities for staff, along with contacts and sources of support with the direct staff team. Managers should demonstrate good practice by taking part in mentoring and coaching new members of staff.</td>
<td>Assign buddies and mentors at induction. For accredited learning on setting up coaching and mentoring schemes see BILD website <a href="http://www.bild.org.uk/our-services/pias/pias-organisations/">http://www.bild.org.uk/our-services/pias/pias-organisations/</a></td>
</tr>
<tr>
<td>Work with each employee on what support they need at work. Also consider their resilience. What factors of support do they have which will help them deal with difficult situations more readily.</td>
<td>The American Psychological Society (APA) ten factors on resilience provide key actions that employees can use to improve resilience at work. Use Practice Supervision to promote emotional wellbeing and improve practice, by increasing understanding of what is happening in relationships and behaviour and why these things are happening. <strong>Work smart, work safe</strong>, guidance on combating violence against staff. <strong>Health and Safety Executive Management Standards Indicator Tool</strong> focused on improving wellbeing in the workplace through its work related stress standards analysis.</td>
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2.5 Develop a culture that focuses on people’s assets and life outcomes

What policy and evidence say
Policy is clear that people who are labelled as ‘challenging’ have the same rights to life and positive outcomes as everyone else. There is a risk that services will consider the prevention or avoidance of behaviour that challenges as the definition of success, and not aim for real success such as people being supported to maintain or develop their relationships, their housing status, their job or their life goals. Not recognising the assets that people have in their life and how they can continue to contribute to their local communities is one of the greatest failings of services.

If organisations retain a clear focus on outcomes and use this evidence to inform staff of the impact of their work, it can create a highly positive feedback loop that encourages renewed staff investment in the success of the services they work in.

Ideas and resources to help make this happen

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<td>Develop and use a range of tools and approaches that can help staff to focus on life outcomes for people and use the resultant data as staff feedback.</td>
<td>NDTi’s <a href="#">Social Inclusion Training Pack</a> is a suite of tools and approaches that staff teams and organisations can use to help achieve better outcomes for people they support with a focus on community inclusion.</td>
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<td>Asset Based Community Development (ABCD) can act as a useful resource that enables staff to look at the key strengths i.e. assets that individuals can bring to enable positive outcomes. The <a href="#">Asset Based Community Development Institute</a> at Northwestern University, USA has a range of resources and mapping tools.</td>
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<td><a href="#">Empowering Communities: community skills development and neighbourhood workforce planning</a>. An evaluation of Skills for Care’s early adopter programme.</td>
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<td></td>
<td>The NDTi <a href="#">Inclusion Web</a> is a tool that can be used across client groups to identify the areas of connection across people’s lives.</td>
</tr>
</tbody>
</table>
Work with clinical teams and others to develop outcome based ways of measuring changes in behaviour over time – linked to staff actions such as Active Support.

Challenging Behaviour: a unified approach sets out ways in which health and social care teams can work together towards positive outcomes.

The Active Support Handbook from the Association for Real Change is a useful tool covering adult social care and a range of groups, including people whose behaviour challenges.

Encourage commissioners to request and constructively and creatively use information on people’s outcomes as a key part of contract monitoring.

The Adult Social Care Outcomes Framework 2012-13 offers commissioner guidance. Domain 4 around safeguarding is of particular importance for those supporting people who challenge services.

Positive outcomes for people to express themselves in different ways. Whilst some people will want to develop new opportunities, for others (e.g. some people with dementia) skills may be lost over time, but the person should still be empowered to shape their own support.

See Adult Social Care Outcomes Framework above.

MacIntyre with Community Catalysts and the Groundswell Partnership: MacIntyre People+ a partnership programme to emphasise the assets of all individuals and their contributions.

| 2.6 Promote choice and control |

What policy and evidence say

A person not being listened to is one of a number of starting points to behaviour that challenges. Embedding a culture of promoting the ‘voice’ of people, their families and carers and maximising their control over their life and supports, are thus central to effective organisational practice. A holistic, personalised approach to supporting people that challenge involves; providing a space for the individual’s voice and preferences to be heard; giving access to independent information, advice and advocacy to support choice and control; and to ensure that those choices are well informed, and involving families and other supporters.

Staff also need an understanding of a person’s preferred communication approach. There are various tools available, for example the Makaton tool which is often used for people with autism.
In terms of regulation, the Care Quality Commission’s *Essential Standards of Quality* sets out that a person’s choice should not be diluted nor their voices ignored. Information should be available to allow individuals or their families to make informed choices, and all support should be provided in line with the Human Rights Act 1998, Mental Health Act 1983, Mental Capacity Act 2005, and the Deprivation of Liberty Safeguards.

**Mental Capacity Act 2005**

The Mental Capacity Act 2005 is unique in that it covers the two main agendas of independence and safeguarding. It assumes that a person has the capacity to make their own decisions unless demonstrated otherwise, yet safeguards them the consequences of a decision that they may be making without capacity by providing a framework that enables others to make decisions for them. At the same time, the Act ensures that decisions taken by a third party are done so in the best interests of the individual concerned. The Mental Capacity Act Deprivation of Liberty Safeguards (formerly known as the Bournewood Safeguards) were introduced into the Mental Capacity Act 2005 through the Mental Health Act 2007 and came into force on 1 April 2009. The safeguards are there to protect anyone over 18 living in a residential care setting or in hospital being inappropriately deprived of their liberty, unless this is in their best interests and ensures their safety and security.

In terms of working with people who challenge services, it is key to ensure staff are confident of their role in supporting the person and maintaining a positive relationship with that person and their family, as well as Independent Mental Capacity Advocates (IMCA).

Guidance for adult social care staff can be found in the Office of the Public Guardian guidance *Making decisions: a guide for people working in health and social care – the Mental Capacity Act.*


**Ideas and resources to help make this happen**

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<tr>
<th>Idea to action</th>
<th>Resources and ideas</th>
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<tr>
<td>Co-production: Ensure co-production is at the heart of how the organisation operates. 'Do with', rather than 'do to' so that staff understand this is a core element of how they behave at work.</td>
<td>Department of Health’s <em>Don’t just do it – co-produce and live it!</em> (a guide to co-production for older people and organisations, transferable across ‘client’ groups).</td>
</tr>
<tr>
<td>Review organisational practices to maximise how a person’s voice is central to decision making – both about their own life but also wider organisational actions.</td>
<td>See Department of Health guidance and Ministry of Justice code of practice above.</td>
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<td>For people who cannot use words and/or cannot read and write, make information available by using easy read options and other communication tools.</td>
<td>See the Mencap guide to <em>Communicating with people with profound and multiple learning disabilities</em>.</td>
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</table>
| Draw up decision making agreements, including advance directives, with individuals, families and supporters which recognises the individual’s right to make decisions for which they have capacity and be supported and included even if they lack capacity. | A best practice approach to Decision Making Agreements can be found in: Creating Person-centred organisations (Stirk and Sanderson 2012) 
Good practice for advance care planning in care homes for older people can be found in Butterworth et al (2008) 
The NHS National End of Life Care Programme guidance *Capacity, care planning and advance care planning in life limiting illness* provides guidance for staff working in health and social care, particularly those supporting people with dementia. |
| Be aware of the ways that self neglect and self-harm can be examples of behaviours that challenge and need attention, possibly through consideration of mental capacity and advance decisions. | NDTi’s Self-Care checklist sets out clear guidance on establishing the cause of self neglect, the legal context (including mental capacity and Deprivation of Liberty Safeguards), and provides assessment tools and case studies to help people support those who neglect themselves effectively. |
| Consider the ways in which physical interventions are used for different client groups (see more on this subject in section 3.6) | Some useful papers have been developed to provide guidance to people supporting those with learning disabilities (Paley and Brooke 2006), and older people (Counsel and Care 2002). |
2.7 Partnerships that use one another’s expertise

What policy and evidence say
The best outcomes are achieved by bringing together a range of different types of knowledge and expertise to support people and their families – no single organisation possesses all the answers and should not have to work alone. Across all client groups, there is an expectation of integrated working – with social care providers making use of expertise from friends and families, from people using services, healthcare professionals, social workers/care managers and others. In addition, many important resources are available from outside the traditional health and social care sectors and so social care providers will also need to possess those wider relationships.

Ideas and resources to help make this happen

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<tr>
<td>Ensure positive working relationships exist with specialist NHS teams, and use their expertise in appropriate ways.</td>
<td>Work with multidisciplinary teams in your locality, offer integrated training across traditional health and social care boundaries.</td>
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<tr>
<td>Develop an outward looking approach to community inclusion by developing links with mainstream resources and support people to use those resources effectively.</td>
<td>NDTi’s <em>Inclusion Programme</em> offers tips on embedding community inclusion into your approach and working with external partners such as health, housing, and wider community support organisations.</td>
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<tr>
<td>For an individual service, or one bought by the person using an individual budget, there is a likelihood that the individual will be receiving support from a number of different staff or providers. Planning and agreeing both approaches to support and outcomes being aimed for should be coordinated with all involved.</td>
<td>Circles of Support can be informal but can also be encouraged into an organisational approach. The guidance <em>Circles of Support and Personalisation</em> looks at ways in which Circles can be developed at scale.</td>
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</table>
“Putting my disability second and seeing me as a human being first.”

“[Person centred approaches] ... helping people to make positive choices, promoting responsibility and accountability”

(Raise Mental Health)
Section three: building workforce skills and knowledge

In developing this guide, we have consulted widely to help establish a framework for the key sets of skills that staff need to have in order to work effectively with people who challenge services. This has led to the development of the following broad headings. Against each, we outline why this has been identified as an important staff training and development need, and then give examples that people have proposed of good resources that will help develop staff skills in these areas.

3.1 Understanding the nature of behaviour that challenges

Why this is important
Understanding behaviour that challenges, why it occurs and the evidence of how to support people effectively is an essential starting point for all staff. Misunderstandings about the social model of disability can result in staff and organisations not using evidence based approaches. There is some evidence that people are best supported in ordinary community settings, pursuing individualised and personalised approaches. Studies by Bhaumik et al (2009) and Golding et al (2005) find that community based support does result in some reduction in behaviour that challenges, but the Institute for Public Care review of the evidence shows that this is limited. However, this review only considered literature later than a date after which much of the evidence from the learning disability sector in particular was published. Services that group people who challenge together in the same setting are not generally as good compared to services that are built around the individual. It is important to bear in mind the essential point that there is more that is the same between individuals whose behaviour challenges and those that do not. Focusing on the commonalities helps to identify what we are aiming to achieve before focusing on the differences.

Ultimately, employers need to ensure they are using approaches such as Positive Behaviour Support (PBS) as part and parcel of everyday activity throughout the organisation, at all levels. The benefits of PBS were highly evidenced in the IPC evidence review, with most studies indicating that PBS training improves staff performance and behaviour, with others finding more mixed outcomes for people receiving PBS. There is a lack of evidence to support more punitive staff practices such as physical or chemical restraint on people whose behaviour challenges, including people with dementia.
## What organisations can do

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<tr>
<th>Idea to act on</th>
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| **Ensure that all people in the organisation, in particular leaders, managers and those who are planning services and negotiating contracts, are aware of the evidence base about how to design services for people who challenge.** | *The Mansell report* provides a strong evidence and practice base  
*Applied Behaviour Analysis – the La Vignia Framework*  
The IPC Resource Mapping report (November 2012) gives a wide range of available solutions |
| **Put in place detailed learning activities and awareness for all staff who might be working with people who challenge, that covers the basics of the evidence about what works and how to support people who challenge.** | Positive behaviour support training  
**QCF Units:**  
- HCF 3045 Promoting Positive Behaviour Level 3  
- HSC 3065 Implement the positive behaviour support model level 4  
- HSC 3058 Enable individuals with behavioural difficulties to develop strategies to change their behaviour level 3  
- 032 Lead positive behavioural support level 7  
E-learning courses in areas such as equality and diversity.  
Specific client group training such as dementia awareness.: Skills for Care has published its *Common Core Principles for Supporting People with Dementia*  
Sensory deprivation awareness: the SeeAbility online resource on eye care for people with multiple disabilities provides a wide range of information and advice. Improving Health and Lives (IHaL) has developed *A guide to making reasonable adjustments* to eye care services for people with learning disabilities. |
The Tizard Centre run a range of **short courses** which includes positive behaviour support and active support.

| Put in place training and development for individuals receiving support. | Raise Mental Health offer **training** for both individuals and organisations run by trainers with lived experience. |
| Work with user led organisations that employ trainers with lived experience. | Integrating various training followed up by coaching, observations (filmed if possible) and reflection is one way of doing this. |
| Ongoing staff development of complex skills such as supporting people who challenge is best achieved through a variety of learning pathways. | |
| Ensure all staff are trained to be alert to the impact that physical illness and/or pain can have on behaviour so that potential indications of illness or injury are noticed and appropriately responded to. | **NHS Choices** provides good sources of reliable health information for all groups. |
| Staff should be clear on their responsibilities to seek health/medical advice and on recording and reporting potential symptoms. | Improving Health and Lives (IHaL), a three year project aimed at addressing health inequalities for people with learning disabilities, have a range of **good practice publications** aimed at commissioners and providers of healthcare. |

### 3.2 Understanding positive strategies to support and address behaviour that challenges

**Why this is important**

Whilst the social model of disability emphasises the importance of starting with the person, their needs and their wishes, it also recognises the importance of using specialist expertise and techniques to intervene and support a person in difficult times. Staff therefore need both proactive and reactive strategies to manage the support of people who challenge services. They also need to understand a range of positive approaches that are evidenced to be effective, and have those at their disposal when designing and delivering personalised support. Understanding the unique nature of the behaviour and life wishes of each individual is a central starting point for effective support.
## What organisations can do

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| Ensure awareness amongst both managerial and staff teams of core tools and techniques of how to support people who challenge | The Tizard Centre at the University of Kent has a dedicated [online resource on active support](#)  
Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists.  
[Challenging Behaviour: a unified approach](#) |
| Ensure that a core of staff receive in-depth training on how to design services and supports for people who challenge – and so are a resource to the wider organisation. | Tizard Centre [training for trainers](#)  
CITRUS training (Creative Intervention Training for responding to Untoward Situations)  
Non Violent Crisis Intervention training |
| Ensure that each person who may challenge services has their own particular challenges understood as part of their person centred planning (see below). The support plan for that individual should be available both in summary and as a more detailed behaviour support plan. Ensure appropriate additional, evidence based interventions are planned for them. | Use of individual support guidelines for each person that may challenge  
Individual communication profiles  
Use of cue cards and pictorial communications systems  
Communication charts  
The Social Care Institute for Excellence (SCIE) also provide [resources and links](#) to training for Positive Behaviour Support as well as the British Institute for Learning Disabilities (BILD), who provide a range of service around positive behaviour support, including training, events and qualifications. BILD also run the [Physical Intervention Scheme](#) |
3.3 Using person centred approaches

Why this is important
Both policy and the evidence base are clear that effective services start by listening to the individual, their wishes and aspirations, and planning and designing services around that (Robertson et al 2005). Effective person centred planning is the best way of achieving this – and thus has to remain at the heart of staff practice – no matter how great the challenges that a person presents. Person centred planning works best for people who challenge services when an organisation listens to and empowers their own staff. Understanding the unique nature of the behaviour and life wishes of each individual is a central starting point for effective support.

What organisations can do

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<tr>
<td>Ensure wide staff awareness of the principles of person centred working.</td>
<td>Richard Williams and Helen Sanderson <a href="https://www.personalisation.gov.uk/learning/about-person-centred-organisations">What are we learning about person centred organisations?</a></td>
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<td>Department of Health Personalisation through Person Centred Planning Putting People First guidance</td>
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<td>Educating staff in a range of different approaches to person centred working, so that they can use the one that works best for each individual – rather than apply one approach for everyone.</td>
<td>Essential Lifestyle Planning – <a href="https://www.personalisation.gov.uk/learning/about-person-centred-organisations">Increasing Person Centred Thinking</a> by Amado and McBride (2001) of the University of Minnesota provides information on using ELP</td>
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<td>Training resources for PATH originated by Jack Pearpoint in the USA can be found here on <a href="https://www.personalisation.gov.uk/learning/about-person-centred-organisations">here</a></td>
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<td>A manual on the use of SPELL (Structure, Positive, Empathy, Low Arousal, Links) has been produced by the Tizard Centre at University of Kent. Further details on this resource can be found <a href="https://www.personalisation.gov.uk/learning/about-person-centred-organisations">here</a></td>
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3.4 An appropriate ‘personal style’ of staff

**Why this is important**

Supporting people who challenge can often be a difficult thing to do and can require personal particular styles and approaches by staff. Whilst the ability to clearly follow plans and structured interventions is important, so too is having a range of personal styles that experience shows includes being creative, facilitative, communicative, being self aware, resilient, empathetic, striving for excellence and demonstrating leadership.

**What organisations can do**

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<tr>
<td>Effective leaders in all settings and at all levels that have the ability to create teams who have a range of personal styles to successfully support people who challenge to live fulfilling lives.</td>
<td>The <a href="http://www.clickstart.org.uk/page/view/cat/3546">Leadership Qualities Framework</a> from the National Skills Academy for Social Care sets out how employers can work with staff at all levels to develop the specific qualities needed for successful leadership and ultimately the best support for the people they are working with.</td>
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<td>Supportive leaders that have the ability to coach team members who deal with behaviour that challenges.</td>
<td><a href="http://www.clickstart.org.uk/page/view/cat/3546">Great Interactions</a> facilitation skills module.</td>
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<td>Confident leaders who are effective at providing honest and clear feedback and encourage team members to reflect on practice.</td>
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Encourage the use of person centred approaches not only for people who use services, but for workers and family carers and as a technique for future planning of services or to resolve difficulties.

The McGill Action Planning System (MAPS) – a tool designed to help you work out how to move into the future effectively and creatively. The MAP helps you to collect information about you and your family.

[http://www.clickstart.org.uk/page/view/cat/3546](http://www.clickstart.org.uk/page/view/cat/3546) is an accessible online person centred planning tool designed for use by individuals with support needs.
A core competency framework could be pulled together that includes areas with specific relevance to people with complex communication support needs. This is then developed in line with personalisation requirements to take account of individual preferences.

Skills for Care’s QCF Units DEM 205, DEM 210 and DEM308 focus on communication needs of people with dementia, and HSS/CH155 on alternative and augmentative communication systems.

### 3.5 Communication skills

**Why this is important**
As previously noted, the most effective starting point for understanding behaviour that challenges is to acknowledge that it is functional – i.e. people’s behaviour is a way of communicating something – whether that be that they are unhappy, in pain, bored, are not being listened to, and so on. Therefore, staff need to have access to a range of approaches to communication that will enable the person’s voice, and the voices of their families and carers, to be clearly heard (whether they are able to speak or not) and staff respond accordingly.

**What organisations can do**

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<tr>
<td>The organisation should have access to a range of different communication techniques such as cue cards/pictorial communication systems, communication grid/chart, solutions circles</td>
<td>Active listening – see SCIE’s <a href="https://www.dementia.org.uk/gateway-case-study">Dementia Gateway case study</a> on how active listening can be successfully used to support people with dementia.</td>
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<tr>
<td>This should be a core part of staff training for working with people who challenge. Every person who challenges, including those with obvious verbal skills, should have a communication plan as part of their person centred plan that focuses on how the person communicates, including non-verbal cues, and how staff can develop the range of communication they use to interact with them. All analysis of behaviour that challenges should focus on what is being communicated or what is being achieved by the behaviour. Interventions should seek to address that need pro actively.</td>
<td>The Foundation for People with Learning Disabilities <a href="http://www.foundationfpld.org.uk/communicationforpersoncentredplanning">Communication for Person Centred Planning</a> guidance gives advice on the use of a range of communication aids such as Communication passports. Intensive Interaction (Caldwell, Hewitt) <a href="http://www.intensiveinteraction.co.uk">http://www.intensiveinteraction.co.uk</a> <a href="http://www.greatinteractions.org.uk">Great Interactions</a> programme from MacIntyre <a href="http://www.wrapinternational.com">Wellness Recovery Action Plan (WRAP)</a> is a powerful communication tool that can benefit staff as well as individuals.</td>
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Good support and communication will include both an understanding of the functional nature of the behaviour the person shows, but also essential is communication which engenders emotional engagement. Whilst intensive interaction has been developed with people with learning disabilities and autism, it is increasingly useful with those with dementia or other issues which effects their interactions and understanding of those around them.


For other approaches to creative communication: Goldbart and Caton (2010) Communication with the people with the most complex needs: what works and why this is essential.

3.6 Non-aversive interventions

Why this is important
Aversive behaviour intervention can be described as punishing an individual in order to suppress the behaviour that challenges. Over the past two decades the emphasis has been on intervening before the challenge occurs using ‘non-aversive interventions’. Such interventions are essentially how positive behaviour support can be described (McDonnell 2010).

Sometimes, people whose behaviour challenges will act in ways that are a danger to either themselves or to other people – and staff may need to intervene to reduce that risk. This needs to be done in a way that respects their rights and their physical safety – and the safety of others - and this should always be done in ways that are non-aversive. All staff that may work with people who challenge in ways that result in such behaviour need to be trained in appropriate non-aversive techniques – and understand the limits of when and where they should use such approaches.

What organisations can do

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<tr>
<td>Establish an expert group within the organisation who are highly knowledgeable about the use of non-aversive techniques and use them to support staff and quality assure interventions that are used. This should be done alongside use of guidance and continual learning and support for members of the expert group.</td>
<td>Make use of in-house expertise as a resource. Department of Health guidance for Physical Restrictive Interventions Reducing the use of restrictive practices with people who have intellectual disabilities. This book takes a practical approach that describes whole organisational approach to reducing the use of physical interventions.</td>
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</table>
Have a training programme, bringing in external expertise as needed, to train staff who might work with people who challenge in a range of non-aversive interventions and where and when to use them.

A list of training organisations that have been approved by the BILD Physical Intervention Scheme can be found here Positive Behaviour Support training.

Consider the impact of self harm and develop ways to positively support those individuals with a view to minimising self-injurious behaviour.

Harm minimisation after repeated self-harm: development of a trust handbook

National Self-harm Network

Working Towards a Harm Minimisation Policy for Self Injury presentation by Duperouzel and Fish.

3.7 Positive work with families

Why this is important
The person’s family is often the most important, long-standing connection in their life. Family carers are true experts and need to be included as equal partners in understanding and working with behaviours that challenge. By working with families, organisations can identify an individual’s preferences and learn how best to provide active support that works for that individual. The ability of staff to work positively and inclusively with families and carers is ultimately a core staff skill.

What organisations can do

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<tr>
<td>Ensure that all staff receive training and support to work with families and that organisational policies and procedures recognise the importance of this. Encourage families themselves to help provide any training and help write relevant policies.</td>
<td>The Challenging Behaviour Foundation offers training in working with families, and work closely with parents and families themselves.</td>
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<td></td>
<td>Skills for Care provide knowledge sets, including guidance on working in partnership with family carers. Available on <a href="http://www.skillsforcare.org.uk">www.skillsforcare.org.uk</a></td>
</tr>
</tbody>
</table>
Ensure that the families of people the organisation supports are aware of the evidence and good practice in what works and are enabled to question and challenge how the service is being delivered.

The Social Care Institute for Excellence (SCIE) has produced a series of resources for families of people who challenge. *Challenging Behaviour: guide for family carers* provides guidance for families of adults with behaviour that challenges.

| Involve families from the outset in the design delivery and review of services, as well as in the provision of training. |
| NDTi’s Better Lives families and personalisation programme *outcomes summary* project was run for adults with learning disabilities and their families, the learning is transferable across groups. |
| *Stronger partnerships for better outcomes protocol* - a set of principles and good practice behaviours developed by Think Local, Act Personal (TLAP). |

“Person centred support involves me, rather than being directed or forced onto me.”

“Tell me and I forget. Teach me and I remember. Involve me and I learn”

(Raise Mental Health)
Section four: using learning tools and resources

How you identify the best training solutions available for your teams

There is a wide range of training and learning products on the market, and as employers working with limited resources, you need to be certain that the learning solutions you are using are the right ones for both your teams, and the people they are supporting.

4.1 Using internal coaches and mentors

Many organisations make use of experienced staff that are familiar with and use person centred approaches to support newer members that are undergoing induction, or who are in their first role working with people who challenge. Training itself may be useful alongside mentoring/buddying schemes and the specific art of coaching, but using in-house resources may provide an innovative, effective, and immediate solution to ensuring readiness of teams. Specialist development staff whose role it is to train, coach and develop staff in a specialist area across a wider organisation, or group of organisations can also be also exceptionally effective. Alongside this, organisations need to continually refresh their understanding of good practice to ensure they do not become over focused internally.

4.2 What to look for when selecting a learning solution

Selecting a trainer or learning solution (e.g. webinar, masterclass, buddy scheme, mentoring, coaching) should be undertaken as a self-audit, by assessing the responses to the questions below.

- Are you clear about the outcomes you need the learning to achieve?
- If using a training company or individual trainer, is it/are they accredited?
- Does the learning solution state how it will encourage delegates to measure outcomes?
- Who is being trained i.e. what level?
- How will you know that the outcomes have been achieved?
- Will the solution match the learning style of the individual(s) undergoing the learning?

The BILD Code of Practice provides independent and comprehensive guidance to those commissioning training in relation to positive behaviour support and physical interventions.
4.3 Measuring training outcomes

The effectiveness of training can be measured by way of independent evaluation, comparing staff confidence before and after the training, in supervision and appraisal. Feedback from people that they support and their families is of course central to ascertaining the effectiveness of training. People who challenge need to achieve positive outcomes as a result of improvement in practice as a direct result of learning, be that through traditional training, or mentoring and coaching.
Section five: specialist approaches

Additional considerations for working with different people

Organisations providing support for people who challenge services have much in common. However, we recognise that in some cases there are specific approaches that need to be taken, for example when dealing with a frail older person that challenges services, compared to an individual that has more physical strength. This section describes these specific approaches, and further resources can be found in Appendix One.

5.1 Learning disability

Specialists working with people with learning disabilities will find a wide range of resources about people who challenge, with recent policy and guidance, most notably the findings of the review of services following the closure of the Winterbourne View specialist hospital for people with autism and learning disabilities (see page 3).

The government’s three-year strategy, Valuing People Now (2009), is the key policy around learning disability good practice. Chapter 2 on personalisation sets out the areas that commissioners and providers need to get right in order to provide a truly person centred approach that gives individuals choice and control. For example, providers need to set up services around people, rather than groups, and enabling more individuals to commission their own support.

The late Professor Jim Mansell’s report Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs was aimed at commissioners and updated in 2007. Published by the Department of Health on their website, the report sets out the foundation of person centred care by describing the ‘characteristics of exemplary services’ as:

- commitment
- individualisation
- effective service characteristics
- good management
- investment in relationship and networking

These features are enhanced in Mansell’s later report, Raising our sights: service for adults with profound intellectual and multiple disabilities, where Mansell highlights the increasing need to extend good practice for the current number of adults that are currently living with a profound learning disability (16,000 in England alone), and a projection of 22,000 by 2026.
Mansell made a number of recommendations to government towards improving, and identifies elements of a good service as:

- individual and person centred
- involving families and treating them as experts
- focusing on quality of staff relationships with the person
- providing sustained packages of care.

The Challenging Behaviour National Strategy Group has established a charter that organisations are asked to sign up to – committing to implement evidence based services for people who challenge. The strategy group has also published a range of guides, including one aimed at commissioners of adult services *Pamphlet for Commissioners: services for adults with learning disabilities who display challenging behaviour: well matched and skilled staff*.

### 5.2 Autism

People on the autistic spectrum are often categorised together with people with learning disabilities. However it ought to be remembered that autism is a discrete condition, and that there are individuals with autism that also have other conditions such as mental health problems and learning disabilities.

Looking at the ways in which we support people with autism who may challenge, it is important to consider that there are specific sensory issues that can trigger behaviour that challenges due to stress. These sensory issues can also be associated with restraint (see section on Non-aversive interventions and guidance on using restraint above).

NDTi’s *Reasonably Adjusted* programme looked at the mental health support for people with autism and learning disabilities. The resource offers guidance on communication styles such as using a quiet voice, using clear, literal statements, not demanding eye contact, avoiding an angry or aggressive tone of voice, and giving time for the person being supported to establish trust.

Phoebe Caldwell prefers the term ‘distressed’ rather than ‘challenging’ behaviour, and her model of *Intensive Interaction* uses imitation to give people with autism a reference point outside of themselves and enables positive interaction. Using intensive interaction helps override hypersensitivity to sounds that may produce distressed behaviour.
Developing person centred approaches for people with autism (Sanderson and Lunt 2009) by ensuring the right individuals are being supported by the right workers is related to a number of communication skills, but shared common interests are also key and should be kept high on the selection criteria when recruiting and matching. Skills for Care’s Autism Skills and Knowledge List helps employers to enhance staff awareness, with clear guidance on achieving the best outcomes for people with autism.

5.3 Mental health

Behaviour that challenges is sometimes associated with those with mental health problems when they are unwell. The government has committed to addressing stigma around mental health by signing up to the Time to Change campaign, and has published a national framework for mental health and wellbeing.

The cross government strategy No health without mental health sets out six priorities, one of which is related to ‘a positive experience of care and support’. This includes experiencing choice and control over an individual’s own life, and access to the latest interventions that are available.

The Mansell report gives guidance on working with individuals with mental health problems whose behaviour challenges. Other useful resources can be found in the National Institute for Health and Clinical Excellence (NICE) guidance on mental health and behavioural conditions – these are split into individual conditions including self harm, violence and dementia.

The Royal College of Nursing (RCN) mental health guidance page provides links to a wide range of guidance for those supporting people with mental health problems. The Department of Health has also developed a mental health policy implementation guide, which is a learning and development toolkit for the whole of the mental health workforce across both health and social care.

Further Department of Health guidance can be found in the Best practice in managing risk: principles and guidance for best practice in the assessment and management of risk to self and others in mental health services.

The National Personality Disorder Programme provides a range of guidance and insight for staff supporting people who challenge that have mental health and personality conditions.

Employment is often a challenge for people with mental health problems, and employers supporting people who challenge equally need to illustrate that they are positive about employing people with mental health problems to support others. Signing up to the Mindful Employer Charter sets an organisation out as being positive about mental health
Recovery is a personal and unique process, everyone with a mental health problem develops his or her own definition of recovery. However, people can and do recovery fully. For example, 15% of people who have experienced full blown mania never experience another episode in their lifetime and for every five people diagnosed with schizophrenia, one will go on to make a full recovery within the first five years of their first psychotic episode (Raise Mental Health).

### 5.4 Older people

Older people, particularly those with dementia, have not traditionally been recognised as a group of people who challenge services. Anecdotal evidence suggests that this is because behaviour that challenges in older people is not perceived as such, and therefore responses to it may be inappropriate. Forms of restraint used such as locked doors, and medication (including the inappropriate use of anti-psychotics) may be seen as care and support rather than recognised as a deprivation of liberty and potentially abuse.

However, as the condition is set to become more prevalent with a prediction of 940,000 people with dementia in the UK by 2021, many of whom will be younger with early-onset dementia, it will be important for those working with older people to have the right skills and competencies in place.

The Prime Minister’s Challenge on Dementia, launched in March 2012 with a progress report in November 2012, sets out a range of commitments to addressing the condition, including improving the quality of dementia care. The document provides a policy backdrop that employers need to bear in mind when developing services and support for staff.

The skills and understanding required for supporting people with dementia are based on the same principles as for working with other groups: using person centred approaches is key, as well as keeping in mind that the behaviour is a result of the condition. Enabling people living with dementia to take part in meaningful activity can help reduce frustration that may lead to behaviour that challenges.

Detailed guidance on working with people with dementia can be found in Skills for Care’s Common Core Principles for Supporting People with Dementia: a guide to training the social care and health workforce. The guide includes a plan for training and development, which can be used alongside alternatives to training, such as highly experienced and skilled in-house mentors and coaches.

An interactive online tool, Care Fit for VIPs, provides information and advice for those managing residential care for people with dementia, and tackles ‘challenging behaviour as a form of communication’, with access to a range of tools and frameworks. The tool helps care homes to embed person centred approaches.
Progress for Providers offers a number of accessible assessment tools to assist providers for people with dementia to develop person centred services. The Quality of Interactions Schedule provides a way of observing interactions without participating and is used in residential settings including care homes for people with dementia. PIECE-dem, developed at the University of Worcester as part of the PANICOA project, provides an observational tool to highlight the perspectives of people living with advanced dementia.

People with enduring mental health problems who have reached 65 are another group that face considerable risk. Because mental health services tend to focus on people of working age, older people with mental health problems do not receive the same services once they reach pensionable age. Therefore it is important that people working with older people that challenge due to mental health problems understand the barriers that this group already face. Positive behaviour support can be applied to older people, provided any additional needs are taken into account.

5.5 Multiple conditions

A key area that has implications for the ways in which people who challenge will receive support is around multiple conditions. People born with disabilities are living far longer. For example, at the beginning of the last century a child with Down’s syndrome was not expected to survive beyond ten years. Today, life expectancy has increased to just over 50.

The Royal College of Psychiatrists guidance Dementia and People with Learning Disabilities suggests that by 2020 the number of people with a learning disability who are aged 65 and over is set to double. With regard to behaviour that challenges, the Royal College recommends the same support mechanisms as for other groups; comprehensive assessment that includes functional assessment and providing support in a person centred way in a positive behaviour support framework.

Employers will need to embed a dual diagnosis sensibility in their teams and work to build relationships with health partners to ensure a holistic approach to support. There are existing challenges in the non-disabled population around diagnosis, and this presents additional challenges for people with learning disabilities where the symptoms of dementia or mental health problem may be mistaken for behaviour associated with the disability.

The British Institute for Learning Disabilities (BILD) has a range of guidance, including Down’s syndrome and Dementia: a resource for carers and staff, which covers behaviours in detail.
Appendix one: useful contacts

**Anchor**
2nd Floor, 25 Bedford Street
London
WC2E 9ES
Large provider of housing and residential care for older people
[www.anchor.org.uk](http://www.anchor.org.uk) 0800 270 7061

**British Institute for Learning Disabilities (BILD)**
A membership organisation that aims for people with learning disabilities to be valued equally, participate fully in their communities and be treated with dignity and respect.
Campion House
Green Street
Kidderminster DY10 1JL
[www.bild.org.uk](http://www.bild.org.uk) 01562 723010

**British Psychological Society**
The representative body for psychology and psychologists in the UK.
St Andrews House
48 Princess Road East
Leicester
LE1 7DR
[www.bps.org.uk](http://www.bps.org.uk) 0116 254 9568

**Challenging Behaviour Foundation**
A charity that provides information and support to families and professionals caring for individuals with severe learning disabilities who are described as having challenging behaviour.
c/o The Old Courthouse
New Road Avenue
Chatham
Kent
ME4 6BE
[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) 01634 838739

**Chartered Institute for Personnel and Development**
The world’s largest Chartered HR and professional development body.
151 The Broadway
London
SW19 1JQ
[www.cipd.co.uk](http://www.cipd.co.uk) 020 8612 6202
City University, Royal Free Hampstead NHS Trust, Barnet and Chase Farm Hospitals NHS Trust, Age UK
Dignity in Care Project
http://www.staff.city.ac.uk/~jacky/dignity/resource.htm

Department of Health
The government body for health and social care.
Richmond House
79 Whitehall
London SW1A 2NS
www.dh.gov.uk 020 7210 4850

Helen Sanderson Associates
An international development, training and consultancy organisation.
34 Broomfield Road
Heaton Moor
Stockport
SK4 4ND
www.helensandersonassociates.co.uk 0161 442 8271

In Control
A national charity whose mission is to create a fairer society where everyone needing additional support has the right, responsibility and freedom to control that support.
Carillon House
Chapel Lane
Wythall
West Midlands
B47 6JX
www.in-control.org.uk 01564 821650

Investors in People
Specialise in transforming business performance through people.
UKCES, Sanctuary Buildings
20 Great Smith Street
London SW1P 3BT
www.investorsinpeople.co.uk 0300 303 3033
MacIntyre
A charity dedicated to providing the widest range of teaching and learning, support and care services to people with learning disabilities.
Leighton Road
Aylesbury
Buckinghamshire
HP22 4PA
www.macintyrecharity.org  01296 681274

Mindful Employer
Increasing awareness of mental health at work and supporting businesses in recruiting and retaining staff.
Workways
Second Floor
11-15 Dix’s Field
Exeter
EX1 1QA
www.mindfulemployer.net  01392 677064

National Council for Voluntary Organisations
The largest umbrella body for the voluntary and community sector in England.
Society Building
8 All Saints Street
London
N1 9RL
www.ncvo-vol.org.uk  020 7713 6161

National Development Team for Inclusion
A non-profit social change agency, concerned with promoting inclusion and equality for people who risk exclusion and who need support to lead a full life.
18a James Street West
Bath
BA1 2BT
www.ndti.org.uk  01225 789135

National Skills Academy for Social Care
A membership organisation created by social care employers to transform the quality of leadership, management, training, development, and commissioning.
85 Tottenham Court Road
London
W1T 4TQ
www.nsasocialcare.co.uk  020 7268 3082

1 from 4th June 2013, the address will be First Floor, 30/32 Westgate Buildings, Bath, BA1 1EF
Northwestern University  
633 Clark St Evanston  
IL 60208  
United States  
[www.northwestern.edu](http://www.northwestern.edu)  (312) 503 8649

Raise Mental Health  
A national mental health training and consultancy that is unique in that everyone employed has  
experience of mental illness  
1st floor  
108 Sinclair Drive  
Basingstoke  
RG21 6AD  
[www.raise.org.uk](http://www.raise.org.uk)  01256 476981

Real Life Options  
National non-profit organisation providing direct support for people with severe learning  
disabilities.  
David Wandless House  
A1 Business Park  
Knottingly Road  
Knottingly  
West Yorkshire  
WF11 0BL  
[www.reallifeoptions.org](http://www.reallifeoptions.org)  01977 781800

Royal College of Psychiatrists  
The professional body responsible for educating, training, setting and raising standards in  
psychiatry in the UK.  
17 Belgrave Square  
London SW1X 8PG  
[www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)  020 7235 2351

Royal College of Speech and Language Therapists  
The professional body for speech and language therapists in the UK; providing leadership and  
setting professional standards.  
2 White Hart Yard  
London  
SE1 1NX  
[www.rcslt.org](http://www.rcslt.org)  020 7378 1200
Social Care Institute for Excellence
An organisation that improves the lives of people who use care services by sharing knowledge about what works.
5th floor
Cockspur Street
London
SW1Y 5BH
www.scie.org.uk  020 7024 7650

Skills for Care
The employer-led authority on the training and development of people working in adult social care in England.
West Gate
5 Grace Street
Leeds LS1 2RP
www.skillsforcare.org.uk  0113 2451716

Tizard Centre at University of Kent
One of the leading UK academic groups working in learning disability and community care.
University of Kent
The Registry
Canterbury
Kent
CT2 7NZ
http://www.kent.ac.uk/tizard/  01227 764000

University of Minnesota
Institute on Community Integration
100 Church Street
Southeast Minneapolis,
MN 55455,
United States
www.umn.edu/twincities/  (612) 625-5000

University of Worcester
Association for Dementia Studies
Riverside Centre
113 Hylton Road
Worcester.
WR2 5JN
www.worcester.ac.uk  01905 855000
Appendix two: references


