JRF
JOSEPH
ROWNTREE
FOUNDATION

REPORT

LEARNING FOR CARE HOMES FROM ALTERNATIVE RESIDENTIAL CARE SETTINGS

Liz Burtney, Davina Figgett, Deirdre Fullerton, Paul Buchanan,
Karen Stevens, Madeline Cooper-Ueki

What can providers of residential care for older people learn about improving quality of care from other sectors?

This review explores the learning from delivery of care in residential services for children and young people, residential services and supported housing for people with learning disabilities and hospice care, and considers how this can be applied in care homes for older people.

The report:
- finds that, while evidence of effectiveness is limited, there are promising ideas that could improve the culture of care homes, experiences of care and support for staff;
- presents evidence of how residential care homes in other sectors have created positive organisational cultures and increased relationship-based care to improve the quality of care offered;
- looks at how greater involvement of people who use services and their families can improve experiences of care.

INSPIRING
SOCIAL
CHANGE

CONTENTS

LIST OF ABBREVIATIONS

ACP	Advanced care planning
CAF	Common Assessment Framework
CQC	Care Quality Commission
DOLS	Deprivation of Liberty Safeguards
ECM	Every Child Matters
ED	Electronic documentation
ELCQuA	End of Life Care Quality Assessment
EPaCCS	Electronic Palliative Care Co-ordination Systems
FRS	Flexible Response Service
GIRFEC	Getting it Right for Every Child
HTS	Holding the Space
JRF	Joseph Rowntree Foundation
NEoLCP	National End of Life Care Programme
NICE	National Institute for Health and Care Excellence
REA	Rapid evidence assessment
SAB	Safeguarding Adults Board
SCIE	Social Care Institute for Excellence
SIRCC	Scottish Institute for Residential Child Care
UNCRC	United Nations Convention on the Rights of the Child

EXECUTIVE SUMMARY

Introduction

This report was commissioned by the Joseph Rowntree Foundation (JRF) to investigate the scope for improving the quality of care provided by residential care homes in the United Kingdom through learning from other providers of residential care. Three 'comparison settings' were chosen for inclusion: residential services for children and young people, residential services and supported housing for people with learning disabilities, and hospice care. The review did not include residential care for older people.

Methods

A rapid evidence assessment (REA) was undertaken to identify research evidence, then this was screened for relevance and quality before inclusion. While this approach has strengths in terms of transparency, rigour and consistency, there are notable limitations. In particular, while there was published evidence across the comparison settings, comprehensive searching highlighted that evidence of effectiveness was limited. To help with this, the researchers searched extensively for grey or unpublished literature, and conducted a 'sense check' with six organisations across the three comparison settings. However, the lack of evidence of effectiveness has made it difficult to extract robust and transferable learning in this report. The researchers have spoken with practitioners about ways to extract transferable learning and to ensure nothing important has been left out.

Overview of findings

Regulation, risk management and safeguarding

Regulation and inspection form a core part of social care. For some they create workplace tension and stifle creativity, for others they raise the profile of the risk management and safeguarding agenda. In an attempt to improve the regulation process, the views of those who use services and 'experts by experience' are increasingly sought. Currently there is only anecdotal evidence available to support this approach and so transferable learning is limited. However, if this approach was evaluated there could be an opportunity for care homes to build on existing participation and encourage residents to formally contribute to the inspection process, for example through the use of 'peer inspectors'.

Risk management tends to be treated negatively. However, there is some evidence that a more person-centred approach is being taken and

that the focus is shifting to what can be done rather than what can't. Joint risk assessments and advocacy may help support this shift. To fully benefit from the person-centred approach and balance the tensions between risk and choice, government policy must be supported by practical guidance for providers and shared learning between care homes, and combined with existing care planning processes. Consideration might be given to how care homes can work more closely with external advocacy agencies in a proactive and strategic manner to develop organisational policy in this area.

Safeguarding is crucial to prevent abuse and reduce the risk of harm to vulnerable adults while enabling them to maintain control over their lives. Safeguarding in adult social care is under scrutiny from the media, regulatory bodies and recent government reviews that have set out clear steps for improving safeguarding outcomes. Alongside this, learning from other settings suggests that paying attention to factors that help prevent abuse may be important, including strong leadership, good recruitment processes, effective information sharing and inclusion of the views of residents.

Developing a positive culture for caring

A positive organisational culture has the potential to impact on the lives of residents, families and staff. Studies that have examined the impact of residential services emphasised that features of a positive culture are complex and depend on a number of factors, including organisational structures, management arrangements, the physical environment, skilled staff and teamwork, and positive staff and resident relationships.

There are a number of approaches to promoting relationship-based care within residential settings which could be applied to care homes for older people. Social pedagogy is one approach that lends itself to transferable learning, focusing on nurturing residents, treating them as equals and training staff to become risk competent. Other examples of approaches include Holding the Space and Lifespace, which both focus on building relationships and breaking down barriers in care homes to create a more open and caring community. In residential care for older people there are already examples of relationship-based care. My Home Life focuses on improving the experience of residents in care homes while valuing staff through a relationship-based approach to care. There is an opportunity for care homes to consider how relationship-based care could help them move toward personalisation and positive risk-taking, drawing on these principles and learning from these examples.

In addition, dignity therapy and Namaste Care approaches encourage staff to engage more with residents and to build relationships through specific activities. Namaste Care is currently being evaluated in six care homes to determine the impact on residents and this learning should be shared with others.

Finally, the physical environment has an impact on positive caring cultures. While there is limited formal evaluation of this, feedback from residents indicates features such as choice over a single room or sharing, contact with the natural world, space for families and social interaction and spiritual meeting places have an impact on care. Residential care homes could focus on their physical environment to create a more homely atmosphere, or use audit tools available such as the 15 Step Challenge to check what more could be achieved.

Personalisation

Personalisation of services is key within health and social care policy, but there are potential tensions where individual choices may conflict with organisational

policy. However, there is some evidence that good communication, a positive culture, the creation of a defensible trail of decision-making, good relationships, participation and a strong and skilled workforce can help relieve some of these tensions. While many residential care homes are shifting toward person-centred approaches, they should consider the importance of these factors. In particular there is some evidence that suggests person-centred working can have a positive impact on quality of choices, risk management, safety and implementation when people who use care and support services are more involved. Care home providers should work to identify the most appropriate way for residents to become more involved, including through community participation for example via volunteers.

Another aspect of personalisation is ongoing work to promote independence. The evidence from other settings supports re-ablement to improve physical capacity, quality of life, emotional functioning and mobility in people receiving care. However, more research is needed as the evidence base remains limited.

Co-ordination of care

Advance care planning (ACP) is an approach that encourages decisions to be taken before a situation or crisis arises in order to reduce the chances of individuals being treated in a way which does not fit with their desires, values and beliefs. The limited evidence base indicates ACP can improve satisfaction with care received, increase a sense of control and create greater alignment between care desired and care received. Care homes are already considering ACP, but to reach the potential of this approach fully, care providers need to deliver relationship-based care, train staff adequately, build in sufficient time for residents to embrace it fully and ensure the organisational values match those underpinning the approach.

There is some evidence that electronic documentation (ED) for care co-ordination can improve outcomes for professionals but more research is needed on the impact on quality of care for residents. When exploring the use of IT-based systems, care homes should ensure:

- effective inter-agency working from the outset, such as between primary care and social care services;
- senior staff and IT staff are working together to design a system;
- understanding of how new systems integrate or replace previous systems;
- clear scope of functionality of any new systems and access points;
- a clear consent process and data-sharing protocols for residents;
- training for staff in the new system including peer support and use of champions;
- consideration of the impact of ED on staff relationships.

Staff selection and skills

Value-based recruitment and the involvement of people using care and support services in staff selection are emerging in other settings, but more evidence is needed to determine their effectiveness. Social care is moving in this direction and learning from other settings suggests that recruitment can be improved by:

- having clear organisational values set out explicitly for residents, staff and potential staff;
- involvement of residents in selection and interview processes;
- ensuring that values have appropriate and potentially equal weighting to skills in the selection process;
- including interaction with staff and residents in the selection process.

There is limited evidence available on what makes a good care worker in the comparison settings but important skills include communication, the ability to form and maintain relationships, the ability to empathise and good alignment of personal and organisational values. It is challenging to extract transferable learning because of the limitation. However, there is some evidence to suggest care settings should continue to be mindful of the range of skills necessary to deliver quality care, in particular focusing on relationship building, as the emphasis for care delivery is moving toward personalisation, choice and joint decision-making.

Staff stress and burnout

Staff stress and burnout are real concerns for residential care settings and can be caused by increased workload demands and unsupportive environments. There is also some limited evidence to suggest that working in a progressive environment, where higher goals and aspirations are set out for residents, can increase stress, as staff have to deal with more complex work demands. The literature gives examples of a number of mediators at organisational, team and individual levels, although there is limited evidence of the effectiveness of these. While care homes may already have some mediators in place, care providers could gather information at a local level using features of good practice as a guide for considering how fully they are addressing staff support. In addition, care providers could investigate further the Schwartz Care Rounds approach and its applicability in care home settings.

At an individual level, self care is an important concept that acknowledges staff have to take care of themselves before being expected to be able to care effectively for others. Other settings have found that, while it is the responsibility of individuals to care for themselves, employers can highlight the importance of self care to staff, perhaps through existing strategies like employee assistance programmes. In addition, employers could look for resilience during the recruitment process.

INTRODUCTION AND BACKGROUND

Purpose of this research

This report was commissioned by the Joseph Rowntree Foundation (JRF) to investigate the scope for improving the quality of care provided by residential care homes in the United Kingdom. The investigation focused on three questions (see Appendix 1 for further details):

- How do other sectors deliver quality care services?
- What is better about delivery of care in other sectors?
- What is the transferable learning for residential care homes for older people?

What constitutes good and effective practice in residential settings in relation to risk management and quality care? Given the breadth of the questions, we carried out a rapid evidence assessment (REA) between February and July 2013. The REA was based on:

- review level evidence from international and national literature;
- primary level evidence from the UK on effective practice and characteristics of good practice;
- published and unpublished literature containing evaluations and opinions of people using services from the three residential settings selected for review (see below);
- feedback from frontline practitioners and managers on the accuracy of findings and extractable learning for others.

Comparison settings

We selected three comparison settings for the review. These were:

- end of life care in hospice settings, as much attention has been given to providing dignity and respect in the face of death and inclusion of the wishes of people using care and support services and their families;
- residential learning disability services and supported housing, as in recent years there have been many developments in improving communication and relationships between staff and the people using care and support services;

- children's residential services, as recent policy has included a strong drive to promote excellence. Policy has stressed the rights of the child, joined-up working and the quality of the relationships between children and staff.

Definitions to frame the research

It is important to clarify the language and terms that were used for the purposes of the REA.

- 'Care homes' included adult social care homes (without nursing care, although it should be noted that this distinction was not always apparent in the literature).
- 'Hospice setting' was provision of care that involves decision-making, care planning and relationship building rather than management of pain or medical interventions.
- 'Residential settings for people with learning disabilities' included supported housing.
- 'Residential care for children and young people' included care away from home, but excluded care provided by kin carers or foster carers.

Methodology

Identification of evidence

The agreed search terms, given in full in Appendix 2, reflected the breadth of the key review questions and we categorised these into risk management and relationships, outcomes, approach and effectiveness. We considered systematic reviews, literature reviews, primary studies from the UK, and, where appropriate, opinion papers published in the English language during or after 2002 for inclusion in the review. Reports on medical interventions and medication management were excluded.

Studies identified through the search process were stored on Endnote, assessed for relevance and critically appraised before the findings were summarised in a narrative report grouped by theme.

Quality assessment and review

Papers identified using the REA approach were checked for relevance, and if they consisted of a review or a primary study on effectiveness, they were assessed for quality (see Appendix 2 for further details). However, while attention was paid to the quality and applicability of the research selected for review, there remained some limitations, as described below.

Inclusion in the report

The review incorporated a broad range of search terms and areas for consideration (see Appendix 2 for the key terms used). Following quality assessment and review, key findings were extracted and grouped by topic from the studies for potential inclusion. However, in areas where findings from the evidence were inconclusive, weak or lacked transferability across to the residential care setting for older adults, we made the decision not to include them in this report. The purpose of this report is to focus clearly on what we can learn from other settings, so papers where there was no transferable learning were excluded.

Strengths and limitations of the REA

The methods used were transparent, systematic in approach and replicable. The approach design included a critical appraisal of the strength and quality of the evidence and sought feedback from practitioners to provide access to additional and unpublished material as well as formal involvement to 'sense check' the findings.

However, the reader should note that as per the rapid approach adopted, this report does not provide detailed descriptions of all aspects of care in the three settings, but rather focuses on effective or promising approaches that might have transferable lessons for residential care settings for older people. As such, although many of the aspects of care were pertinent to the different settings, there was not always documented evidence of the effectiveness of approaches in order to address these issues in all three settings.

Authors have noted that rapid evidence reviews have some limitations and challenges (Thomas *et al.*, 2013). The timescale and resources available for the research meant a pragmatic yet thorough approach was adopted to scope out the literature, but the report does not present an exhaustive analysis of all aspects of quality care within the three settings.

Furthermore, across the three settings there was an absence of robust evidence of the effectiveness of approaches. It is important to note that much of the literature concentrated on describing and discussing needs and/or flaws in the services to address some of the concerns raised, rather than documenting the evidence on effectiveness of approaches. Where evidence was available (i.e. from the therapeutic models) one of the major challenges was identifying the essential 'ingredients' of the models and translating these to other care settings and client groups.

A further challenge for the care sector is achieving the balance between quality care and bottom-line efficiencies. The focus on measurable outcomes as an indication of effectiveness in the report does not necessarily reflect the complex care within residential settings that require softer, more qualitative measures.

Transferability of learning

The purpose of the review was to extract learning from three care settings that might be of use to residential care settings for older people. Therefore the review process focused clearly on hospice care, residential settings for people with learning disabilities and residential settings for children and young people. The review did not focus on residential care for older people and there was an argument to suggest that other settings could learn from some of the innovative and robust practice being driven forward in this setting, for example, My Home Life (see Developing a positive culture for caring, page 23). However, this was not in the remit of this review.

When considering transferable learning, the authors did look to the literature and practice in residential care for older people to see whether the learning was already established, being tested or being considered here. By the very nature of the process, this was not an exhaustive list of practice but it did draw on examples which were identified through the reflection process and in partnership with colleagues.

This review was very much the first step in the process of applying learning from other settings to the residential setting for older people, and more work is required to 'map' and extract learning and good practice from within this setting to complement the findings of this review. One example would be to look at work within the dementia care setting, which might have more to offer across the board.

The issue of transferability was central to this review. While there was learning from the different settings, many approaches had been developed in response to their specific context. As such, we only describe interventions and approaches that have direct relevance to the care of older people in this report.

1 CURRENT POLICY CONTEXT IN 'COMPARISON' SETTINGS

This chapter highlights the main policy influences for the three comparison settings to provide a context for the sections that follow.

For adults in residential care there are five main themes emerging from policy and practice, which provide an important context for this research. These are:

- personalised and preventative care;
- safeguarding;
- exposure to risk and response to this;
- co-production;
- and empowerment.

Policy in hospice care

Hospice care tends to fall under the broader end of life care and palliative care policy frameworks set out by the Department of Health. Such policy reflects the need to consider care for people who are terminally ill in advance of death and helps practitioners think about established care pathways. Hospice care is one of a number of potential settings for end of life care. Many hospices are in the voluntary sector and until recently the profile of end of life care within the NHS and social care sector was relatively low.

The publication of the *End of Life Care Strategy* (Department of Health, 2008) has raised the profile of this issue. The strategy promotes high quality care for all adults approaching the end of their lives with the understanding that each individual will have a differing view of what constitutes a 'good death'. Strategic commissioning, care planning, identification of those

approaching the end of their lives, co-ordination of care, rapid access to care, high quality services and care after death are addressed in the strategy. For hospices, the strategy highlights the need to maximise:

- the use of IT to enhance co-ordination;
- partnership working to extend hospice ethos;
- and providing education to staff in alternative settings.

End of life care continues to be a priority area, despite the completion of the National End of Life Care Programme (NEoLCP) in March 2013. Strands of remaining work have been taken into NHS Improving Quality and the Dying Matters Coalition, led by the National Council for Palliative Care.

Policy in residential care settings for children and young people

The United Nations Convention on the Rights of the Child (UNCRC) implemented in the UK by various acts (Children's Act 1989, Children Act 1995 (Scotland), Children's Rights and Human Rights Act (1998) has contributed to the development of a listening culture at policy and practice level to hear the voices of children and young persons and created an improved role for advocacy at practice level, including advocacy through external agents.

Other important policy documents, including *Every Child Matters* (ECM) (Department for Education England, 2004) and *Getting it Right for Every Child* (GIRFEC) (Scottish Government, 2008), highlight the multifaceted nature of the child's needs requiring multi-agency responses. ECM sets out five desired outcomes – that children are healthy, stay safe, enjoy and achieve, make a positive contribution and that they achieve economic well-being. GIRFEC describes similar positive outcomes – that children are safe, healthy, achieving, nurtured, active, respected, responsible and included. In England the Common Assessment Framework (CAF) is a standardised approach to practitioner assessment across children's services to provide more integrated responses to needs. The CAF approach encourages joined-up approaches to care and may have transferable messages for adult social care. In Scotland there is a single assessment to record and plan services overseen by key children's services.

Policy in residential services and supported housing for people with learning disabilities

Recent decades have seen a radical transformation for people with learning disabilities, from living in institutionalised homes and hospitals as passive recipients of care provided by the state to community-based living with a range of housing and support options. This shift reflects changes in legislation, policy and funding regimes alongside the rise of a collective voice for people with learning disabilities, underpinned by a social model of disability that has called for them to have greater control over their lives.

Valuing People (Department of Health, 2001) is regarded as one of the most important pieces of policy for people with learning disabilities. Based on the principles of rights, independence, choice and inclusion, it was the first clear policy endorsement of person-centred approaches to service delivery.

Subsequent Department of Health papers, including *Our health, our care, our say* (2006), *Putting People First* (Department of Health, 2010a) and *Think Local, Act Personal* (Department of Health, 2011a), with a strong focus on personalisation, have further cemented the goals of *Valuing People* and extended them beyond the field of learning disabilities. *Our health, our care, our say* also established the need to develop a risk management framework, taking into account the needs of people managing their own care and support.

The updated *Valuing People Now: A new three year strategy* published in 2009 acknowledges the significant improvements made in giving adults with learning disabilities more choice and control over their lives through person-centred working, advocacy and direct payments. More recently the publication of *Transforming care: A national response to Winterbourne View Hospital* (2012) and subsequent investigations by the Care Quality Commission (CQC) have increased government and public interest in the lives of vulnerable people. As a result the Department of Health has published a concordat setting out a plan of action to ensure such abuse can never happen in the future.

2 REGULATION, RISK MANAGEMENT AND SAFEGUARDING

In this chapter we review approaches to regulation and inspection, risk management and safeguarding, as well as their effect on quality of care in different contexts.

Overview

Regulation and inspection form a core part of social care, although there are differing views as to their usefulness. While some argue that regulation and inspection create tension in the workplace and stifle creativity, others believe they raise the profiles of risk management and safeguarding, which are crucial to care provision. There is emerging evidence that the views of people who use services and 'experts by experience' are feeding into some areas of the regulatory system.

Risk management, the process of handling rather than eliminating risk, has tended to be treated negatively in the past. However, there is a growing body of evidence, particularly among learning disability services, that indicates a more person-centred approach is being taken and that the focus of risk is being shifted to what can be done rather than what can't. This still needs to be carefully balanced against a range of internal and external factors, not least the impact upon the people who use care services.

Safeguarding issues, and within registered settings the Deprivation of Liberty Safeguards (DOLS), inform risk management approaches. Within the field of learning disabilities, external managers for safeguarding and small multidisciplinary teams can help identify and manage issues within the context and culture of the organisations.

Regulation

Health and social care are subject to clear regulation. The CQC is responsible for monitoring and maintaining standards within hospices and registered learning disability services, while Ofsted regulates residential childcare. The regulatory framework ensures that standards are enforced through annual, unannounced inspections observing care and collecting direct feedback from staff, people using services, families and carers. The CQC also carries out themed inspections, for example in June 2012 a review of learning disability services focused on 'care and welfare' and 'safeguarding'. If a provider is found to be in breach of the regulations, action is taken to ensure its practice changes to meet the standards set out.

Regulation and inspection are generally acknowledged as playing important roles in improving and maintaining the quality of services in adult social care. However, this is not without controversy. Some claim they stifle creativity, are overly bureaucratic and turn people's homes into workplaces. The Department of Health has described the role of regulation in terms of enabling (potential) users of services and their families to assess the quality of various services and for managers to improve ailing services (Department of Health, 2005; 2006).

Impact of regulation

We did not identify any studies in the course of this REA that directly focused on the impact of the regulatory systems in place. However, the information that is available through inspections can offer learning in terms of the characteristics of care that score particularly highly.

In 2011, Ofsted published a report on the characteristics of children's homes that achieved and sustained an 'outstanding' score in its inspections. Feedback from the young people in these homes indicated that staff (particularly key workers) had built strong relationships with them, helped them feel positive about themselves, involved them in how the home was run and gave them stability. This made them feel safe and instilled a belief that staff would not give up on them. These homes had positive leadership with strong visibility, a focus on improvement, and involved all staff in maintaining and improving quality.

The importance of creating a positive physical environment was also stressed (i.e. providing a homely and welcoming home for young people) because the feedback showed that where young people are treated with respect, they treat their environment with respect in return.

Practice examples

Joint inspections

The Care Inspectorate in Scotland undertakes inspections of children's residential care in a strategic fashion, bringing together professionals from the care, social work, health, police and education regulators. They provide public assurance about the quality of services aimed at giving children and young people the best start in life, and make recommendations about what needs to improve. Each inspection team includes specially trained 'young inspectors' who can speak to children and young people about their experiences.

Risk management

Current thinking in health and social care describes risk management in relation to minimising risk and maximising choice and control on the part of people who use care and support services. Government policy stresses the importance of balancing the positive benefits of taking risks against the negative effects of encouraging risk-taking. However, there are tensions between managing individual perspectives and organisational factors such as regulation, accountability, fear of consequences and can't-do attitudes (Finlay *et al.*, 2008; Glynn *et al.*, 2008; Neill *et al.*, 2009; Scherer, 2010; Bates *et al.*, 2012). There is some evidence of a shift in attitude toward positive risk-taking and of providers enabling individuals when following informed decision-making (Department of Health, 2005; 2007; Neill *et al.*, 2009).

Recently, policy at a local level has been setting out guidance and frameworks for providers to encourage a positive risk-taking outlook (e.g. Department of Health, 2007). Within our comparison settings, joint risk assessments and advocacy in particular helped move toward positive risk-taking. However, evidence of effectiveness was lacking so transferable learning is somewhat limited on this basis.

Joint risk assessment
One approach is to involve people who are using the services in the decision-making process. One small-scale study (Kilcommons *et al.*, 2012) found that there was awareness among people using the services of the reason for undertaking risk assessments and an appetite for being involved in the process.

Positive questioning for jointly assessing risk
1. What are the physical, social and financial risks associated with the task?
2. What are the likely outcomes of taking this risk, and who is at risk?
3. How likely is it that any given outcome will happen if the risk is taken and what is the timescale?
4. Is the outcome so serious that the risk cannot be countenanced?
5. Can any action be taken to reduce the impact of the outcome if problems do occur?
6. What will the person gain from the experience that requires risk to be taken?
7. How likely is it that this experience will be useful or pleasurable to the person?
8. What will the individual lose if the risk is not taken?
9. Does the likelihood of harm outweigh the likelihood of benefit?
10. What would I choose for myself, or members of my family?
11. What do colleagues feel that they would choose?
12. How much awareness of the likely risks and outcomes does this client have?
13. Can this client weigh up the costs/benefits of this particular decision about risk?
14. If not, is there consensus about what should be done among those who know the client well?

Sources: Fyson *et al.* (2007), Kilcommons *et al.* (2012)

Advocacy

Extensive research into risk management in care homes has been published (Joseph Rowntree Foundation, 2013) outlining the key issues facing care homes. This has concluded that the voice of residents is largely absent and that choice and control appear to be limited. Some argue this is likely to change in the future, as tomorrow's older people are likely to be more demanding consumers who are accustomed to higher levels of independence and choice than the post-war generation. This view is echoed in the overview of the Commission on Residential Care (Demos, 2013).

In the meantime advocacy services have emerged, particularly for people with learning disabilities and children and young people in residential care. Advocacy provides a collective voice for groups of people with shared interests and can play a role in drawing attention to good or poor practice. Advocates also work with individuals receiving care to facilitate their decision-making.

There is some limited evidence that advocacy benefits decision-making bodies and practitioners as well as the individuals they work with (Speaking Up, 2007). More recently, a review of international literature identified seven factors associated with effective advocacy for young people (Commission for Children and Young People, 2013):

- independence (avoiding conflicts of interest);
- confidentiality (enabling trust and control to be established);
- child-focused (prioritising their views and preferences over others);
- empowering (recognising the child's rights and capacity to contribute);
- adequately funded;

- long-term relationships between the child and their advocate (to develop trust);
- a remit of 'caring advocacy' rather than 'justice-based advocacy' (based on being attentive and respectful listening).

These factors could equally apply to other settings within adult social care, including residential care for older people where advocacy tends to happen only during periods of crisis, rather than being embedded in good practice as a matter of course.

Organisations like *Help the Hospices* act as advocates for the setting and offer a range of more co-ordinated services including policy updates, support to maintain quality and standards, help with professional development and examples of benchmark tools for use in hospice settings. There are similar organisations in the care sector (e.g. English Community Care Association, National Care Forum, Residential Forum). It would be worth considering in more detail the similarities between these organisations and where learning can be shared across the board.

Safeguarding

The aim of safeguarding, as outlined in Department of Health policy, is to 'prevent and reduce the risk of significant harm to vulnerable adults from abuse or other types of exploitation, whilst supporting individuals in maintaining control over their lives and making informed choices without coercion' (Department of Health, 2011b). Additional policy has been introduced which is specifically designed to protect the interests of people in need of care and support who lack the capacity to make decisions for themselves. In practice, a lack of training and consistency of implementation has undermined the effectiveness of safeguards but there is ongoing research to investigate this further (NIHR, 2012).

There has been significant work in adult social care services in this area following incidents of abuse and neglect. Recent publications have been aimed at tackling abuse and neglect in care homes as well as other residential health and social care settings, for example *Transforming care: A national response to Winterbourne View Hospital* (Department of Health, 2012) which sets out factors associated with abuse.

Research in the area of learning disabilities (research from children's services was not included in this study as the starting points are so different) suggests that characteristics of successful safeguarding include:

- commitment from senior management;
- a clear statement of the agency's responsibility toward residents, which is available to all staff;
- a clear policy of accountability within the organisation for work on safeguarding and promoting the welfare of residents;
- service development that takes into account the need to safeguard and promote welfare and is informed where appropriate by the views of residents;
- staff training on safeguarding and promoting the welfare of children for all staff working with or who are in contact with residents;
- safe recruitment procedures;
- effective information sharing.

Sources: Kalaga and Kingston (2007), Wallcraft *et al.* (2011)

There is limited evidence that users are being involved in safeguarding – although some good practice models include:

- family group conferences – although these lack robust evaluation, feedback from families is positive;
- Safeguarding Adults Boards (SABs) – these can include representation from individuals but again have not been sufficiently evaluated;
- Safeguarding Adults Forums – these enable people using services to gain expertise and provide a two-way communication channel with the SAB.

Transferable learning

As previously stated, the evidence base across these topics is limited in terms of the impact of different interventions, making it difficult to extract robust transferable learning. However, some elements of successful and innovative practice may have potential for application in care homes.

Joint inspections may offer some progression toward better regulation and the CQC has recently introduced 'experts by experience' into the inspection process. As this progresses, care home providers may well want to include the views of their own residents more formally, for example through peer inspectors.

There was some evidence that residents were keen to have a greater degree of involvement in managing individual risks and person-centred working will advance this. However, more work is needed to engage with care homes to establish current innovative practice, involve residents more in joint risk assessments and to assess the impact on quality of care. There is also a need for care homes to share practices and learning, for example to establish how this approach is to be combined with existing care planning processes.

Limited learning from advocacy services in other areas can be applied to care homes. While there are external agencies providing advocacy services they tend only to be drawn in under crisis situations. It is worth considering how care homes can work more closely with local advocacy services to address collective as well as individual concerns and take a more proactive approach to improving services.

Lessons from other settings to reduce abuse suggest that care homes need to be aware of the factors associated with abuse and of mitigating factors like strong leadership, clear policies, staff training and sound recruitment. There is some evidence that this can be supported by the input of an external perspective and care homes could consider this as part of existing safeguarding procedures if they are not already doing so.

3 DEVELOPING A POSITIVE CULTURE FOR CARING

In this chapter we look at ways in which residential care settings could be improved by creating positive cultures and consider relationship-based approaches to care.

Overview

Creating positive organisational cultures within residential care settings has the potential to improve the lives of residents, staff and families. Studies that have examined the impact of a positive environment on residential care users have emphasised that features of a positive culture are complex. They depend on a number of factors including organisational structures, management arrangements, the physical environment, skilled staff, teamwork, and positive staff and resident relationships.

There are a number of approaches to promoting relationship-based care within residential settings that could be applied to care homes for older people. Social pedagogy is one approach that lends itself to transferable learning, focusing on nurturing residents, treating them as equals and training staff to become risk competent. Other examples of approaches include Holding the Space and Lifespace (see page 25 for more detail). All of these place importance on building relationships and breaking down barriers in care homes to create a more open and caring community. In addition, dignity therapy and Namaste Care approaches encourage staff to engage with residents and to build relationships through specific activities.

Finally, some studies have found that the physical environment has an impact on positive caring cultures. While limited formal evaluation exists, feedback from residents indicates features such as choice over a single room or sharing, contact with the natural world, space for families and social interaction and spiritual meeting places have an impact on care experiences.

There is evidence in the literature relating to people with learning disabilities that suggests creating a positive organisational culture can improve the lives of residents and staff. A number of studies identified characteristics for developing a positive organisational culture as:

- a clear vision of and approaches to delivering care, and shared organisational understanding of these;
- strong management planning and practices;
- supportive and clear staff policies and procedures, which are interwoven with the vision and approaches to care delivery;
- staff development and training in the policies and organisational approaches;
- teamwork, good support and good communication between staff;
- skilled staff who display a positive attitude;
- space for residents to meet or form a group;
- attention given to group living and recognition that practitioners need a clear sense of how residents function as a group to provide positive support for this;
- a comfortable physical environment and attention given to private and shared space;
- work done with 'champions' (staff who display a passion for the work and have agreed to lead change in that particular area) who can become facilitators for action learning and person-centred approaches.

Sources: Emond (2003), Robertson *et al.* (2005), Broadhurst *et al.* (2007), Beadle-Brown *et al.* (2008), Smith (2009), Lawrence *et al.* (2010), Camble (2012)

Relationship-based approaches to care

Moving beyond the organisational structure, adopting a holistic approach to care has the potential to contribute to a positive caring environment. This approach is based on the relationships between staff, between staff and residents and between residents (Dowling *et al.*, 2007). Relationships are built on trust, consistency, warmth, respect and a caring attitude (Mansell, 2007, 2010; Carr, 2010; Wallcraft *et al.*, 2011; Ofsted, 2011; Camble, 2012). A number of specific models have been identified in the literature that aim to promote relationship-based approaches to care and develop a positive environment for living.

Social pedagogy

Social pedagogy was developed in several countries in Europe and can be applied to work with people in many formal or informal institutional settings. It can be understood as a process of nurturing, whereby residents are treated as equals and their ideas and beliefs are valued. The focus is on staff becoming 'risk competent', that is, knowledgeable and skilled in assessing risk in order to promote empowerment (Eichsteller *et al.*, 2009). Other principles of social pedagogy include:

- a focus on the resident as a whole person;
- using residents' rights as a foundation for practice and understanding that this is not limited to procedural matters or legislated requirements;
- the practitioner seeing herself or himself as a person in a relationship with the resident;
- residents and staff are seen as inhabiting the same 'lifespace', as opposed to existing in separate hierarchical domains;

- sharing in many aspects of children's daily lives and activities;
- an emphasis on teamwork and on valuing the contributions of others;
- relationships being central to care and, allied to this, the importance of listening and communicating.

Source: Petrie *et al.* (2006)

Practice example

Aberlour
In Scotland, Aberlour Sycamore Services aims to provide consistent, safe and therapeutic care for children and young people by adopting a socially pedagogical approach. Reflecting the principles of social pedagogy, all staff (including cooks, managers, domestic staff, administrative staff and practitioners) are introduced to the approach and supported to adopt this across the range of services they provide (Elseley, 2006; Milligan, 2009).

Camphill Communities
Camphill Communities provide social pedagogy-based services for people of all ages with learning disabilities. The communities emphasise the notion of 'home' and the idea is that staff work with, not for residents.

Social pedagogy as applied to residential childcare services is one of the few models of care to have undergone external evaluation in the UK, with favourable findings (Cameron *et al.*, 2011; Cameron, 2012).

In Scotland there has been recent discussion on the need for a 'life course' (SCIE, no date) model of social pedagogy and some argue that the skills that define a pedagogue are as important in the adult social care and health sectors as in the children's sector (Children in Scotland, 2012). The Children in Scotland report concluded that the '"essence of the pedagogue" fits well with the person-centred services that the adult health and social care sectors want and need to deliver' (Children in Scotland, 2012).

Lifespace
The care delivery approach Lifespace, used in residential childcare, is shown in the literature to be receiving more attention in the broader care sector, with some authors proposing that what happens in the time when the resident and worker interact outside treatment or therapy is just as important as in more formal 'professional' interventions (Smith, 2009). The Lifespace is a mini society in its own right, in which people learn to interact, build relationships and feel included. While the concept of Lifespace (Smith, 2009) is discussed and described in the literature, our review did not identify any formal evaluations of this as a standalone approach.

Holding the Space
Holding the Space (HTS) is a therapeutic model used in residential care for children and young people where relationships are central in enabling residents to find an emotional language and a sense of belonging. For staff, the aim is to provide an effective way to reflect with each other and to transform the residence into an open and caring community using creative skills, reflective practice, The Way of Council methods (Action for Children, 2009), and focusing on the relationship in the moment (Stevens, 2010). A case study evaluation of HTS found a reduction in negative behavioural outcomes, an improvement in the ethos of the care home, improved

relationships and different communication methods used during the period of training and implementation (Stevens, 2010).

Dignity therapy

Dignity is a major Department of Health policy theme that encourages a cultural shift to ensure care is person- not task-focused. A number of studies have examined the characteristics of dignity in hospice care, and despite the lack of robust and conclusive research in general these studies have concluded that dignity is socially constructed and mediated in our relationships with others. The concept of dignity embraces modesty, protects self-respect, helps retain a sense of control and maintains good communication and good relationships (Edith Cowan University, 2006; Thompson *et al.*, 2008; Gerry, 2011). Delivery of dignified care relies on staff attitudes, kind and professional behaviour, compassion and strong relationships (Chochinov, 2007).

Dignity therapy is a brief intervention designed to address legacy needs among residents at the end of their lives. By offering recorded therapy sessions that encourage residents to talk about their lives and what matters most to them, care providers give individuals a written record of their thoughts to share with family and friends. It is not historical, but rather focused on thoughts, ideas and events that hold particular meaning. Findings from a randomised, controlled trial (Chochinov *et al.*, 2011) suggested that while the intervention did not mitigate outright distress, depression or desire for death, there were significant self-reported benefits in terms of resident experiences, such as improved quality of life and a sense of dignity. In the UK, a smaller scale study (Hall *et al.*, 2012) reported that participants felt their life was more meaningful and their sense of purpose was heightened. It could be argued that social interaction, which came as part of research participation, was an important contributor to the findings. Indeed, other studies have shown that social relationships and feeling valued are important aspects of dignity in care homes.

Namaste Care

The word *namaste* means 'to honour the spirit within' and the Namaste Care programme, developed in the US, is an innovative approach which developed from end of life care for people with dementia and is used in hospice care settings. The approach engages with people through the stimulation of the five senses, for example through setting up a lavender-filled room, hand-holding, the presence of others, reading, playing music, family meetings and life story (Simard, 2013). Evidence from the US suggests that this approach reduces agitation, aggression and anxiety (Kong *et al.*, 2009).

The importance of the physical environment

The importance of creating a positive physical environment has been reflected in policy (Department of Health, 2008) and there is some limited evidence that a high quality physical environment can impact on care experiences and outcomes for residents (Waller *et al.*, 2011; Elseley, 2009) although more evidence is required to form more conclusive answers. Nonetheless, important characteristics of the environment that can improve experiences of care for residents, families and staff, have been identified in the literature (see Table 1).

Table 1: Characteristics of the physical environment linked to improved experiences

Characteristic	Description
Homeliness	Residents wanted to feel 'at home' in the setting and some studies reported individuals personalising space with their belongings to make it feel more like home.
Single rooms	Some residents and family members preferred single rooms for privacy, more control etc. while others preferred the distraction of a busy ward. Prior discussion to establish preference was key.
Proximity to family	An important aspect was proximity for family and friends to visit and maintain the closeness of relationships.
Contact with the natural world	Residents in many studies reported a sense of enjoyment when in contact with the outside world, via windows letting in natural light and access to outside space and gardens.
Space for social interaction	Some residents were keen to remain socially active as long as possible, to use lounges and dining areas and engage in mutual support. However, choice is the key as not everyone will want to interact.
Facilities for families	Having adequate space to accommodate families overnight as well as administer medical tasks, have care discussions, etc. was important for staff and families alike.
Spiritual places	Often an important aspect for older people, the need for a place to worship or meditate was felt to be beneficial to residents and families.

Sources: Waller *et al. (2008, 2011), Rigby et al. (2010), Brereton et al. (2011)*

Transferable learning

In adult social care, work to promote relationship-based care in care homes is already ongoing (e.g. My Home Life, as discussed on page 23) but there are also opportunities to draw more broadly on learning from others, such as Aberlour Sycamore Services and Camphill Communities. By focusing on relationships, taking an assets-based approach to care, taking a more egalitarian view of the 'space' where there is no hierarchical domain, having a work-with rather than work-for attitude and acknowledging the group as well as the individual in residential care settings, care homes could change the organisational culture and improve care outcomes for residents. In adult social care, the move toward co-production (SCIE, 2009) addresses some of these factors, for example Merevale House works with the premise that there is no 'them' and 'us' and instead the care home takes an asset-based approach to service planning and places a positive value on social relationships and networks.

Specific approaches to building relationship-based care such as social pedagogy and Holding the Space can be beneficial to care homes as they provide a set of values, staff training approaches and guidance for implementation. In particular, they give practice examples that suggest a clear vision supported through management, policies, training, involvement of residents and the monitoring of the feel of the home, all of which contribute to a more outcome-focused approach to care delivery. There are opportunities for care homes to consider the different approaches described and consider how best these could be adopted in their organisation. Tools like an adapted version of the 15 Step Challenge can help providers monitor progress.

In terms of specific interventions, dignity therapy and Namaste Care may offer some learning for care homes that are working with people approaching the end of their lives in particular. By spending more time with the person, rather than overly concentrating on tasks associated with support needs, there is potential to improve well-being, care experiences and relationships. St Christopher's Hospice has started working with six nursing homes to evaluate the impact of the Namaste Care programme on older people in residential care. Early findings from the evaluation are promising but it is too early to draw any firm conclusions.

The importance of the physical environment has been identified in the literature, indicating support for creating better experiences for people who use care and support services. While some care homes already pay attention to the physical environment and 'homeliness' of the setting, there may be some value in considering the tools existing in other settings within a residential care setting in order to improve the physical environment for residents. By doing so, the services can create a sense of home and a positive milieu in which to develop good relationships between staff and residents.

4 APPROACHES TO PERSONALISATION

This chapter explores key themes for personalisation in care services, and reviews characteristics that are evident in comparison settings that have implemented person-centred approaches.

Overview

Person-centred approaches are key within health and social care policy and care homes for older people cannot avoid them. There are obvious potential tensions between these and risk management, as individual choice can conflict with organisational policy. However, there is some evidence that characteristics such as good communication, a positive culture, creation of a defensible trail of decision-making, good relationships and a strong and skilled workforce can help organisations move toward more person-centred working.

Participation of care users in care delivery is promoted in government policy and examples of this include increasing user choice, increasing user voice and changing work practices and lifestyle choices. Our review found some evidence in broader NHS literature that user participation had an impact on the quality of choices, risk management and safety, and on implementation of a person-centred approach to care delivery.

Choice and control, which are key themes for personalisation, are explored more in settings for people with learning disabilities than in others. Important characteristics of settings that implement these themes include staff supporting choice and controlling focus on good information, organisational support for making and changing decisions, good relationships and positive staff attitudes. However, the lack of evidence of implementation makes it difficult to consider the potential impact of choice and control on people who use care services.

Re-ablement is an emerging theme in end of life care, based on a philosophy of enabling people to live as actively and as independently as possible until they die. There is support for re-ablement from staff and

residents who are keen to remain as independent as possible through the course of their disease. Reports of improvements in functional capacity, quality of life, emotional functioning and mobility are emerging but the evidence base remains limited.

Personalisation is at the heart of current health and social care policy:

"[Although it] goes under many different names, including 'independent living', 'person-centred support' and 'self-directed support' [they] are all based on the same principle: if disabled people are to participate and contribute as equal citizens they must have choice and control over the support they need to go about their daily lives."
(Glynn *et al.*, 2008)

While person-centred working is central to government policy, translation into practice is slower. The scale of change required to shift from service-focused delivery, where outputs (such as the number of people using the service) are measured, to an individual-focused approach, where experiences and quality of care are central, is challenging.

Across the settings covered by this review, there was evidence of disparate, but often unevaluated, approaches to achieving personalisation, including person-centred working, participation, advocacy, choice and control and re-ablement.

Person-centred approaches

Person-centred working puts individuals and their families at the centre of care planning and decision-making to ensure these respond to personal preferences, needs and values. The approach focuses on individuals' strengths and interests rather than on assessing what they can't do (Department of Health, 2010a). While there is no single definition of person-centred working, there is some agreement that it involves:

- development of a relationship between staff and the individual;
- shared decision-making;
- good communication;
- an organisational culture that embraces empowerment and inclusion;
- an organisation that is willing to take risks;
- the creation of a defensible trail of decision-making;
- joined-up working across multidisciplinary teams;
- strong leadership;
- a trained workforce.

Sources: Dowling *et al.* (2007), Neill *et al.* (2009)

Evidence of impact
Within learning disabilities settings, there is emerging evidence that a person-centred approach can improve outcomes for people using services. Hoolahan (2012) reviewed an ambitious personalisation project that took place in Southwark, where person-centred plans had been used to establish what each individual really wanted in their life. As well as transforming the lives of 83 people with learning disabilities, the author noted that the project

had created substantial cost savings. Robertson *et al.* (2005) evaluated the impact of a person-centred approach on the quality of life of 93 people with learning disabilities. They found that it increased the size of social networks, active contact with family and friends, participation in community activities, choice and the number of hours involved in scheduled day activities.

It should be noted, however, that the success of working in a person-centred way is down to more than creating a plan. Quality of life can only be improved if the staff implementing the approach are properly trained and supported, and good quality plans tend to be equated with higher levels of engagement in meaningful activities (Adams *et al.*, 2006). Furthermore, Robertson *et al.* (2005) concluded that person-centred working appears to work better for some people than others, because their specific needs tend to dictate the type of plan they receive (if they receive one at all). One review of existing evidence (Dowling *et al.*, 2007) and a subsequent primary study (Glynn *et al.*, 2008) looked at the potential barriers to successful implementation of personalisation and person-centred planning for people with learning disabilities (see Table 2).

Table 2: Barriers to effective person-centred care

Characteristic	Description
Staff attitudes/skills/ knowledge	Staff need to relinquish the idea that they know what is best for people who use services through training in empowerment and by giving time to building relationships which help people who use services to realise their own potential.
Inflexibility of service provision	People who use services shouldn't have to fit existing services; services should be shaped to meet their needs.
Insufficient information	People who use services require accessible, appropriate and high quality information to make decisions.
Insufficient resources	People who use services may not seek out or exercise choice because they are concerned about local authority charging or eligibility criteria.
Risk and regulation	Service providers (and families) must not use risk or regulation as a reason to prevent people who use services from exercising choice and control. Too much attention is placed on measuring 'hard' targets at the expense of softer measures that are better suited to personalisation.
Cultural/language/ geographical differences	There is a need to ensure that everyone can communicate their views and be heard and understood. There can be geographical differences in service provision and people's choices can be limited by transport difficulties.
Institutionalisation/ previous experience	Staff and people who use services can be reluctant to change the way they have always done things. If people who use services have had a negative experience of user participation in the past they may not be willing to have another go.
Slow pace of change	Personalisation may be at the heart of government policy, but the pace of change at grassroots level can be slow.
Mismatch of expectations	The choices expressed by people who use services may be at odds with the priorities of service providers.
Communities/ networks	Not everyone is part of a community or an informal network, but these are seen as crucial to success.

The authors suggested that in order to overcome these barriers, it is important for organisations to:

- take a person-centred approach as part of their core values;
- to involve people who use services in decision-making through improved consultation;
- to develop good relationships built on trust and that enable positive risk management;
- to employ positive and enthusiastic staff who facilitate involvement and instil confidence;
- to share best practice;
- to promote the approach widely;
- to work in partnership with others;
- to provide good information and support for individuals and their families.

Practice example

Westminster Learning Disability Partnership

The Flexible Response Service (FRS) evolved in recognition of the importance of social inclusion for people with learning disabilities. The key elements of the approach are:

- Service philosophy: commitment to social inclusion, person-centred working, proactive working and positive culture;
- Service structure: assessment of individual preferences and needs, relationship-building starting in 'safe places' and moving to community spaces and Circle of Support meetings;
- Capable environments: key to the success of the approach is staff who are trained to deliver proactive, planned and monitored support in creative ways.

A number of evaluative approaches and benchmark tools have been put in place to ensure the service is developing in response to demands (Carnaby *et al.*, 2010).

Participation

User involvement

Healthwatch England is the independent consumer champion for health and social care and is leading work on user involvement (often referred to as personal and public involvement or PPI in health settings), which aims to involve individuals and communities in shaping health and social care services. As with other areas, tensions exist between participation and translating this into care delivery (Bates *et al.*, 2012).

There are different expectations about what involvement can achieve but Andersson *et al.* (2007) outlined three key areas: increasing user choice, increasing user voice and changing working practices and lifestyle choices.

There is some evidence of the impact of user involvement in the hospice care setting, predominantly through initiatives such as advanced care planning (which is discussed further on page 40), although beyond this there is limited evidence of impact within this setting.

Nonetheless, some evidence exists in the field of learning disabilities and in literature from general healthcare that suggests involving the public and people who use services results in:

- better involvement in decisions and management of care;
- improved risk management and safety of individuals;
- better decisions made for the individual, resulting in improved care experiences;
- better implementation of person-centred care;
- co-production of care.

Sources: Coulter *et al.* (2006), Glynn *et al.* (2008)

Several studies across hospice care and learning disabilities settings identified characteristics of effective user involvement:

- Family members (or 'circles of support' if no family member is available) should be involved as well as residents.
- Health information and literacy is fundamental to resident engagement.
- Communication skills should be the main mechanism by which professionals learn about and gain competences in the principles and practice of shared decision-making.
- Communication about risk is a key component of shared decision-making.
- Moving forward to self care and self management requires more than just information-giving and best results have been identified through educational programmes.
- Involvement of the broader community and involvement in the broader community is vital through employment, education and leisure opportunities.

Sources: Robertson *et al.* (2005), Coulter *et al.* (2006), Mansell (2010), Carr (2010), Gandy *et al.* (2012)

Barriers to involvement from a professional perspective were discussed in a paper by Black (2012) with specific reference to a hospice setting. These included:

- difficulty asking for participation when individuals are at the end of their lives;
- the assumption that users are too ill to be involved or will have more pressing matters to think about;
- concern that while some individuals will be informed, others might not fully understand the bigger picture, i.e. they may not understand the resource constraints of the NHS that will limit what care is available;
- risks that people who have had poor experiences of care may dominate the discussions with these experiences;
- misconceptions about the definition of user involvement.

Community engagement

While there is no research evidence linking community engagement to quality of care delivery, public perception is important to consider when contemplating community engagement. Currently, the public perception of hospice care is relatively positive. A recent study by Help the Hospices (2013) indicated that 69 per cent of respondents to a large-scale survey (Populus, 2013) thought hospices were a place that offered compassionate care, and a further 60 per cent felt they were somewhere you go to experience good quality of life before you die. This could be linked to the fact that hospice care has its roots within the third sector and delivers a single model of care focused on treating individuals' holistic needs: those that are clinical, emotional and spiritual.

In contrast, residential care for older people expanded in the 1980s in response to the privatisation agenda and while care homes are based on a similar vision and set of values to hospices, there is no central thread holding them together and public perception is very different. While the studies are not directly comparable, 70 per cent of UK adults who took part in a recent survey (Ipsos Mori Social Research Institute, 2013) said they would be scared to move into a care home in the future.

Within the residential care sector there is also a feeling that public perception could be improved and there have been some moves toward this. Care homes are linking together for the National Care Home Open Day initiative supported by the Department of Health, CQC, the National Association for Providers of Activities for Older People and SCIE. This is an attempt to present care homes in a positive and proactive light and make lasting connections between local communities and care homes. A further initiative is the Social Care Commitment which is a voluntary agreement between employers and employees to improve the quality of care and support services and public confidence in these services. The Social Care Commitment gives clarity to employers and employees about what is expected of them when delivering care services.

The role of volunteers

Volunteers are integral to the work of hospices, with an estimated 100,000 people volunteering in hospices across the UK worth over £112 million (Help the Hospices, 2006). There is an increasing Department of Health policy emphasis on volunteers overall but in the current financial climate there is a danger that volunteers could be employed inappropriately.

In 2012, Help the Hospices published a working paper on the role of volunteers, including recommendations encouraging hospices to:

- think of volunteers as essential to any strategy for extending reach and impact;
- grow the volunteer workforce and think more strategically about their role;
- consider approaches to sustaining and nurturing volunteers;
- enable volunteers to take on a significant role in helping people understand care patterns.

Morris *et al.* (2012) conducted a review into the contribution of volunteers in end of life services and identified a number of factors relating to individual volunteers and organisations. Themes that emerged from research on individuals fall under a number of headings:

- Motivation: includes altruism, civic responsibility, leisure, personal gain, self-promotion.
- Characteristics of volunteers: they tend to have personal experience of death, empathetic concern, openness and extraversion.
- Coping and stress: volunteer impact can be reduced by poor communication, lack of training, lack of emotional support, dealing with death and dying, feeling undervalued, helplessness.
- Role boundaries: volunteers have varying role boundaries depending on location but can include fundraising, befriending and outreach.
- Value: volunteers can be very cost-effective, provide a complementary role to professionals, give emotional support and sustain relationships with families.

The organisational themes were:

- Recruiting for diversity: one criticism is that only a small section of the community becomes involved in volunteering and providers need to encourage diversity.
- Support and training: providers need to show a sense of commitment and connection and give support and training when working with volunteers.
- Volunteers' place in the system: there are tensions between the flexibility of informal volunteering and formalising/professionalising the role of volunteers.

Morris *et al.* are now in the process of writing up their findings from primary research, which was conducted with staff, volunteers, people receiving care and family members. They will draw conclusions on the impact of volunteering, management practice, the relationships of these with the external context, and the role of volunteering in the hospice.

Choice and control

Choice and control are major themes for personalisation, and are prominent in the field of research relating to people with learning disabilities. They are recognised in current government policy, but again they are slow to find its way into practice (Jingree *et al.*, 2006). This is because they require organisational change and are often hindered by inspection regimes and organisational policy, as well as a focus on the larger issues rather than everyday choices, communication difficulties and paternalistic attitudes (Finlay *et al.*, 2008). A number of factors for enabling choice and control were identified in the literature. These included:

- appropriate and accessible information about the choices available;
- support at an organisational level if plans need to change;

- support to help people using care and support services make decisions and learn about making decisions;
- good relationships with others;
- staff having listening skills and a positive stance on choice and control;
- a positive approach to risk management in the residential setting;
- support for staff to understand the inspection system rather than to fear it.

Sources: Glynn *et al.* (2008), Finlay *et al.* (2008), Curtice *et al.* (2012)

Some evidence is available linking the roles of technology and telecare (where various technological devices are used to monitor an individual's health condition remotely) to increased choice and independence, as well as reducing risks and increasing privacy and dignity for people with learning disabilities (Wood *et al.,* 2010; Perry *et al.,* 2012). Anecdotal evidence has suggested that the quality of life for some individuals has improved following the introduction of telecare, as it has empowered more independent living. This improvement has helped overcome some initial resistance from professionals.

> **Practice example**
>
> Get a Plan project
> Ahmed (2011) reported how the Get a Plan project provided training to practitioners, carers and people who use services and led to an increase in the independence of people with learning disabilities by enabling them to have more choice over the support they received. By maximising the use of person-centred plans, and by developing circles of support, service providers have become more creative in helping people to achieve what they want within the wider community, rather than focusing solely on traditional, statutory social care. We were unable to establish evidence that this approach has been evaluated.

Curtice *et al.* (2012) discuss the importance of family dynamics in relation to choice and control. On the one hand, there are families who seek to empower their relatives and ensure that their individual wishes are heard and met, while on the other, there are those who seek to restrict the independence of the person with learning disabilities. For some this is not an issue – having someone to make decisions for you or with you can be reassuring if you are not comfortable doing so by yourself – but for others this is not acceptable. Within residential care for older people there appears to be, anecdotally at least, a presumption that residents are happy for others to make decisions on their behalf. However, older people are becoming more demanding consumers and in future we can expect that they will not wish to be passive recipients of care and will instead want to exercise more choice and control over their environment and day-to-day lives.

Rehabilitation and self management

The philosophy of hospice care is:

- to enable the dying person to live as actively as possible;
- to maximise physical and mental capacity with control and independence where possible; and
- to help people adapt to their condition.

Rehabilitation underpins this philosophy and requires a multidisciplinary approach to care delivery. Typically, rehabilitation services include physiotherapy sessions, breathlessness management, enablement training on the ward and promotion of independence within daily care. This approach challenges how individuals with advanced conditions are cared for to promote and empower greater independence (Cane *et al.*, 2011).

Practice examples

LOROS
In the Leicestershire and Rutland Organisation for the Relief of Suffering (LOROS) hospice, a programme was set up to train healthcare assistants to take a physical rehabilitation approach to care, therefore promoting independence. The training focused on breathlessness, mobility, independence in personal care and equipment to enable independence. The findings indicated that educating healthcare assistants in this way has the potential to improve the rehabilitation of palliative care patients, but that it needs to be delivered in a way that fits around other work demands.

The Rehab Project
St Christopher's Hospice runs a training programme called The Rehab Project, which is delivered to nurses and healthcare assistants by occupational therapy and physiotherapy staff. The aim of the training is to benefit staff and residents through a united rehabilitation approach to care and to improve collaboration between professionals (Cane et al., 2011). Details of the course were given in the literature but unfortunately no evaluation results of the training were presented.

The concept of rehabilitation is gaining attention in the literature, as staff and people receiving care express a desire to remain as independent as possible through the course of their disease. Two reviews (Javier *et al.*, 2011; Jennings, 2013) concluded that the evidence base is currently limited but emerging findings support improvements in physical functional capacity, quality of life, mobility, emotional and cognitive functioning and levels of participation.

Some characteristics of effective rehabilitation have been identified, including:

- functional assessment upon admission;
- enablement training for staff to safely facilitate independence;
- joint nursing and physiotherapy assessment and care plans;
- promotion of independence in daily care by the whole care team;
- daily exercise rehabilitation groups in a gym by a physiotherapist;
- an individualised weekly timetable of activities for each resident.

Source: Jennings (2013)

Transferable learning

Residential care homes for older people are moving toward a person-centred approach, but would benefit from looking at examples evidenced in learning disability settings, where greater participation across the board by residents, family and the wider community has been seen to have a positive impact on the delivery of personalisation.

The current lack of a consistent or communicated ethos for adult social residential care has potentially damaged its public reputation. More research on how hospice care has maintained a positive public understanding could inform strategies for improving the public opinion of care homes. In addition, increasing the role of volunteers could increase engagement with the wider community, as is the case within the hospice movement.

Evidence from learning disability settings, healthcare and the hospice movement suggest that there is merit in working with people who use services, and their families, to work co-productively to make joint decisions, improve risk management and to improve individual care experiences.

Choice and control are well embedded in services for people with learning disabilities and there may be some learning from within the adult care setting itself. From this review it is clear that factors such as access to information, good relationships between staff and residents and trained staff who are able to listen and translate views into action are all-important in improving choice and retaining control. Providers could also consider the role of digital technology to help older people retain their independence.

Barriers do exist in care homes when it comes to rehabilitation and self management (Garrett, 2012) and there is currently insufficient evidence to draw firm conclusions about the impact of rehabilitation in care homes (Crocker *et al.*, 2013). Nonetheless, care homes could consider in more detail that the role of re-ablement for residents, at a pace that suits individuals, may have a positive impact on their quality of life and functioning in a range of areas.

5 CO-ORDINATION OF CARE

In this chapter we look at different approaches to the sharing of care planning within organisations, particularly among those providing hospice care. We also discuss the use of electronic systems to co-ordinate care.

Overview

Advance care planning (ACP) is an approach which is promoted in end of life care to encourage decisions to be taken before a situation or crisis arises, thereby reducing the chances of residents being treated in a way which does not fit with their desires, values and beliefs. The fundamental building block for this is a strong and trusting relationship with the care provider, who outlines the options, risks and consequences of decisions made by residents and their families.

The evidence base is limited, but there is some indication that ACP can improve the sense of satisfaction with care received, increase a sense of control and create greater alignment between care received and care desired.

Electronic systems for care co-ordination are promoted for end of life care and in Scotland there is currently a push for a single IT system built up around the electronic health records in this area. There is some evidence from all three comparison settings that this approach can improve outcomes for professionals but more research is needed on the impact on quality of care for residents.

Co-ordination of care can happen at various levels between team members, across teams in a single organisation or between organisations. In all three comparison settings there is movement toward greater co-ordination and sharing. For example, in children's services *Every Child Matters* and *Getting it Right for Every Child* are being implemented with more co-ordination using

the Common Assessment Framework and Single Outcome approaches. There is evidence to suggest care co-ordination improves quality of life for recipients (Ouwens *et al.*, 2005; Au *et al.*, 2011). However the evidence base is compromised by variation in the use of the term 'care co-ordination' and the quality of the evaluation and review evidence available across all three comparison settings. Nonetheless, care co-ordination is a key aspect of quality improvement for Department of Health policy, which can be witnessed in recent announcements around health and social care, the Common Assessment Framework and other initiatives, including ACP and the use of electronic records.

Advanced care planning

ACP is used and promoted as part of an approach to documenting end of life care. It can be defined as:

> *"A voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future, and if they wish, set on record: choices about their care and treatment and/or advance decisions to refuse a treatment in specific circumstances."*
> (NEoLCP, 2011)

It differs from care planning in that it focuses on anticipating how a person's condition might affect them in future and how their care should be managed when that point arrives (Joseph *et al.*, 2010). As with care planning, risk assessment is part of ACP, facilitated by health and social care professionals. While this is currently targeted at people nearing the end of their lives, there are examples of use in the wider population, such as in the United States, where living wills used by the general population adopt a similar approach (individuals can indicate that they wish to refuse particular treatment in case at a later stage they are unable to communicate this wish).

Our review identified three studies that considered the impact of ACP on care. The main findings were that:

- individuals indicated a stronger sense of control and hope;
- relationships with others were stronger;
- improved quality of care was reported;
- there were improved outcomes for carers e.g. reduced stress and anxiety;
- staff confidence increased;
- there was some indication of a reduction in inappropriate hospital admissions.

Sources: Clifford *et al.* (2007), Detering *et al.* (2010), NEoLCP (2010b)

More has been written about approaches and key principles involved in the delivery of ACP. These can be summarised as:

- effective, person-centred communication carried out with compassion and sensitivity;
- respect for decisions made by the individual, including the decision not to participate in care or ACP;
- full participation of the individual in choosing and signing off the content of care or ACPs;

- supportive and adequate information available to meet the needs of the individual;
- appropriate timing of discussions in an appropriate context;
- regular reviews of care planning documentation;
- facilitation by staff with the appropriate skills and training, who have ideally built up a relationship of trust with the individual;
- involvement of key stakeholders and effective communication across teams;
- engaging with individuals' morals and beliefs.

Sources: Lorenz *et al.* (2009), IAHPC (2009), Horne *et al.* (2009), Payne *et al.* (2009), NEoLCP (2010a), Henry *et al.* (2011), NEoLCP (2012)

Conversely, barriers to implementing ACP include:

- a lack of organisational support;
- inadequate time;
- lack of staff skills allowing them to raise sensitive topics and deal with own emotions;
- concern over raising expectations that cannot be delivered in local framework.

Sources: Weiner *et al.* (2004), Curtis *et al.* (2005), Stobbard-Rowlands (2009), Detering *et al.* (2010), Stein *et al.* (2013)

There have already been some moves to introduce ACP into care homes for older people which are supported by guidance, toolkits (NEoLCP, 2011, 2012) and training (Adshead *et al.*, 2011). These are often delivered through hospices' education teams (for example the London-based St Joseph's Hospice and St Christopher's Hospice). While the evidence base is limited, and often targeting nursing homes (Hayes *et al.*, 2011), there is some support for the use of ACP to help improve satisfaction with care and involve residents in decision-making and planning for the future. For example, Stobbart-Rowlands *et al.* (2012) concluded that ACP in care homes contributes to overall improvements in care, including improvement in communication skills and a more open organisational culture. However, more work is needed to determine the full impact of ACP and specifically to examine issues around staff training to enable appropriate and increased use of ACP in care home settings.

In addition, it is important to address barriers to the approach in order to increase uptake (Froggatt *et al.*, 2009; Addicott, 2011). Barriers include staff confidence and knowledge, lack of staff time, staff discomfort with the topic and constraints in implementing people's wishes (Froggatt *et al.* 2009). Workforce development is an important consideration and Stobbart-Rowlands *et al.* (2012) found an increase in the use of ACP following staff training.

Electronic systems for co-ordination of care

Within end of life care, electronic systems for co-ordinating care feature prominently in policy including *The National End of Life Strategy* (Department of Health, 2008). The rationale behind electronic palliative care co-ordination systems includes the need to provide the right information, care, time, resources and place to ensure person-centred approaches for individuals can be implemented. Locality registers identified in the review (now called electronic palliative care co-ordination systems or EPaCCS)

were viewed as playing a key role in improving co-ordination of end of life care services. This view was reinforced in the NICE Quality Standard (2011), the Palliative Care Funding Review and Standard ISB 1580. This national standard encourages an electronic approach.

Practice examples

End of Life Care Quality Assessment (ELCQuA)
The National End of Life Care Programme has developed the ELCQuA tool. This freely available, online tool is designed to help professionals self assess and monitor progress against the NICE Quality Standard for end of life care, share good practice with others and make good investment decisions to support the delivery of high quality care at the end of an individual's life. It can be used by health and social care staff and overcomes the issue of interoperability as it is stored online.

CHASE
CHASE Hospice Care for Children began to develop an electronic data collection system for children's hospices in the UK. The CHASE team is multidisciplinary and worked together to identify routinely collected information that could be stored usefully on a computer database, before developing a system for doing this. A paper by Menezes et al. (2007) reported up to ten other children's hospices using the same system.

Impact of electronic systems
The EPaCCS approach outlined above has been evaluated and provides some support for the move to electronic systems to help co-ordinate care (NEoLCP, 2012; NHS Improving Quality, 2013). The evidence base is limited but there is emerging evidence of improved co-ordination of care, relationships between professionals and patients and relationships between hospices that use EPaCCS and those about to implement the system. In addition, there was evidence of:

- 90 additional deaths in usual place of residence (as opposed to in hospital) over four pilot sites;
- reduction in cost for admissions to hospital that end in death in the pilot sites, although this cannot be directly linked to EPaCCS;
- recurrent savings after four years of over £100,000 per annum and a cumulative net benefit over four years of around £270,000 for a population of 200,000 people.

Evaluators emphasised that the findings were from four pilot sites and that care needs to be taken when translating these to other areas, which will have local distinctiveness. In addition, there was some evidence of reduced role satisfaction for team members, linked to challenges that new systems presented, such as frustration when using them and concern over impact on existing relationships.

In the United States, a survey of hospices identified different characteristics of those using electronic documentation (ED) compared with those not using ED, and concluded that those using ED were more likely to engage with ACP, reflect on cultural needs and collect information on resident experiences as they approached death, suggesting ED leads to improved data collection and reporting in a hospice setting (Cagle *et al.*, 2012).

In terms of characteristics of care providers moving toward ED, Eason *et al.* (2012), in their study of two UK local health communities, suggested that sharing information happened effectively where organisations had:

- worked to move forward together through joint planning;
- a clear understanding of local pathways;
- matched specific needs for information sharing between organisations.

Little has been written about the barriers to introducing electronic systems within a hospice setting, but a review by Gagnon *et al.* (2012) identified individual and professional factors (such as lack of familiarity, time constraints, perceived usefulness), human environment (such as residents' attitudes to technology, interference with relationships) and organisational environment (such as lack of support, training and implementation strategy) as being significant. In addition there were issues of interoperability both between systems of different organisations and with individual organisations' existing systems.

Within residential care, there are software packages available to support an electronic approach to documentation; for example, Care and Clinical, which helps nursing and care staff plan, review and evaluate residents' care. However, research within care homes (Afridi *et al.*, 2013) has suggested that while existing IT-based systems can be adapted, more bespoke approaches are necessary in order for systems to be useful. However, the study did conclude that ED could be a better method of capturing frontline care data and save time.

Transferable learning

There is some evidence to suggest that ACP can improve care outcomes for residents, improve staff confidence and help build positive relationships between staff and residents. While care homes are beginning to consider the value of ACP, managers need to identify and address the barriers for uptake at an organisational level, with staff and potentially with families and residents, in order for the full potential of the approach to be reached in this setting.

Learning from other settings would suggest that there needs to be the following in place:

- training and ongoing support for staff to engage with the approach, develop communication skills and overcome any confidence issues;
- adequate time built into care assessment processes and reviews;
- organisational culture that values the approach;
- evaluation in order to share learning with other providers.

ED has the potential for wider use and the findings from the evidence would support this. While care homes are already exploring the use of IT-based systems, there are a number of learning points from other settings worth highlighting:

- clear idea of stakeholders and engagement from the outset, supported by inter-agency working;
- senior staff and IT staff working together to design a system;
- senior staff involved who are able to make decisions;
- understanding of how new systems integrate or replace previous systems;

- clear scope of how any new systems and access points can be used in care settings;
- patient information, step-by-step consent process and data-sharing protocols;
- training for staff involved in the new system, including peer support and use of champions.

Source: Ipsos Mori Social Research Institute (2011)

In addition, attention could be paid to the impact on existing relationships, and how the new approach could be used to strengthen these relationships rather than undermine them, as well as looking at the added value of ED.

6 STAFF SELECTION AND SKILLS

In this chapter we review the skills of care and support staff and investigate various approaches to recruitment.

Overview

Different approaches to recruitment were evident in our review. These included value-based recruitment and involvement of people using care and support services. However, more evidence is needed to determine the effectiveness of such approaches.

There was limited information available on what makes a good residential care worker in the comparison settings, but skills that are important have been identified and include communication, the ability to form and maintain relationships, the ability to empathise and good alignment of personal and organisational values. More specific examples of effective communication skills have been noted in the literature, but limited evidence of impact is available beyond short-term outcomes.

Staff selection

While there are already formal processes in place for staff selection, there were some approaches evident in the comparison settings that might be of use to residential care employers. One in particular is to place importance on selecting staff on the basis of personal and organisational value alignment. However, much of the discussion regarding this approach has been based on practitioner experience alone. There is little evidence of effectiveness available, but it is hoped that over the coming months more will emerge.

The argument regarding this approach is that everyone brings their own personal attributes, ambitions and reasons for wanting to work in their chosen role to an organisation. They cannot be treated as empty vessels into which formal processes and organisational values can be transferred (Felce

et al., 2002a, 2002b). Instead, employers need to consider how the personal characteristics of staff fit into the organisational culture, both formal and informal, to determine the outcome for people who use the services.

Fyson *et al.* (2007) reported, in a large-scale qualitative study, that several managers aimed to recruit staff who did not have a background in a specific care setting, preferring to train them on the job so that they would embrace the setting's organisational values first and foremost. The argument here was that a comprehensive induction programme could be used to embed the necessary values of supporting people alongside the practical skills required to deliver the care. Feedback from this practice supported the notion that staff are not empty vessels but come equipped with their own personal and professional values. The authors concluded that the match between the two is crucial to quality delivery of care and organisational direction.

Individual job roles might require specific characteristics and values, but there were some pointers in the research evidence which related to caring roles in general. Staff should:

- empathise rather than sympathise with people they are caring for;
- show willingness to undertake a range of activities relevant to the individuals they care for;
- actively choose to work in their role, which can indicate a level of job commitment;
- have a strong sense of wanting to make a difference;
- have behavioural and cognitive strategies for coping with difficult caring situations such as death;
- be clear of personal and professional boundaries.

Sources: Ablett *et al.* (2007), Pitt (2011), Bates *et al.* (2012)

Feedback from the organisations interviewed for this research confirmed the importance of these characteristics and the importance of attitudes and values. However, they also recognised the difficulty in actually pinpointing these in an interview situation. There was a view that training in this might help with recruitment, and also that involving people in need of care and support in identifying good characteristics of staff might ensure a good match between client and caregiver. Models such as social pedagogy incorporate user involvement into staff selection. For example in one children's residential care organisation, young people were involved in the interview process for certain posts.

Practice examples

Value-based interviewing (VBI)
VBI is a two-day NSPCC training course for individuals responsible for conducting recruitment interviews with potential staff and/or volunteers who are going to work with children. The VBI method builds on good recruitment and safeguarding practice, including pre-employment checks. It is an important added-value tool, rather than a 'toolbox' to cover safeguarding in recruitment.

Recent evaluations have found that VBI significantly reduces or eliminates so-called 'gut feeling' (Cleary et al., 2008). Managers who use VBI have

more in-depth information on which to base decisions about candidates' suitability. It provides insight into candidates' values and behaviours and how they are aligned with those of the organisation.

Users involved in selection
Who Cares? Scotland has a three-stage approach to recruitment, involving young people in the selection procedure as a means of identifying how the candidate relates to young people and what their value base is for working with them.

Scenario-based interviewing
The Avenues Trust poses various scenarios to potential staff, who are then asked to draw out the problems and challenges of these in a presentation to the employers. Candidates are then asked to outline how they would go about improving the scenario for people who use care and support services.

In health and social care, there is a move to consider the values of a candidate and how they may or may not suit working in this sector. Within social care, *A Question of Care* is a new video-based resource that is being developed across the UK to help potential recruits understand what the work is really about and whether they are suited to it or not. It enables people to assess their own suitability in terms of the values and attitudes that employers regard as important.

Skills for Care, in partnership with the National Skills Academy and McIntyre, has developed a toolkit to help employers at the recruitment stage to think about organisational and personal value match and aims to increase the likelihood of 'right first time' appointments. This toolkit is currently being evaluated and the results are due in summer 2014. This approach could be used to determine the impact of value-based recruitment on both the quality of staff recruited and, importantly, retention in the sector.

Staff skills

Beyond the professional skills and qualifications required to do the job, literature from the three settings highlighted a number of skills useful for staff to develop in order to deliver quality care in the current practice and Department of Health policy context. Table 3 highlights some of the aspects of skill development that were shown to be important in the three comparison settings. However, while there have been individual evaluations of specific training programmes, there is no robust evidence of impact for the general areas commented on below.

Table 3: Key areas for staff skill development

Area for staff skill development	Commentary
Communication skills	Characteristics of effective communication include time to build relationships, respect of faith, culture and life choices, availability of privacy, ongoing support for people using care services, active listening with skilled staff. Sources: IAHPC (2009), Fineberg *et al.* (2008), Stobbart-Rowlands (2009), Henry *et al.* (2011), Skills for Care (2012)
Relationship-building skills	Important to identify and understand fully the behaviour of people using care services to help facilitate positive risk-taking. Characteristics of relationship building are discussed further above (see page 23). Sources: Glynn *et al.* (2008), Mansell (2010), Carr (2010), Camble (2012)
Risk management	Skills to be able to identify and manage risk are important and these are discussed above (see page 19). These are particularly important when working with people from different cultures. Sources: Carr (2010), Cole *et al.* (no date)
Cultural awareness	This includes staff understanding of sensitivities when working with people from different ethnic or cultural backgrounds and the need to update knowledge in this area. Source: Cole *et al.* (no date)
Working with people whose behaviour challenges	Some important pointers for more effective handling of challenging behaviour include an initial strong relationship resulting in a more positive outcome, de-escalation techniques, strong cultural and management support for staff, a positive culture and a skilled staff. Sources: Steckley *et al.* (2008a, 2008b), Steckley (2010)
Developing person-centred teams	There is training available to help support social care teams in refocusing delivery of services to person-centred approaches with relationships at their heart.

Within social care, there is a spectrum of training available to staff and it is difficult without a full review of training in residential care to extract learning from other sectors. What is clear from the data is that there is a large number of staff in social care (42 per cent) who have no formal qualifications (Skills for Care, 2013) so it is important for on-the-job training to play a role, perhaps more so than in hospice care or residential care for young people, in ensuring staff are skilled and competent to deliver the quality of care required.

Transferable learning

In selecting staff for caring roles, there are moves toward a more value-based approach to recruitment within the health and social care sector. However, this could be enhanced through:

- increased participation in value-based recruitment;
- clear organisational values set out explicitly for residents, staff and potential staff;
- involvement of residents in selection and interview processes;
- ensuring that values are given appropriate and potentially equal weighting to skills in the selection process;
- interaction with existing staff and residents during the selection process.

It is more challenging to extract transferable learning for staff training as the evidence is very limited, but there are areas that have been highlighted as important to consider when putting together a workforce development plan. Residential care settings should continue to be mindful of the range of skills necessary to deliver quality care, in particular relationship-building skills, as the emphasis for care delivery is starting to move toward personalisation, choice and joint decision-making.

7 ONGOING SUPPORT FOR STAFF

In this chapter we consider the well-being of staff working in residential care settings and how this may impact quality of care. We also look at the concept of, and approaches to, self care.

Overview

Staff stress and burnout are real concerns within residential care settings and can be caused by increased workload demands and unsupportive environments. Within the field of learning disabilities, there is some limited evidence to suggest that working in a progressive environment, where higher goals and aspirations are set out for residents, can increase stress, as staff have to deal with more complex work demands.

The literature gives examples of a number of mediators at organisational, team and individual levels, although there is limited evidence of the effectiveness of these.

Self care is an important concept that acknowledges that staff have to take care of themselves before being expected to be able to care effectively for others. It can be divided into four main areas: physical, emotional/cognitive, relational and spiritual. When all four areas are addressed, they can enable staff to maintain a strong sense of self and develop resilience to ongoing work pressures.

Staff stress and burnout are issues identified for people working in residential care settings and with groups whose behaviour can be described as unpredictable or challenging (Campbell, 2007; Mansell, 2007). The increasing emphasis on person-centred approaches in policy and practice delivery creates potential for more stress and burnout to occur, due to the increasing demands and deeper involvement which individual situations required.

Sometimes called compassion fatigue, burnout can be defined as a state of mental and/or physical exhaustion caused by excessive and prolonged

stress with symptoms that can include stress arousal and exhaustion (Keidel, 2002; Sharp *et al.*, 2002; Campbell, 2007; Mansell, 2007; Peters *et al.*, 2012). This can result in negative personal and professional consequences as well as situational risk factors (e.g. lack of support for work/life balance, isolation, feeling poorly managed and resourced) all of which are important to prevent as stress and burnout have been identified as predictors of abuse (Pillemer *et al.*, 1991 in Lawrence *et al.*, 2010).

While there are specific issues for different settings that might lead to staff stress and burnout, there are a number of frequently-quoted causes which cut across all three settings:

- Work-related demands: the workload, clinical demands and need for continuous high quality care all place stress on staff working in a changing environment often with limited resources.
- Unsupported staff: staff who feel alienated from their employer or who are poorly supported.
- Organisations that set high goals for staff and aspirations for people using services.

Sources: Broadhurst *et al.* (2007), Mansell (2007), Peters *et al.* (2012)

Mediators and supports

While staff may have personal attributes that provide them with resilience to absorb stress, there are techniques and supports that can be used to further reduce the effects of stress and burnout. There was limited evidence available in the comparison settings, but some work has been conducted in palliative care that sets out responses which can be used to support staff. In addition, a small-scale study (Beadle-Brown *et al.*, 2008) was conducted with staff working in the learning disabilities field that found the following supports in place:

- Organisational level supports:
  — positive working environment and culture;
  — guidance for staff and help to recognise the signs of compassion fatigue or burnout;
  — well-balanced workloads;
  — emotional safety policy outlining responsibilities of employers to keep staff safe;
  — safe and supported routes through which to report poor practice.

- Team level supports:
  — peer support and good team relationships;
  — structured debriefings, including bereavement debriefings;
  — good leadership and management;
  — access to team leader or manager;
  — good quality supervision that is able to recognise the impact of stress on the staff member.

- Individual level support:
  — education and training, especially communication skills and deeper understanding of resident behaviours;
  — mentoring and coaching sessions;
  — professional supervision;

- support from managers;
- self care including physical, emotional/cognitive, relational and spiritual factors;
- strong relationships with families and individuals;
- access to external facilitation;
- constructive feedback;
- celebration of success.

Sources: Kennard (2004), Sharp *et al.* (2002), Bromley *et al.* (1995) in Campbell (2007), Beadle-Brown *et al.* (2008), Running *et al.* (2008), Aycock *et al.* (2009), Swetz *et al.* (2009), Lawrence *et al.* (2010), Pereira *et al.* (2011), Peters *et al.* (2012), Slocum-Gori *et al.* (2011), The Hospice Foundation (2013)

Practitioners identified other supports including a 'no blame' culture, accountability across the team, team briefings, meetings that allow staff to help each other, opportunities to vent frustration and managers providing informal as well as formal staff meetings.

Practice example

Schwartz Care Rounds

First introduced by the Schwartz Center in the United States, Schwartz Care Rounds have been supported by the recently established Point of Care Foundation in the United Kingdom as an important contribution to the delivery of compassionate care in acute settings. Many hospices are now embracing the approach, and Macmillan Cancer Support has contracted the Schwartz Center to train its staff. The approach has also been rolled out in hospital wards in England.

The theory behind Schwartz Care Rounds is that staff can only provide compassionate care when they themselves feel supported in their work. Indeed there is some evidence to support this claim (Goodrich, 2011). The aim is to give staff the opportunity to reflect on experiences of care. It is not designed to be a problem-solving session. The desired outcomes are improved relationships and communication between staff and residents and among staff. This is achieved through a multidisciplinary forum, where staff meet once a month to discuss the non-clinical aspects of caring for residents (such as the emotional and social challenges associated with their jobs).

Evidence from evaluations of the approach indicated:

- better team working;
- less stress being self-reported;
- increased likelihood of staff engaging with self care;
- improved relationships between staff and residents;
- impact on working together toward a strategic vision;
- successful transfer of the approach from the United States to England.

Sources: Lown *et al.* (2010), Goodrich (2011), Goodrich *et al.* (2012)

Staff self care

The premise of self care is that you cannot meet the needs of people you care for when your own needs are not met (The Hospice Foundation, 2013) and there was some evidence in the literature that compassion fatigue is

exacerbated when staff do not pay attention to self care (Abendroth *et al.*, 2006, Merluzzi *et al.*, 2011). Self care rests with individual practitioners and can include practices to maintain health and well-being, taking time to explore beliefs and feelings about grief and death, seeking support and engaging in activities outside the caregiving situation. Hill Jones (2005) outlined four aspects of self care: physical (e.g. rest, exercise, healthy eating), emotional/cognitive (e.g. reflection and internal dialogue), relational (e.g. supportive relationships and conflict resolution) and spiritual (e.g. 'bigger picture' outlook).

Evidence of the impact of particular interventions aimed at supporting self care was more limited. While there were a number of primary studies from the United States, no review-level literature was identified. In the United Kingdom, the small number of examples identified tended to be outside the comparison settings, such as those by Galfin *et al.* (2010) and Hopkins (2013), which provided some support for the use of psychological interventions.

Transferable learning

There have been very few studies in care homes that look specifically at staff burnout and stress levels, let alone in connection with organisational factors and workload structures. However, from the research that is available, we can infer that staff burnout is an issue for those working in care homes as they face many of the same challenges as those in other settings. Without a full review of practice it is difficult to comment on the current state of play in residential care homes in terms of supporting staff and attention paid to compassion fatigue.

In general healthcare, there are numerous examples of workforce development approaches being used to develop supportive and learning organisations, for example through leadership skills (Skills for Care, 2012; National Skills Academy, 2012), supervision skills within social work and training to promote reflective practice.

In terms of learning from other settings, there would seem to be justification for distributing more information on staff burnout among care staff, building on the factors identified above. Providers could gather information at a local level using these factors as a guide to help raise awareness. It is important that providers are prepared to consider organisational, team and individual supports when addressing this area.

Specifically, learning from the Schwartz Care Rounds should be considered in the context of care homes. While the name sounds like it applies to a medical setting, the approach is ultimately about supporting staff in a safe environment. There is an opportunity to use this approach in care homes to reap some of the benefits found in other environments, such as in hospital wards and hospice settings. However, it would be beneficial to think about this as a pilot project at first and build on the findings and first-hand experiences of others who introduced this model. Talking to those who have previously implemented Schwartz Care Rounds, for example, and then reflecting on the challenges and facilitators, would seem like a sensible step forward.

The notion of self care is important in other settings and could aid the retention and job satisfaction of care home staff. It has been found that while it is the responsibility of individuals to care for themselves, employers can highlight the importance of self care to staff, perhaps through existing strategies like employee assistance programmes. In addition, employers could look for some aspects of resilience and self care during the recruitment process.

CONCLUSIONS

This research set out to identify ways in which the quality of care provided by care homes for older people could be improved by applying potential learning from other settings. There were inherent challenges in using this approach, which became apparent as the research progressed. Throughout the report, the lack of evidence of impact or effectiveness in the comparison settings is noted. This limited the extent to which robust and conclusive learning could be transferred to care homes for older people.

The review focused on the three comparison settings chosen at the outset and did not include a full review of current evidence or practice in care homes. While we have presented a general commentary on the state of play in care homes throughout the report, this should be viewed as the first step in the process of applying learning from other settings, rather than the end point. It is important to consider the findings from the review in the broader context of provision in care homes. Care homes should work with partners to identify the areas with most potential for transferable learning by reflecting on current practice and areas for change. With this in mind, here are a number of themes and areas for further investigation that emerged.

Increased involvement

Involving the people who receive care and support is an important emerging theme that cuts across a number of aspects of care delivery. At an individual level, this means involving residents in planning care, managing personal risks and giving them input into formal and informal processes. At an organisational level, it involves increased participation in formal inspections (e.g. as a peer inspector), greater links and involvement with the community and volunteer working. While care homes already involve residents to varying degrees, it would be useful to reflect on current practice both at a local level and also to share learning between care homes to identify opportunities for greater participation.

Positive cultures

The evidence indicated that the culture of the organisation has an important role to play in improving relationships between staff and also between staff and residents. Currently relationships are affected by tensions between the residential care setting's function as a workplace versus it being a home. It was evident in the research that there is a need for a culture supported by strong leadership, trained staff and clear policies to be balanced with keeping the resident at the heart of care. In addition, the physical environment has

a significant role to play in promoting a positive culture. It is important that people who use services feel at home, that there is a range of room options, social space, contact with the natural world etc., as the evidence suggested this can influence the experience of care. A number of practical pointers for care homes emerged in the research, as well as examples of good practice that care homes could refer to when considering the current culture of their organisation.

Holistic approaches

Person-centred and holistic models of care delivery cut across many of the themes listed above. Social models of care that have been used in other settings can be applied to residential care for older people. For example, social pedagogy is used both within children's residential care and care for people with learning disabilities, and the evidence is growing for this approach and similar models in the United Kingdom. There is work in Aberdeen to encourage undergraduates in social care to be trained to apply holistic and relationship-based approaches in care settings for people of all ages rather than in a particular setting or institution. It remains to be seen whether this will be successful but in terms of moving forward this approach would help with risk management, creating a positive culture, improving choice and control, as well as building relationships in the workforce and with residents in care homes.

Co-ordination of care

Care co-ordination has an important role to play in the delivery of holistic approaches. There is support for staff discussing options with the individuals receiving care and support, and of sharing with other staff both inside and outside of the organisation in order to improve relationships, perception of care quality and staff confidence. However, this is dependent on a trained, skilled and supported workforce to enable care to be co-ordinated across different parts of the health and social care sector. Within end of life care, one mechanism to support staff is the increasing use of electronic documentation. Therein lays a challenge for care homes to reflect on the current efficiency of their paperwork systems and the impact of this on care delivery.

Workforce issues

The workforce is key to the delivery of care and while learning from other settings was limited in this area, some key approaches may prove useful. Staff selection based on competencies is commonplace but consideration of the match between organisational and personal values at the recruitment stage emerged in the literature as a useful approach contributing to positive organisational cultures. Ongoing support for staff is another area where there is potential for learning in residential care. Comparing current processes with key characteristics from the evidence at organisational, team and individual levels would help residential care providers identify gaps in their staff support provision. In addition, the potential for other models of support such as Schwartz Care Rounds and how these might be applied in a care home setting would be of value.

To conclude, while the evidence base of effectiveness was limited in the literature, there are key points that providers of residential care could consider within the context of their own practice and in partnership with others to improve the culture of care homes and the experience of care and support for residents. This report provides a starting point for ideas, which need to be explored in more detail both with care home providers as well as partners in the comparison settings.

REFERENCES

Abendroth, M. and Flannery, J. (2006) 'Predicting the risk of compassion fatigue'. *Journal of Hospice and Palliative Nursing*, 8(6), pp. 346–355

Ablett, J. R. and Jones, R. S. (2007) 'Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work'. *Psycho-Oncology*, 16(8), pp. 733–740

Action for Children (2009) *Research update: Holding the Space*. Available at: www.actionforchildren. org.uk/media/95884/action_for_children_briefing_holding_the_space.pdf [accessed 10th February 2014]

Adams, L., Beadle-Brown, J. and Mansell, J. (2006) 'Individual planning: an exploration of the link between quality of plan and quality of life'. *British Journal of Learning Disabilities*, 34(2), pp. 68–76

Addicott, R. (2011) 'Supporting care home residents at the end of life'. *International Journal of Palliative Nursing*, 17(4), pp. 183–187

Adshead, L. and Lenton, J. (2011) *Supporting people to live and die well: test site final report*. London: St Christopher's Hospice

Afridi, A., Warmington, J. and Foreman, W. (2013) *Paper cuts: Is excessive paperwork in care homes undermining care for older people?* York: Joseph Rowntree Foundation

Ahmed, M. (2011) 'Anything's possible, with the right support'. *Community Care*, 1885, pp. 32–33

Andersson, E., Tritter, J. and Wilson, R. (2007) *Healthy democracy: The future of involvement in health and social care*. London: NHS – The National Centre for Involvement

Au, M., Simon, S., Chen, A., Lipson, D., Gimm, G. and Rich, E. (2011) *Comparative effectiveness of care coordination for adults with disabilities*. Washington DC: Center on Health Care Effectiveness

Aycock, N. and Boyle, D. (2009) 'Interventions to manage compassion fatigue in oncology nursing'. *Clinical Journal of Oncology Nursing*, 13(2), pp. 183–191

Bates, P., Hardwick, K., Sanderson, K., Sanghera, R. and Clough, J. (2012) 'Almost invisible: providing subtle support in community settings'. *Tizard Learning Disability Review*, 17(4), pp. 156–162

Beadle-Brown, J., Hutchinson, A. and Whelton, B. (2008) 'A better life: the implementation and effect of person-centred active support in the Avenues Trust.' *Tizard Learning Disability Review*, 13(4), pp. 15–24

Black, J. (2012) *A framework for evaluating and measuring the impact of user involvement in end of life care*. London: National Council for Palliative Care

Brereton, L., Gardiner, C., Gott, M., Ingleton, C., Barnes, S. and Carroll, C. (2011) 'The hospital environment for end of life care of older people and their families: an integrative review'. *Journal of Advanced Nursing*, 68(5), pp. 981–993

Broadhurst, K. and Pendleton, T. (2007) 'Revisiting children "home on trial" in the context of current concerns about the costs and effectiveness of the Looked After Children system: findings from an exploratory study'. *Child and Family Social Work*, 12(4), pp. 380–389

Bromley, J. and Emerson, E. in Campbell, M. (2007) 'Staff training and challenging behaviour: who needs it?' *Journal of Intellectual Disabilities*, 11(2), pp. 143–156

Cagle, J., Roskoske, F., Durham, D., Schenck, A., Spence, C. and Hanson, L. (2012) 'Use of electronic documentation for quality improvement in hospices'. *American Journal of Medical Quality*, 27(4), pp. 282–290

Camble, A. (2012) 'Person-centred support for people who exhibit challenging behaviour'. *Learning Disability Practice*, 15(2), pp. 18–20

Cameron, C. (2011) 'Social pedagogy: what questions can we ask about its value and effectiveness?' *Children Australia*, 36(4), pp. 186–197

Cameron, C., Petrie, P., Wigfall, V., Kleipoedszus, S. and Jasper, A. (2011) *Final report of the social pedagogy pilot programme: Development and implementation*. London: Thomas Coram Research Unit, Institute of Education, University of London

Cameron, C. (2012) *Social pedagogy in the UK: time to reflect*. Available at: http://www.communitycare.co.uk/2012/03/02/social-pedagogy-in-the-uk-time-to-reflect/#.UpNiyNJIa8A [accessed 7th February 2014]

Campbell, M. (2007) 'Staff training and challenging behaviour – who needs it?' *Journal of Intellectual Disabilities*, 11(2), pp. 143–156

Cane, F., Jennings, R. and Taylor, J. (2011) 'A rehabilitation training programme at the end of life'. *End of Life Care Journal*, 1(1)

Care Quality Commission (2011) *The operation of the Deprivation of Liberty Safeguards in England, 2009/10*. London: CQC

Care Quality Commission (2012) *Monitoring the impact of the Mental Capacity Act Deprivation of Liberty Safeguards in 2011/12. Summary*. London: CQC

Carnaby, S., Roberts, B., Lang, J. and Nielsen, P. (2010) 'A flexible response: person-centred support and social inclusion for people with learning disabilities and challenging behaviour'. *British Journal of Learning Disabilities*, 39, pp. 29–45

Carr, S. (2010) *Enabling risk, ensuring safety: Self-directed support and personal budgets*. London: SCIE

Children in Scotland (2012) *The pedagogues – An evening of discussion*. Available at: http://www.childreninscotland.org.uk/docs/pubs/PedagogyReport.pdf [accessed June 2013]

Chochinov, H. (2007) 'Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care.' *British Medical Journal*, 335(7612), pp. 184–187

Chochinov, H., Kristjanson, L., Beritbart, W., McClement, S., Hack, T., Hassard, T. and Harlos, M. (2011) 'Effect of dignity therapy on distress and end-of-life experiences in terminally ill patients: a randomised controlled trial'. *The Lancet*, 12(8), pp. 753–762

Cleary, K. and Golokoz, V. (2008) *NSPCC value based in interviewing: Report into the development and evaluation of the effectiveness of a value based interviewing method used in recruitment and selection of individuals to work with children and young people*. London: NSPCC

Clifford, C., Badger, F., Plumridge, G., Hewison, A. and Thomas, K. (2007) *Using the Gold Standards Framework in care homes: an evaluation of the phase 2 programme*. Birmingham: University of Birmingham

Cole, A. and Burke, C. (no date) *Reaching out to people with learning disabilities and their families from black and minority ethnic communities*. London: Foundation for People with Learning Disabilities

Coulter, A. and Ellins, J. (2006) *Patient-focused interventions: A review of the evidence*. London: The Health Foundation

Crocker, T., Forster, A., Young, J., Brown, L., Ozer, S., Smith, J., Green, J., Hardy, J., Burns, E., Glidewell, E. and Greenwood, D. (2013) 'Physical rehabilitation for older people in long-term care'. *Cochrane Database of Systematic Reviews*

Curtice, L. and Trew, C. (2012) *The same as you? 2000–2012: Evaluation of progress from the perspectives of people with learning disabilities and family carers*. Scotland: Scottish Consortium for Learning Disabilities

Curtis, J.R., Engelberg, R.A., Wenrich, M.D. and Au, D.H. (2005) 'Communication about palliative care for patients with chronic obstructive pulmonary disease'. *Journal of Palliative Care*, 21, pp. 157–164

Demos (2013) *The Commission on Residential Care* (CORC). Available at: http://www.demos.co.uk/projects/corc [accessed 10th February 2014]

Department for Education (2004) *Every Child Matters.* London: Department for Education

Department of Health (2001) *Valuing People.* London: Department of Health

Department of Health (2005) *Independence, well-being and choice: Our vision for the future of social care for adults in England.* London: Department of Health

Department of Health (2006) *Our health, our care, our say: A new direction for community services.* London: Department of Health

Department of Health (2007) *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.* London: Department of Health

Department of Health (2008) *End of Life Care Strategy: Promoting high quality care for adults at the end of their life.* London: Department of Health

Department of Health (2009) *Valuing People Now.* London: Department of Health

Department of Health (2010a) *Putting People First.* London: Department of Health

Department of Health (2010b) *Nothing ventured, nothing gained: Risk guidance for people with dementia.* London: Department of Health

Department of Health (2011a) *Think Local, Act Personal.* London: Department of Health

Department of Health (2011b) *Statement of Government policy on adult safeguarding.* London: Department of Health

Department of Health (2012) *Transforming care: A national response to Winterbourne View Hospital.* London: Department of Health

Detering, K., Hancock, A., Reade, M. and Silvester, W. (2010) 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial'. *British Medical Journal,* 340, p. 1345

Dowling, S., Manthorpe, J. and Cowley, S. (2006) *Person-centred planning in social care: A scoping review.* York: Joseph Rowntree Foundation

Dowling, S., Manthorpe, J. and Cowley, S. (2007) 'Working on person-centred planning: from amber to green light?' *Journal of Intellectual Disabilities,* 11(1), pp. 65–82

Eason, J., Dent, M., Waterson, P., Tutt, D. and Thornett, A. (2012) 'Bottom-up and middle-out approaches to electronic patient information systems: a focus on healthcare pathways'. *Informatics in Primary Care,* 20(1), pp. 51–56

Edith Cowan University (2006) *Guidelines for a palliative approach in residential aged care.* Australia: The National Palliative Care Program

Eichsteller, G. and Holthoff, S. (2009) *Risk competence: Towards a pedagogic conceptualisation of risk in children.* Available at: http://www.thempra.org.uk/downloads/Eichsteller%20&%20Holthoff%20-%20Risk%20Competence.pdf [accessed June 2013]

Elseley, S. (2006) *Going the extra mile: An evaluation of a residential unit for younger children provided by Aberlour Sycamore services.* Stirling: Aberlour Child Care Trust

Elseley, S. (2009) 'Who else has a magic wand? *An evaluation of a residential unit for younger children'. Scottish Journal of Residential Care,* 8(1), pp. 11–18

Emond, R. (2003) 'Putting the care into residential care: the role of young people'. *Journal of Social Work,* 3(3), pp. 321–337

Felce, D., Lowe, K. and Jones, E. (2002a) 'Association between the provision characteristics and operation of supported housing services and resident outcomes'. *Journal of Applied Research in Intellectual Disabilities,* 15(4), pp. 404–418

Felce, D., Lowe, K., Jones, E. (2002b) Staff activity in supported housing services. *Journal of Applied Research in Intellectual Disabilities* 15 (4): 388-403

Fineberg, I. and Miller, P. (2008) *Literature review of 'communication' for the Irish Hospice Foundation's Hospice Friendly Hospitals Programme.* Dublin: Hospice Friendly Hospitals Programme

Finlay, W. M. L., Walton, C. and Antaki, C. (2008) 'Promoting choice and control in residential services for people with learning disabilities.' *Disability and Society,* 23(4), pp. 349–360

Froggatt, K., Vaughan, S., Bernard, C. and Wild, D. (2009) 'Advance care planning in care homes for older people: an English perspective'. *Palliative Medicine,* 23, pp. 332–338

Fyson, R., Tarleton, B. and Ward, L. (2007) *Support for living? The impact of the Supporting People programme on housing and support for adults with learning disabilities.* Bristol: Norah Fry Research Centre

Gagnon, M., Desmartis, M., Labrecque, M. and Palgliari, J. (2012) 'Systematic review of factors influencing the adoption of information and communication technologies by healthcare professionals'. *Journal of Medical Systems,* 36, pp. 241–277

Galfin, J. and Watkins, E. (2010) *Developing and evaluating a psychological intervention for use in palliative care.* Exeter: University of Exeter

Gandy, R. and Wilford, S. (2012) 'End of life services: public and patient involvement'. *British Journal of Healthcare Management,* 18(3), pp. 144–151

Garrett, D. (2012) *Promoting self-management: Should we help residents in care homes to self-manage their long-term conditions?* London: British Geriatrics Society

Gerry, E. (2011) 'Privacy and dignity in a hospice environment: the development of a clinical audit'. *International Journal of Palliative Nursing,* 17(2), pp. 92–98

Glynn, M., Beresford, P., Bewley, C., Branfield, F., Butt, J., Croft, S., Pitt, K. D., Fleming, J., Flynn, R., Parmore, C., Postle, K. and Turner, M. (2008) *Person-centred support: What service users and practitioners say.* York: Joseph Rowntree Foundation

Goodrich, J. (2011) *Schwartz Centre Rounds: Evaluation for the UK pilots.* London: The King's Fund

Goodrich, J. and Levenson, R. (2012) 'Supporting hospital staff to provide compassionate care: do Schwartz rounds work in English hospitals?' *Journal of the Royal Society of Medicine,* 105(3), pp. 117–122

Hall, S., Goddard, C., Opio, D., Speck, P. and Higginson, I. (2012) 'Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: a phase II randomized controlled trial of a brief palliative care psychotherapy'. *Palliative Medicine,* 26(5), pp. 703–712

Hayes, N., Kalsi, T., Steves, C., Martin, F., Evans, J., Schiff, R. and Briant, L. (2011) 'Advance Care Planning (PEACE) for care home residents in an acute hospital setting: impact on ongoing advance care planning and readmissions'. *BMJ Supportive and Palliative Care,* 1(99), p. 114

Hayrinen, K., Saranto, K. and Nykanen, P. (2008) 'Definition, structure, content, use and impacts of electronic health records: a review of the research literature'. *International Journal of Medical Information,* 77(5), pp. 291–304

Help the Hospices (2006) *Quality matters: Quality projects that are making a difference in hospice and palliative care services.* London: Help the Hospices

Help the Hospices (2012a) *Towards excellence in hospice care.* London: Help the Hospices

Help the Hospices (2012b) *Volunteers: Vital to the future of hospice care.* London: Help the Hospices

Help the Hospices (2013) *Public concerned about the rising demand for hospice care survey shows.* Available at: http://www.helpthehospices.org.uk/media-centre/latest-news/public-concerned-about-rising-demand-for-hospice-care-survey-shows/ [accessed 10 February 2014]

Henry, C. and Sherwen, E. (2011) 'A framework for the best end of life care planning'. *Nursing and Residential Care,* 13(3), pp. 137–140

Hill Jones, S. (2005) 'A self-care plan for hospice workers'. *American Journal of Hospice and Palliative Medicine,* 22(2), pp. 125–128

Holroyd, J., Lorenzetti, D., Straus, S., Sykes, L. and Quan, H. (2011) 'The impact of the electronic medical record on structure, process and outcomes within primary care: a systematic review of the evidence'. *Journal of the American Medical Informatics Association,* 18(6), pp. 732–737

Hoolahan, S. (2012) *ISF in action: Personalising block contracts – A research report.* Sheffield: The Centre for Welfare Reform

Hopkins, M. (2013) 'Review of "The compassion fatigue workbook: creative tools for transforming compassion fatigue and vicarious traumatisation"'. *British Journal of Guidance and Counselling,* 41(3), pp. 341–343

Horne, G., Seymour, J. and Payne, S. (2009) 'Advance care planning: evidence and implications for practice'. *End of Life Care,* 3(1), pp. 58–64

Hughes-Hallett, T., Craft, A., Davies, C., Mackay, I., Nielsson, T. (2011) *Funding the right care and support for everyone: Creating a fair and transparent funding system; the final report of the Palliative Care Funding Review.* London: Palliative Care Funding

Information Standards Board (2013) *Standard ISB 1580.* Available at: http://www.isb.nhs.uk/library/standard/236 [accessed 10 February 2014]

International Association for Hospice and Palliative Care (2009) *The IAHPC Manual of Palliative Care.* Houston: IAHPC

Ipsos Mori Social Research Institute (2013) *Public perceptions of the NHS and social care. An ongoing tracking study conducted for the Department of Health, December 2012 Wave.* London: Ipsos Mori

Javier, N. and Montagnini, M. (2011) 'Rehabilitation of the hospice and palliative care patient'. *Journal of Palliative Medicine,* 14(5), pp. 638–648

Jennings, R. (2013) 'A rehabilitative approach to palliative care'. *Hospice Information Bulletin,* 9(1)

Jingree, T., Finlay, W. M. L. and Antaki, C. (2006) 'Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meetings'. *Journal of Intellectual Disability Research,* 50(Part 3), pp. 212–226

Joseph, S., Chapman, S. and Regnard, P.C. (2010) *The difference between general care planning and advance care planning.* London: National End of Life Care Programme

Joseph Rowntree Foundation (2013) *Care homes: Risks and relationships. How can approaches to risk in care homes support good relationships and quality of life?* Available at: http://www.jrf.org.uk/work/workarea/care-homes-risks-relationships [accessed 10 February 2014]

Kalaga, H. and Kingston, P. (2007) *A review of literature on effective interventions that prevent and respond to harm against adults.* Edinburgh: Scottish Government Social Research

Keidel, G. (2002) 'Burnout and compassion fatigue among hospice caregivers'. *American Journal of Hospice and Palliative Medicine,* 19(3), pp. 200–205

Kennard, D. (2004) 'The therapeutic community as an adaptable treatment modality across different settings'. *Psychiatric Quarterly,* 75(3), pp. 295–307

Kilcommons, A. M., Withers, P. and Moreno-Lopez, Á. (2012) 'Do service users with intellectual disabilities want to be involved in the risk management process? A thematic analysis'. *Journal of Applied Research in Intellectual Disabilities,* 25(5), pp. 433–444

Kong, E., Evans, L. and Guevara, J. (2009) 'Nonpharmacological intervention for agitation in dementia: a systematic review and meta-analysis'. *Aging and Mental Health,* 13(4), pp. 512–520

Lawrence, V. and Banerjee, S. (2010) 'Improving care in care homes: a qualitative evaluation of the Croydon care home support team'. *Aging and Mental Health,* 14(4), pp. 416–424

Lown, B.A. and Manning, M.A (2010) 'The Schwartz Center Rounds: evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support'. *Academic Medicine,* 85, pp. 1073–81

Mansell, J. (2007) *Services for people with learning disabilities and challenging behaviour or mental health needs.* London: Department of Health

Mansell, J. (2010) *Raising our sights: Services for adults with profound intellectual and multiple disabilities.* London: Department of Health

Menezes, A., Esplen, P., Bartlett, P., Turner, B., Keel, M., Etherington, V., Conisbee, E., Plant, A., Haslam, V. and England, J. (2007) 'A system of electronic records developed by a children's hospice'. *International Journal of Palliative Nursing,* 13(5), pp. 237–242

Merluzzi, T.V., Philip, E.J., Vachon, D.O. and Heitzmann, C.A. (2011) 'Assessment of self-efficacy for caregiving: the critical role of self-care in caregiver stress and burden'. *Palliative and Supportive Care*, 9, pp. 15–24

Milligan, I. (2009) *Introducing social pedagogy into Scottish residential child care: An evaluation of the Sycamore Services social pedagogy training programme.* Available at: www.celcis.org/media/resources/publications/A4.pdf [accessed 7 February 2014]

Morris, S., Shugarman, L., Lorenz, K., Mularski, R. and Lynn, J. (2012) 'A systematic review of satisfaction with care at the end of life'. *The American Geriatrics Society*, 56, pp. 124–129

National End of Life Care Programme (2010a) *Developing skills: Talking about end of life care. Twelve pilot schemes in England.* London: NEoLCP

National End of Life Care Programme (2010b) *Capacity, care planning and advance care planning in life limiting illness: A guide for health and social care staff.* London: NEoLCP

National End of Life Care Programme (2011) *The route to success in end of life care – achieving quality environments for care at end of life.* London: NEoLCP

National End of Life Care Intelligence Network (2012) *What do we know now that we didn't know a year ago? New intelligence on end of life care in England.* London: NEoLCP

National Skills Academy (2012) *The Leadership Qualities Framework.* NSA: London

Neill, M., Allen, J., Woodhead, N., Sanderson, H., Reid, S. and Erwin, L. (2009) 'A positive approach to risk requires person-centred thinking'. *Tizard Learning Disability Review*, 14(4), pp. 17–24

NHS Improving Quality (2013) *Economic evaluation of the electronic palliative care coordination system (EPaCCS) early implementer sites.* London: NHS Improving Quality

NICE (2011) 'End of Life Care for Adults'. *Quality Standards, QS13.* London: NICE

NIHR (2012) *Using research to find new insights for good practice.* Available at: http://sscr.nihr.ac.uk/PDF/Insights/IN4.pdf [accessed 6 November 2013]

Ofsted (2011) *Outstanding children's homes.* Available at: www.ofsted.gov.uk/resources/outstanding-childrens-homes [accessed July 2013]

Ouwens, M., Wollersheim, H., Hermens, R., Hulscher, M. and Grol, R. (2005) 'Integrated care programmes for chronically ill patients: a review of systematic reviews'. *International Journal for Quality in Health Care*, 17(2), pp. 141–146

Payne, M. (2009) 'Continuing care, community care and end-of-life care'. *End of Life Journal*, 3(4), pp. 32–36

Pereira, S., Fonseca, A. and Carvalho, A. (2011) 'Burnout in palliative care: a systematic review'. *Nursing Ethics*, 18(3), pp. 317–326

Perry, J., Firth, C., Puppa, M., Wilson, R. and Felce, D. (2012) 'Targeted support and telecare in staffed housing for people with intellectual disabilities: impact on staffing levels and objective lifestyle indicators'. *Journal of Applied Research in Intellectual Disabilities: JARID*, 25(1), pp. 60–70

Peters, L., Cant, R., Selleck, K., O'Connor, M., Lee, S., Burney, S. and Karimi, L. (2012) 'Is work stress in palliative care nurses a cause for concern? A literature review'. *International Journal of Palliative Nursing*, 18(11), pp. 561–567

Petrie, P., Boddy, J., Cameron, C., Simon, A. and Wigfall, V. (2006) *Working with children in residential care: European perspectives.* Buckingham: Open University Press

Pillemer and Bachmann-Prehn (1991) in Lawrence, V. and Banerjee, S. (2010) 'Improving care in care homes: a qualitative evaluation of the Croydon care home support team'. *Aging and Mental Health*, 14(4), pp. 416–424

Pitt, V. (2011) 'Falling through the net'. *Community Care*, 1869, pp. 22–24

Populus (2013) *Help the Hospice Poll 2013.* London: Populus

Rigby, J., Payne, S. and Froggatt, K. (2010) 'What evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions? A literature review'. *Palliative Medicine*, 24(3), pp. 268–285

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krijnen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P. and Joyce, T. (2005) *The impact of person centred planning.* Lancaster: Institute for Health Research, Lancaster University

Running, A., Tolle, L. and Girard, D. (2008) 'Ritual: the final expression of care'. *International Journal of Nursing Practice*, 14, pp. 303–307

Scherer, S. and Sexton, S. (2010) *Involving users in commissioning local services.* York: Joseph Rowntree Foundation

SCIE (2009) Research briefing 31: Co-production: an emerging evidence base for adult social care transformation. Available at: http://www.scie.org.uk/publications/briefings/briefing31/ [accessed 10 February 2014]

SCIE (no date) *The life course approach.* Available at: http://www.scie.org.uk/assets/elearning/ mentalhealth/mh10/resource/html/object10/index.htm [accessed 10 February 2014]

Scottish Government (2008) *Getting it Right for Every Child.* Available at: www.scotland.gov.uk/ Topics/People/Young-People/gettingitright [accessed 21 November 2013]

Sharp, K., Murray, G. and McKenzie, K. (2002) 'Stress busters'. *Learning Disability Practice*, 5(6), p. 12

Simard, J. (2013) *The end-of-life Namaste Care program for people with dementia.* Baltimore: Health Professions Press

Skills for Care (2012a) *Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care.* Leeds: Skills for Care, Skills for Health

Skills for Care (2012b) *The impact of qualifications in the adult social care workforce.* Leeds: Skills for Care

Skills for Care (2012c) *Manager Induction Standards: Standards for managers new in post in adult social care, including those managing their own support workers.* Leeds: Skills for Care

Skills for Care (2013) *National Minimum Dataset for Social Care.* Available at: www.nmds-sc-online. org.uk/reportengine/GuestDashboard.aspx?type=QualHeld [accessed 5 November 2013]

Slocum-Gori, S., Hemsworth, D., Chan, W., Carson, A. and Kazanjian, A. (2011) 'Understanding compassion satisfaction, compassion fatigue and burnout: a survey of the hospice palliative care workforce'. *Palliative Medicine*, 27(2), pp. 172–178

Smith, M. (2009) *Rethinking residential childcare – Positive perspectives.* Bristol: Policy Press

Speaking Up (2007) *Making decisions: The Independent Mental Capacity Advocate (IMCA) service.* Department of Health, Ministry of Justice, Office of the Public Guardian, Welsh Assembly Government

Steckley, L. (2010) *Containment and holding environments: Understanding and reducing physical restraint in residential child care.* Scotland: Save the Children

Steckley, L. and Kendrick, A. (2008a) 'Young people's experiences of physical restraint in residential care: subtlety and complexity in policy and practice' in Nunno M., Bullard L. and Day D.M. (eds.) *For our own safety: Examining the safety of high-risk interventions for children and young people*, pp.3–24. Washington, D.C.: CWLA Press

Steckley, L. and Kendrick, A. (2008b) 'Hold on: physical restraint in residential child care' in Kendrick A. (Ed.) 'Residential child care: prospects and challenges'. *Research Highlights* Series, pp. 152–165. London: Jessica Kingsley

Stein, G. and Fineberg, I. (2013) 'Advance care planning in the USA and UK: a comparative analysis of policy, implementation and the social work role'. *British Journal of Social Work*, pp 1–16

Stevens, I. (2010) *Social pedagogy and its links to Holding the Space.* Available at: http://www. actionforchildren.org.uk/media/52170/holding_the_space_and_its_links_to_social_pedagogy. pdf [accessed May 2013]

Stobbart-Rowlands, M. (2009) 'Advance care planning and communication in care homes'. End of life care, 3(3), pp. 30–31

Stobbart-Rowlands, M., Thomas, K. and Giles, L. (2012) 'A survey of advance care planning in care

homes following the GSF care homes training'. *BMJ Supportive and Palliative Care*, 2, p. 201

Swetz, K., Harrington, S., Matsuyama, R., Sahanafelt, T. and Lyckholm, L. (2009) 'Strategies for avoiding burnout in hospice and palliative medicine: peer advice for physicians on achieving longevity and fulfillment'. *Journal of Palliative Medicine*, 12(9), pp. 773–777

The Hospice Foundation (2013) E*nd of life care and supporting staff: A literature review*. Dublin: Hospice Friendly Hospitals

Thomas, J., Newman, M. and Oliver, S. (2013) 'Rapid evidence assessments of research to inform social policy: taking stock and moving forward'. *Evidence and Policy*, 9(1), pp. 5–27

Thompson, G. and Chochinov, H. (2008) 'Dignity-based approaches in the care of terminally ill patients'. *Journal of Palliative Medicine*, 10(5), pp. 1076–1082

Wallcraft, J. and Sweeney, A. (2011) *Adult services report 47: User involvement in adult safeguarding*. London: SCIE

Waller, S., Dewar, S., Masterson, A. and Finn, H. (2008) *Improving environments for care at end of life*. London: The King's Fund

Waller, S. and Finn, H. (2011) *Improving the patient experience: Environments for care at end of life*. London: The King's Fund

Weiner, J., Steven, A., Cole, M. (2004) 'Three principles to improve clinician communication for advance care planning: overcoming emotional, cognitive and skills barriers. *Journal of Palliative Medicine*, 7(6), pp. 817–829

Wood, A. and Greig, R. (2010) *Supported living: Making the move developing supported living options for people with learning disabilities*. Bath: National Development Team for Inclusion

APPENDIX 1: RESEARCH QUESTIONS

Central questions

1. Do other sectors deliver quality care services 'better' than care homes for older people?
- What aspects of (national and local government) **policy** support risk management processes?
- What **models** of risk management/positive risk-taking are employed in the other specified settings to improve quality of life and good relationships in the setting?
- What **evidence** of effectiveness exists to support these models?
- What are the characteristics of success?
- What are the facilitators and challenges for implementing such models/policies?

2. If they do, what in particular is 'better' about other services?
- What is the organisational approach to risk management and positive risk-taking?
- What emphasis is placed on workforce development and what is the role of staff attitudes and values?

3. What is transferable learning for residential care homes for older people?
- What learning can be extracted from other settings to apply to residential care homes for older people?
- What constraints or parameters should be placed on this learning?

Subsidiary questions to frame the research

What constitutes good and effective practice in residential care for older people and what would 'better' look like?
- Are there examples of effective practice in residential care in relation to risk management and relationships between staff and older people living in residential care?
- What are the key characteristics of effective practice in residential care in relation to risk management/relationship building/positive risk-taking?
- What facilitates and/or challenges effective practice in this context?

APPENDIX 2: SEARCH STRATEGY AND KEY TERMS

Searches were conducted through electronic databases including Scopus, CareKnowledge and Social Care Online. To help with the identification of unpublished literature, a number of key websites were searched and key organisations contacted.

Based on discussions at the inception meeting, the research covered three settings (end of life care in hospices, children's residential care services and residential learning disabilities services) using the keywords below. Searches were conducted as combinations of the agreed search terms (see Table 4).

Table 4: Agreed search terms

Risk management and relationships	Outcomes
Advocacy	Quality of life
Co-production	Quality of care
Safeguarding	Staff client (patient) relation*
Positive risk*	Service user involve*
Risk manag*	Decision-making
Risk assess*	Person centre*
Rights-based*	Personhood
Regulation	Joint care plan*
Risk enablement	
Safeguarding	
Approach	**Effectiveness**
Staff train*	Effectiv*
Staff attitude*	Success*
Staff value*	Best practice
Policy devel*	Facilitators
Workforce devel*	Challenges
Learning and development	Good practice
Environ*	Guidance
Process*	

* Incomplete words used to search for multiple phrases at once

Underlying research assumptions

These were:

- that there will be sufficient literature in the three comparison settings to begin to extract transferable learning for residential care for older people;
- that all care homes are subject to and face the same regulatory constraints and policy directives.

Search strategies

Our search strategy for the REA involved a search of the key databases:

Table 5: Key databases

NHS Evidence (includes Cinahl, Embase, PsycINFO, Cochrane Library, MEDLINE, British Nursing Index)	Social Care Online
Skills for Care Research Knowledge Base	Scopus
CareKnowledge	Social Care Institute for Excellence (SCIE)
Education Resources Information Center (ERIC)	Trip
Applied Social Sciences Index and Abstracts (ASSIA)	Web of Science
Social Science Citation Index (SSCI)	Google Scholar

This was supported by searches of the following websites

Table 6: Supporting websites

The Economic and Social Research Council (ESRC) Society Today	The King's Fund
Skills for Care	Department of Health
Joseph Rowntree Foundation	Research in Practice for Adults
The Institute for Research and Innovation in Social Services (IRISS) (Scotland)	National Care Homes Research and Development Forum
Personal Social Services Research Unit (PSSRU)	British Geriatrics Society
Age UK	National Institute for Social Care and Health Research (Wales)
National Institute for Health and Care Excellence (NICE)	Scope
Scottish Social Research	Mental Health Foundation
Carers UK	Scottish Government
NHS Institute for Innovation and Improvement	

Table 7: Inclusion and exclusion criteria

Inclusion criteria

Year	Published during or after 2002
Language	Published in English
Nature of evidence	Peer-reviewed international literature Primary studies from the United Kingdom Unpublished literature from the United Kingdom only National-level guidance documents from the United Kingdom only (where relevant)
Study design	Review of reviews Evidence reviews (systematic, rapid, scoping) Primary qualitative and quantitative evaluation studies Primary qualitative and quantitative needs assessments or evidence gathering studies Expert opinion (with cautionary notes)
Topic	Risk assessment and management Building relationships between staff and clients Positive risk-taking Characteristics of good practice in residential settings Focus on workforce development to encourage relationship building
Populations	Older people People with learning disabilities People nearing the end of their lives Children and young people looked after and accommodated by care services
Settings	Care homes without nursing Residential and supported housing for people with learning disabilities Hospices Residential care settings for children and young people
Outcomes	Focus on improving quality of life for residents Improved experience of quality of relationships and care Increased participation in decision-making

Exclusion criteria

Year	Published before 2002
Language	Not published in English
Nature of evidence	International primary studies International guidance Unpublished literature from international audience
Topic	Focused on specific aspects of risk e.g. falls management Primary focus on NHS support and input into care homes Management of medication or medical care Focus on prevalence and statistical analysis
Setting	NHS setting for care homes Nursing homes with care Extra care homes (also known as Assisted Living Housing/Very Sheltered Housing/Housing With Care) Foster care settings

Quality Assessment Procedures

In order to assess the strength of the evidence of relevant primary studies into effectiveness the following questions were posed:

- Is the study relevant to the review questions?
- Are the methods valid and appropriate (design, sampling, data collection)?
- Is there a strong and appropriate analysis of the data and presentation of the findings?
- Have the findings been interpreted appropriately?
- Have the limitations of the study been considered and amendments made to reflect these?

For reviews of evidence the following questions were posed to assess the quality of the review:

- Is the study relevant to the review questions?
- Was there a comprehensive search strategy stated and conducted?
- Was the quality of individual primary studies assessed?
- Were results from primary studies integrated into overall findings adequately?
- Is there adequate data to support conclusions of the review?

For both types of papers a study was classified as 'strong' if four or five of the stated criteria have been met, 'adequate' if two or three of the stated criteria have been met or 'weak' if none or one of the stated criteria have been met. Only strong and adequate studies were taken forward for data extraction. There was one exception to this: in the case of weak studies where no other evidence is available, these will be included in the narrative report with cautionary notes.

Data extraction

The following information was extracted directly into Endnote for individual studies:

- study detail;
- target population and setting (should already be entered);
- intervention or study aim;
- general description of study (e.g. design, scale of study, strength of study);
- relevant findings;
- commentary on study.

ACKNOWLEDGEMENTS

ABOUT THE AUTHORS

Liz Burtney, Davina Figgett and Paul Buchanan work in the Research and Evaluation team at Skills for Care, an employer-led organisation with a remit for developing the skills, knowledge and values of the adult social care workforce.

Liz has worked as a researcher for over 20 years in the public, voluntary and commercial sectors. Her work focuses on innovative practice in social care and promoting the use of evidence in practice.

Davina has over 15 years' experience developing and managing research projects within the public and not-for-profit sectors. Her main area of interest is social work and unpaid carers.

Paul has been a researcher for over 20 years and manages the Research and Evaluation team at Skills for Care. He is particularly interested in ensuring that employers have the opportunity to engage with research and by doing so are able learn from the experiences of others.

Deirdre Fullerton is an independent researcher who worked with Skills for Care on this project as an associate. **Deirdre** is an experienced reviewer and her main research interests include looked after and accommodated young people, teenage health and health improvement.

Karen Stevens and Madeline Cooper-Ueki have a leadership role in Skills for Care area teams to engage employers and other key partners in the adult social care sector to support workforce development.

Karen has a background in organisational development and her areas of interest include dementia, Common Core principles and the link between health and social care.

Madeline has a background in working with people with learning disabilities and mental health needs and supporting organisations to implement personalised, person-centred and inclusive approaches.

JRF JOSEPH ROWNTREE FOUNDATION

INSPIRING SOCIAL CHANGE