Skills around the person

Implementing asset-based approaches in adult social care and end of life care

October 2014
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My thanks to Linda Christie for her skilled, efficient and interested approach to transcribing many hours of digital interviews with good humour and great patience.

Finally, this report is dedicated to the memory of my Dad who died on 1 April 2014.

Melanie Henwood
October 2014
Executive Summary

1 Skills for Care (SfC) has been engaged in a range of work on community skills development since 2008, and has supported a number of local projects to explore ideas in action. This report analyses the latest stage of development and examines a programme of work referred to as ‘skills around the person’ (SATP). A second strand of the programme was concerned specifically with how the SATP model might be developed to support people as they approach the end of life (EoL).

2 Skills around the person starts from an assumption not only that person-centred approaches are vital in ensuring that care and support meets individual needs and preferences, but also that everyone has their own skills, knowledge, experience and attributes which they bring with them. The programme wanted to explore how such skills might be enhanced and supported in order to maximise people’s independence and improve quality of life.

3 The programme was deliberately non-directive and beyond offering some introductory ideas and concepts wished to be as permissive as possible in enabling projects to innovate and develop their own solutions. The products and experience of the projects are accordingly extremely diverse and rich, but there are also many shared themes, conclusions and experiences.

4 There is much in the experience of the projects that will inspire and stimulate other organisations and individuals. The timing of this work is also particularly valuable and has potential to inform the developing policy agenda and implementation challenges in adult social care and support, particularly in addressing the new requirements of the Care Act.

5 The projects were located in a wide range of organisations. In addition to care and support providers (statutory, independent and third sector), this included community groups, timebanks, and creative arts organisations.

6 In many instances the projects experienced unexpected and profound impacts. Major changes with routine systems and processes (such as around assessment) could lead to substantial cultural change both at the level of individuals and across organisations. Projects that addressed the skills and development of staff and of people being supported by services reported particularly fruitful and mutually beneficial outcomes. The SATP approach also provides an innovative model to reconceptualise mandatory training requirements.
The central tenets of the SATP model can be described as asset-based in their focus on personal resources and potential. The resulting increase in social and community capacity building will be of wide interest and resonance for others.

The application of the model to EoL produced similarly varied and innovative approaches. Many of the projects explored – in different ways – how to initiate the ‘difficult conversations’ around death and dying that are an essential precursor to engaging with the realities for people facing the end of life (their own or that of others around them). One of the underlying ideas that the programme wanted to explore was whether adopting the SATP model in such a context would equip people with greater skills and confidence to shape their final days, and to exercise appropriate choice and control.

The SATP and EoL programme has generated a considerable body of innovation and creative endeavour. This owed much to the enthusiasm and commitment of individual project leads, and to everyone who participated in the programme and shared freely their experiences and insights. This report is the foundation for further sharing and dissemination of the underlying principles of SATP, and the hope is that it will inspire further innovation and experimentation. The programme has demonstrated repeatedly the (often hidden) opportunities that exist to harness skills, experiences, aptitudes and passions and to do so in ways that promote individual aspirations, enhance independence and maximise autonomy.
1. Introduction

Skills around the person

1.1. Skills for Care (SfC) has been undertaking a range of work on community skills development since 2008, when it was seen as integral to the seven principles of workforce redesign (recognising the shape of resources available in the local community). Since that time the concept has featured in much of the discourse around social care transformation, particularly in respect of the development of community capacity, and ‘asset-based’ strategies. Building on an evidence review published in 2010, a number of pilot sites were established to explore the concept and application of community skills development. The independent evaluation, published in 2012, found that adopting a skills-led approach – in a variety of settings - and recognising the value of people’s knowledge and experience can have positive impacts on both individuals and their communities.

1.2. The programme evolved from the idea of ‘community skills’ to a focus that we have termed ‘skills around the person’ (SATP). SATP is a co-produced model which fits well with person-centred approaches (which are particularly well developed in support for people with learning disabilities) and needs-led assessment.

1.3. The SATP model looks at skills both in terms of what skills a person needing care and support requires from those supporting them, but also – and crucially – what skills (experiences and attributes) the person needing support has in their own right, and in the resources available in their community. Identifying skills also reveals the skills gaps and deficits that need to be addressed, and what new skills need to be acquired in order to best support the person. Thus the two questions to consider would be:

- In order to remain as independent as possible, what skills (knowledge, experience or attributes) does the person needing support already have and how could their skills be enhanced?
- In order to enable a person to remain as independent as possible what skills (knowledge, experience or attributes) do people directly and indirectly involved in their support already have or need to acquire?

1.4. A second strand of the SATP programme applied the model to end of life (EoL) care. Skills for Care has a track record of working on EoL matters and supporting the National End of Life Programme. A guide to workforce development for care and health workers in applying the common core competencies for end of life care was published in 2012.

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2 Melanie Henwood (2012), Empowering Communities. Community skills development and neighbourhood workforce planning, Skills for Care: Leeds.
3 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 (2012), Skills for Care/Skills for Health/NHS National End of Life Care Programme.
1.5. The SATP model explores whether a community skills approach might add value to support for people nearing the end of their lives. In particular, the model set out to explore whether having a focus on the skills and assets of the person themselves, and of those who support them (formally and informally), and any subsequent skill development, can contribute to a better end of life experience. We wondered, for example, whether adopting the SATP model might:

- enable people to remain at home to the end of life where that is their preference.
- reduce the need for unplanned hospital or care home admissions.
- support people to continue to participate in activities and relationships that they value.
- enable people to be clear about their preferences and what interventions they do or do not want.
- enable people to talk about what matters to them and their preferences as they approach the end of their life.

1.6. Both arms of the SATP programme were non-directive. Beyond suggesting a way of thinking about skills and offering some tools to assist with skills mapping, the intention was to keep the programme as fluid as possible in order to stimulate innovation and creativity. The results of this approach are evident in the disparate approaches taken by widely diverse projects, but also in the many shared themes and issues they identified.

1.7. Before we examine the programme overall and the detailed experience of the projects, we begin by exploring the relevance of this work to wider policy agendas and developments.

Policy context & relevance

1.8. The Care Act received royal assent on 14 May 2014, and provides the most significant legislative reform in social care for 60 years. The Act implements the main recommendations made by the Law Commission’s review of adult social care intended to provide a clearer and more cohesive legal framework, and to replace the “confusing patchwork of conflicting statutes” that had built up over the years with a single adult social care statute. In July 2011 the Dilnot Commission published its report on the funding of care and support and concluded that “the current system is confusing, unfair and unsustainable.” The Dilnot Commission’s recommendations on funding reform and the introduction of national eligibility criteria and a single eligibility threshold, are also key features addressed by the Care Act.

4 Law Commission (2011), Adult Social Care (HC 941), London: TSO.
5 Dilnot Commission (2011), Fairer Care Funding: The report of the Commission on Funding of Care and Support, London: Commission on Funding of Care and Support.
1.9. The government’s white paper Caring for our Future set out the long term programme for reforming care and support and the principles underlying the subsequent Care Act. The central objectives were stated as follows:

“Our vision is one that promotes people’s independence and wellbeing by enabling them to prevent or postpone the need for care and support. We will also transform the system to put people’s needs, goals and aspirations at the centre of care and support, supporting people to make their own decisions, to realise their potential, and to pursue life opportunities.”

1.10. One of the principles underpinning the approach is expressed in these terms:

“The skills, resources and networks in every community are harnessed and strengthened to support people to live well, and to contribute to their communities where they can and wish to.”

Strengthening support within communities and ‘encouraging people to use their skills and talents to build new friendships and connections’ is central to this vision for developing social capital and community capacity. However, the white paper (and now the Care Act) also created some potential leverage for this approach by linking it to individual assessment.

1.11. New national eligibility criteria for social care are to be introduced (in place of the local systems of eligibility operated to-date by individual local authorities and resulting in the widely criticised ‘postcode lottery’ of care):

“We will look at the role of assessment in a reformed system to develop options which will seek to provide both local authorities and individuals with a clear view of the talents, skills and goals of people seeking to access support.”

1.12. In a discussion document on the eligibility threshold issued in June 2013, what this might mean for assessment was explored in greater detail:

“Rather than acting primarily as a gateway to the adult either receiving care and support or not, the future system will place more emphasis on the role of the assessment process in supporting people to identify their needs, understand the options available to them, plan for meeting care needs and for caring responsibilities, and reduce or delay needs where possible.”

6 HM Government (2012), Caring for our Future: reforming care and support, Cm 8378, London: TSO. P.18
8 Department of Health (2013), Draft national minimum eligibility threshold for adult care and support. a discussion document, London: DH, Para 1.8
1.13. Strategic work is being taken forward by the Department of Health, in consultation with people being supported, carers\(^9\), academics, local authorities, social workers, and care and health professionals to develop and test options. Skills for Care is represented on this expert working group and has been able to feed in the insights and experience from the SATP projects. The aspirations of the new approach appear to be significantly different from traditional deficit-based models of assessment which focus primarily on what people are unable to do, rather than considering their own skills, assets, attributes and ambitions.

1.14. The significance of this shift in the model of assessment is considerable, and the scale of the transformation required will not be achieved immediately. A review commissioned from SCIE by the Department of Health highlighted the finding that assessment and eligibility functions are under severe strain because they are serving a number of different and competing functions, and specifically:

“whether it is assessment of needs, of risks, or of outcomes; whether it’s a key element in personalisation, or a mechanism to allocate public funds fairly and efficiently.”\(^{10}\)

1.15. These tensions will not simply disappear, but the changing scope of assessment will drive the shift that needs to take place. The parallel changes in funding for social care and the introduction of a ‘capped cost’ of a lifetime contribution to personal care of £72,000 will bring many more self-funders into the assessment system in order to trigger their individual care account. Local councils have new duties to provide advice and information to all citizens seeking help with care and support, whether or not they meet the eligibility threshold. The system should – in future – offer more of a continuum of response to people’s needs rather than the eligible/ineligible distinction that has characterised much response in recent years.

1.16. The work being undertaken to explore different models of assessment and eligibility determination is ongoing, with piloting planned for 2015/16. It is particularly timely therefore to be able to identify some of the emerging findings about a skills and asset based approach that might inform and illuminate such development.

1.17. End of life care policy and practice also continues to evolve, and the relevance of a ‘skills around the person’ approach to EoL also has considerable – and growing – resonance. The National End of Life Strategy was published by the Department of Health in 2008, and the End of Life Care Programme ran until April 2013. The strategy endorsed a care pathway approach for commissioning services and delivering integrated care and featuring six steps:\(^{11}\)

- Discussions as end of life approaches.
- Assessment, care planning and review.

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9 ‘Carer’ is used in the main text to mean only family and friends who provide social care support, as distinct from social care workers. In some quoted passages, however, it refers to care workers.

10 SCIE (2012), SCIE Assessment and Eligibility Study for Department of Health, P.25

Skills around the person

- Coordination of care for individual patients.
- Delivery of high quality services in different settings.
- Care in the last days of life,
- Care after death.

1.18. The End of Life care pathway is summarised in Figure 1a below. Cross-cutting the six steps are three additional components comprising:

- support for carers and families.
- information for patients and carers.
- spiritual care services.

Figure 1a The End of Life Care Pathway

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
<th>Step 5</th>
<th>Step 6</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Discussions as the end of life approaches</strong></td>
<td><strong>Assessment care planning and review</strong></td>
<td><strong>Coordination of care</strong></td>
<td><strong>Delivery of high quality services in difficult settings</strong></td>
<td><strong>Care in the last days of life</strong></td>
<td><strong>Support for carers and families</strong></td>
</tr>
<tr>
<td>■ Open honest communication</td>
<td>■ Agreed care plan and regular review of needs and preferences</td>
<td>■ Strategic coordination</td>
<td>■ High quality care provision in all settings</td>
<td>■ Identification of the dying phase</td>
<td>■ Recognition that end of life care does not stop at the point of death</td>
</tr>
<tr>
<td>■ Identifying triggers for discussion</td>
<td>■ Coordination of individual patient care</td>
<td>■ Rapid response services</td>
<td>■ Acute hospitals community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels</td>
<td>■ Review of needs and preferences for place of death</td>
<td>■ Timely verification and certification of death or referral to coroner</td>
</tr>
<tr>
<td>■ Assessing needs of carers</td>
<td>■ Rapid response services</td>
<td>■ Ambulance services</td>
<td>■ Support for both patient and carer</td>
<td>■ Recognition of wishes regarding resuscitation and organ donation</td>
<td>■ Care and support of carer and family, including emotional and practical bereavement support</td>
</tr>
</tbody>
</table>

Source: Department of Health (2008), *End of Life Care Strategy: Promoting high quality care for all adults at the end of life.* p.49
In supporting the End of Life Care Strategy, Skills for Care, Skills for Health and the Department of Health undertook work to identify the common core competences and principles for health and social care workers supporting adults at the end of life. As the document pointed out, while traditionally EoL care has been viewed as a specialist area of work, in reality it is much more than this:

“It incorporates all elements of the daily lives of those people nearing the end of their lives – whether from disease progression or old age – and that means a far wider group of workers is involved.”\(^{12}\)

The common core competences and principles were developed to address this wider group of care and support workers, and to increase their confidence to work with people at the end of their lives. The competences address the following dimensions:

- communication skills
- assessment and care planning
- symptom management, comfort and wellbeing
- advance care planning
- overarching values and knowledge.

The competences do not replace the occupation and profession-specific competences. The seven principles that need to underpin all workforce and service development, activity and delivery are summarised in Box 1.1 (page 7).\(^{13}\)

The SATP EoL programme set out to build on the foundation of the competences and principles. As discussed above, the programme was designed to explore what a SATP approach might be able to bring to EoL care and support in a range of contexts. The importance of end of life care, and the continued need to improve the quality of care are recurrent themes in current policy. In 2013 there was mounting criticism of the impact of the Liverpool Care Pathway for the Dying Patient (LCP), which had been introduced in an attempt to replicate in hospitals the quality of care found in many hospices. The independent Neuberger review found repeated evidence of dying patients “being treated with less than the respect that they deserve.”\(^{14}\) The apparent failings of training and inadequate practice guidance on the use of the LCP, far from improving practice too often led to care that was “uncaring, rushed and ignorant.” Poor communication with patients and relatives was at the heart of many of the failures and criticisms of the LCP, and evidence to the Neuberger review found people not being involved in discussions about the care plan or not being given the opportunity to be involved.

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12 Skills for Care, Skills for Health, Department of Health (2009), Common core competences and principles for health and social care workers working with adults at the end of life, p3
13 Skills for Care & Skills for Health (updated in 2014), Common core principles and competences for social care and health workers working with people at the end of life, p4
1.22. The review recommended that the use of the LCP should be phased out and replaced with an individual end of life care plan. The national care of the dying audit for hospitals published in May 2014 observed:

“We only have one chance to get end of life care right and sadly sometimes we don’t.”

The audit echoed many of the findings from the Neuberger review and made a number of recommendations including the important of mandatory training in the care of the dying for all staff caring for dying patients, which should include “communication skills training, and skills for supporting families and those close to dying patients.”

1.23. The focus of the SATP/EoL programme is not on hospital-based care, but many of

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the issues are similar, particularly around matters of communication and being able to
discuss matters of death and dying. Most people, when asked, express a preference
to die at home; the reality continues to be that around half of all deaths occur in
hospital. Wherever people end their lives, the same principles of good quality care
need to be reflected. The findings from the programme reported here should be of
wide relevance and interest to those supporting people as they approach the end of
life.

2. The projects

Skills around the person

2.1. As we outlined in section 1, the SATP model is a person-centred approach to
understanding the skills that are needed to support someone in need of care and
support to live independently in their local community. The programme was designed
to build on the previous work supported by Skills for Care to explore community
skills development. In the course of that work we developed an understanding of
how people approach and deal with the concept of ‘skills’, while we also recognised
the great potential that exists for developing the resources or social capital of people
and their communities. The following quotes from participants in the earlier programme
highlight some of the challenges around the idea of skills

“I think sometimes when we say ‘do you have any skills you could pass on to anyone?’
people don’t realise what skills they actually have.”

“I just say everybody has something that they can offer to somebody else (...) everybody can do something.”

“The existing skills that we found – so, for example, a willingness to get things done,
practical skills, communication, negotiating, knowledge of the local area, and I think
they found that quite powerful.”

2.2. The SATP approach was deliberately non-prescriptive in order to encourage maximum
innovation and a range of application in different contexts. The objective of the
programme was not, for example, necessarily to see projects designing new
assessment tools or paperwork, so much as to support a change of ethos. However,
in a background discussion paper to guide the projects it was suggested that the
essence of the approach would involve two interrelated components: skills mapping
and skills development.

- **Skills mapping** would explore the skills, experiences and aptitudes of the person
  requiring care and support, and the skills, experiences and aptitudes available to
  enable them to continue to live independently in their own neighbourhood.

- **Skills development** builds on the skills mapping and puts in place the necessary

16 Melanie Henwood (2012), Empowering Communities. Community skills development and
17 ibid, p19
18 ibid.
person-centred learning and development to support acquisition of necessary skills to support the person to continue to live independently.

2.3. The skills mapping can be represented diagrammatically:

**Figure 1a The End of Life Care Pathway**
A bubble map was also developed and offered as a tool that projects might find of use in mapping skills, but projects were not required to adopt the tool.

Similarly, although the programme sought to support the development of person-centred learning, there was not a prescriptive approach to skills development. This recognised that the concept of skills is multi-faceted (and not necessarily related to professional or other qualifications), and also that people learn differently and need different methods to help them do so.

The projects
a) Skills around the person

Ten projects were selected to work with Skills for Care and explore the practical application of the idea of ‘skills around the person’ (see Appendix 1). The projects began their work in early 2013 and were funded for 12 months. Support for the projects was provided by Jim Thomas and Audrey Harmer from Skills for Care. Regular meetings took place in Leeds and Cambridge (approximately every eight weeks) to give opportunities for the projects to meet as a learning set and to share progress and experience (with projects invited to attend) one or other of the groups depending on geographical location. Independent research consultant Melanie Henwood was also commissioned to work alongside the projects from the outset and to evaluate the programme as it developed. Pen Mendonça (a graphic facilitator) was commissioned by Skills for Care to develop work to support both the SATP and EoL components of the programme. Pen attended meetings of the learning sets and

19 http://www.penmendonca.co.uk/
had additional contact with some individual projects. Some of her work is included in this paper (see Appendix 3).

2.7. Two interactive pdf questionnaires were circulated to the projects (in Spring and Summer 2013). These provided an opportunity to capture baseline information and to explore progress. More detailed engagement also took place through telephone interviews, and visits to a sample of projects. The 10 projects were based in a range of organisations including local authorities (Wirral Metropolitan Borough Council, Stockport Council, and Suffolk County Council); voluntary and private sector small- and medium-sized service providers (Hft, Star Support, Thera Trust, St Martin’s Centre, and the Cambridge Care Company); and large national level service providers (Sue Ryder and Jewish Care). Four projects were concerned with a single client group (one with older people and three supporting people with learning disabilities), but most projects identified several groups they were working to support, including carers.

2.8. Responses to the questionnaires indicated that motivations for engaging with the SATP programme were various, but project leaders generally recognised the potential the model might offer, particularly for marginalised groups, for example

“The learning disability client group is one of the most marginalised and overlooked client groups in terms of the skills and assets they have to offer each other and the wider communities in which they live.” (Stockport Advocacy)

And

“We want to get better at working with family carers and using their skills and experience. We want to get better at supporting people with a learning disability to be active members of their local community. We want to get better at person-centred recruitment.” (Thera Trust)

2.9. Some organisations recognised that the programme was consistent with and could give further impetus to the strategy they were pursuing, for example:

“Our thinking was that if we could develop this model with this group of people we support [people with profound disabilities and complex health needs], then we would have some good evidence to share across the organisation.” (Hft)

And others were recognising the contribution of asset-based approaches:

“I believe in focusing on the strengths and abilities. We can build on strengths and gain confidence and people will start to believe they can rather than can’t.” (Cambridge Care Company)

b) End of life care

2.10. The EoL projects operated in parallel with the other SATP projects and were underway at the same time (from March/April 2013 for 12 months). Fourteen projects were selected (see Appendix 2), some of which had worked previously with Skills for Care, either on community skills development or on end of life care, while others were new to this territory. Project management was provided by Audrey Harmer and Melissa
Balman, and as with the SATP projects, two learning sets were established (meeting in London and Leeds) and two meetings of each took place.

2.11. The EoL projects were highly diverse, both in terms of the organisations in which they were located, and in their approaches. While some of the organisations had specific expertise in EoL care (for example, Cheshire Living well, Dying well; Jewish Care; St Michael’s Hospice), others were providers with expertise in other areas including social housing (Gentoo; Housing 21), care and support provision and training (Care2Care; Enable; Skills for People), others were local organisations with experience in community development and support (Ulnes Walton; Cambridgeshire Timebank), and others still brought the expertise from different fields of activity including participatory arts (Spare Tyre; Imaginarium).

2.12. As with the SATP projects, two interactive questionnaires were designed, with the first being circulated in early summer 2013 and the second in the early autumn. The range of approaches was illustrated in some of the key aims and objectives stated by projects embarking on their work. For example:

“We will explore support networks and communities concerned with End of Life (...) empowering people to be aware of their options.” (Gentoo)

“The project will focus on developing a ‘Sound track of my years’, an approach to working with service users in which musical memories and likes form the backdrop to conversations about people’s lives and wishes.” (JackDawe)

“The project will engage with people on a one to one basis through a range of arts activities including storytelling, music and visual arts.” (Spare Tyre)

2.13. A number of recurrent themes emerged across projects:

- improving information for carers and public
- dispelling myths about death and dying
- supporting changes in attitudes and behaviour towards end of life
- raising awareness and skills of care and support staff
- identifying and enhancing local support networks.

Next steps

2.14. Having introduced the two components of the SATP/EoL programme, and the projects involved with both dimensions, we turn in the next section to explore the
experience of the projects in greater detail and to reflect on successes and challenges in applying the SATP model in a range of practical settings.

3. Skills around the person in practice

Skills and assets mapping

3.1. A recurrent theme across many of the SATP projects was that significant organisational and cultural transformation was involved in developing and applying the model. In part the transformation reflected the shift in moving away from a deficit model of need, but it also indicated change in the role of organisations. The initial process of skills and assets mapping that most projects undertook in some form or another often produced unexpected results.

3.2. Hft developed a ‘skills assets plan’ template to use with people being supported by the service, but also used it in a training exercise with staff and asked them to complete a plan about themselves:

“Our main interest is to see if by producing Skills Assets Plans for themselves, this makes a difference when staff look at Skills Asset Plans with the people we support, or if they revert back to a ‘needs led’ assessment.”

3.3. Not only did the exercise challenge people to think differently, but it also proved highly revealing in highlighting hitherto unknown skills and abilities in staff members, as described below:

“X has worked with people with learning disabilities for 27 years in a variety of settings (...) over the years they have been moved to suit the needs of the service on a number of occasions without any great attention paid to the particular skills and expertise that she possesses. She has always adapted to her new work situation but when we read out our Skills Asset Plans to each other, X’s plan revealed hidden qualification, talents and passions that her current colleagues and manager of 7 years knew nothing about.”

3.4. In this example the discovery of latent skills led to major change with the person becoming a team leader in two arts projects run by Hft, “where she shares an interest with the people that we support there and where she can make a real impact and at the same time reignite her passion.” This particular experience highlighted the wider importance of recognising and enhancing staff skills, as well as having the right people in the right roles:
“It’s those hidden talents and skills that staff have; it helps you as a manager decide where best to deploy staff in terms of matching the skills of the people we support to the staff skills as well.”

3.5. In supporting people with learning disabilities, Hft – like several of the projects – had considerable experience in person-centred planning. In some ways this was an advantage, but it was also a surprise for people engaging with the project to realise that SATP involved a step change in understanding and assumptions, as this person described:

“I think we thought we’d got it and we thought we’d got everything we needed to pass onto people that we work with, and then you know our thinking’s changed really (...) so we’ve brought in person-centred active support training for the staff to support some of the thinking around this.”

And

“We’ve shifted some people’s thinking from a more needs-led and dependency type model to more of, you know, really focusing in on what skills people bring.”

3.6. In this particular situation a day care service provided by Hft was in the process of relocating from what had been a remote NHS hospital site, to a city centre premises. It was recognised that the upheaval in the location of the service created opportunities to reconfigure the way support was provided and to challenge people to reconsider their approach:

“[the move] is going to start to get people to think differently about how we can support people, and looking at their skills.”

3.7. In working with people with severe learning disabilities and complex health needs it was recognised that there was a tendency to focus on the things that people were unable to do, and to be risk averse, for example:

“So we were saying why can’t the people we support load the dishwasher at [the day centre] out in the kitchen? ‘Why?’ ‘Because they can’t.’ ‘Why?’ ‘Because they might burn themselves’ (...) and this went on and on (...). Sometimes these unwritten rules appear from nowhere. Nobody ever challenges it, they just carry on.”

3.8. Moving to a different way of working could be challenging. As one interviewee remarked, the focus on what people can’t do “is about justifying our existence some of the time” if staff see their role as being there to help with all the things that people can’t do. However, turning things around and looking at support from another perspective was something which people generally embraced with enthusiasm:
“[In the discussions with the staff team] it came out straightaway that people were saying ‘Oh this is all about what everybody can do, not about what they can’t do.’ And I think it was just as simple as that.”

3.9. The project run by Thera was also supporting people with learning disabilities and described similar experiences of developing person-centred planning approaches, and taking them further through community and skills mapping. Thera had made use of ‘bubble maps’ to explore skills for people they supported, their family carers, and the staff working with them. Community mapping was also being used to create visual representations of people’s lives and all the services and activities they were in touch with. A Thera manager described the approach developed with one such map:

“Paul lives in Harwich; that’s his house, and on here are all the different things that he does in the community (...) Paul goes swimming, and he often meets up with his neighbours for parties and stuff like that. The map isn’t completed yet; it will continue to progress. Just around the corner from Paul is the Post Office and they are very helpful, and the Chinese takeaway where Paul gets his takeaway. There’s the bus stop there which takes him into town. We’ve put pictures of the different places he can go to, but we’ve been supporting P to add the different skills that are in the community (...). This is just an example of how he can use the skills that he has already and to develop his skills. Having it on paper, being able to visually see what is in the community is so much better.”

3.10. Being able to share the map with staff and other people involved in support can help in understanding places a person likes to visit; their daily routines, and also their interests and aspirations. Thera had also captured Colin’s story and published it as a case study, as his care worker described:

“As you will see, and Colin will tell you, Colin’s biggest passion is Liverpool Football Club. His second passion without a doubt is watching DVDs; sometimes you have to encourage him to get out a bit because he would quite happily watch films 24/7! But he does like going out too; this year we’ve been to football and the wrestling, and shopping and down the pub.”

3.11. Both Hft and Thera were also exploring how to apply the SATP approach to staff recruitment and ensuring that people with the right interests to support people achieve their aspirations were appointed. Thera had started to develop a board game (and something with potential to become an app) that used different pictures and representations to indicate what people do and don’t like doing and what skills and
attributes they want in staff who support them (see above). This was work in progress but was seen as having potential in helping people use their personal budgets to find personal assistants with the right skills and interests.

3.12. Some projects described a more informal approach to skills and asset mapping, as this manager from St Martin’s day centre (for older people) described:

“The SATP approach] has made me automatically and much more intuitively think about searching, exploring and listening out for latent skills that a supported person has, and those they wish to develop or take up again when I am talking to them and listening to the narrative of their lives.”

Skills development

3.13. In addition to applying SATP to staff recruitment, Hft was also applying the model to shared skills development for staff and people supported by Hft through joint
training opportunities. Box 3.1 (page 18) presents a case study and draws on
reflections from participants that highlight the value and potential of shared learning
and skills development.

3.14. Stockport adult social care focused its SATP project on supporting people with
learning disabilities, observing that:

“The LD client group is one of the most marginalised and overlooked client groups
in terms of the skills and assets they have to offer each other and the wider
communities in which they live (...) It is recognised that many people with a learning
disability have lived for many years in tenancies in Stockport with little or no access to
or support from their local neighbourhood/community, and this is something that we
are keen to resolve.”

3.15. The project focused on a particular day centre and established a timebank initiative
to engage attenders of the day service living in supported tenancies and local
residents. The hope was that the project would facilitate increased self-esteem,
confidence and skill development. Workshops involving tenancy staff and people
being supported enabled people to identify “what they could offer and then [swap]
Box 3.1 Shared learning at Hft

Two joint training courses (for Emergency First Aid at Work and Customer Service Training) took place involving both care staff and people supported by Hft. Feedback and response was positive and saw opportunities for developing the approach.

“The thing that came out of the training was really, really interesting (...) because the staff were saying ‘why haven’t we been doing this? Why on earth haven’t we been doing this!?’ And it just took this project I think to stop and make us think about that as well. Why aren’t we?”

The Emergency First Aid at work course had far exceeded expectations, as this Hft manager described:

“We were clear with people; I think on the first day particularly we said right, it’s Emergency First Aid at Work Course, that’s a qualification; it’s what we want all staff to do, we say it in our mandatory training thing. And we said ‘we’re not going in there in any way saying oh well people might be able to do it or they might not be able to do it.’ We will just deliver it and I had a conversation [with training provider] and they said we will produce a certificate of competence so if people can’t pass the test at the end that you’ve got to pass because it’s a qualification, people will still come out of this (...) with a certificate to say what they’ve been able to demonstrate (...) everyone went away feeling good about what they’d done.”

“I think when more support staff see people do things that they haven’t done before and developing new skills and being supported to do that, hopefully people’s mind set will start to change.”

As the training provider also observed:

“Having delivered the two training sessions it became apparent that those participants with learning disabilities relished each of the training sessions. They took the courses very seriously and wanted to learn and develop, giving their full participation at all times. Overall it was a positive experience for both parties. The people who are supported by Hft embraced the sessions wanting to make the best possible contribution to the learning. They valued the training, support and constructive feedback on the days. The staff members who participated in the training pointed out the value of having the involvement of the people they support on the courses and how it energised them during each of the sessions.”

On the strength of the experience plans were in place for a wide range of additional courses including street art, circus skills, disability sports, health and wellbeing and food hygiene.

As the manager remarked:

“They’re all going to be joint now (...) I couldn’t wait – to be honest – having spent time doing this I couldn’t wait to try some sort of workforce development!”
Box 3.2 Timebanking opportunities in Stockport

“Kieran is a very capable young man with autism. He has not been able to get a paid job but he is coming on board with the timebank project to utilise his admin skills. He will also get out and about in the community, promoting the timebank. He has a role and identity in his local community, and he can also get something back from the timebank from the time he donates to the project.”

“Jeremy is living in one of the supported tenancies. He is already an active volunteer at a local farm shop. He has been encouraged to register with the timebank and will be able to bank the hours he earns at the shop and spend credits to get his bedroom at home painted.”

their offers straight away.” Developing these opportunities for people supported by the council required major cultural and professional changes and for staff to reconsider the balance of positive risk taking and safeguarding. Two of the stories that emerged from the project are presented in Box 3.2 above.

3.16. St Martin’s is a small not for profit day care service for older people, which also involves younger volunteers, some of whom have mental health needs. In this context the service benefits both groups in terms of wellbeing, and skills development opportunities were explored both for older people using the service and those volunteering to support them. The principles and ethos of ‘skills around the person’ were thought to fit well with the approach at St Martin’s:

“We think that’s a good principle, and we’re trying to work with that because it makes our work more relevant. I mean our stray line is ‘enriching people’s lives’ (...) and using the skills around the person approach, it certainly sits well with us.”

3.17. Skills and asset mapping had been used to identify opportunities for skills development, for example:

“We matched up a volunteer recovering from a head injury and an 85-year old physically disabled lady in a gardening project. The volunteer wished to develop his gardening skills and self-confidence and the lady wished to have the chance to get involved in gardening once again, and pass on some of her skills to the younger volunteer.”

3.18. Similar opportunities had been identified through matching members of staff with three older people being supported:

“Both staff members wished to develop their cooking skills and the plan is for the ladies to teach them how to execute certain dishes. Their first project will be to produce apple crumble which will be served for dessert at lunchtime. This would also be an ideal opportunity to include perhaps one or two other people with dementia who
One of the people with dementia using St Martin’s is an Italian man who used to run a restaurant which he reminisces about. The manager at the day centre decided to create an opportunity for him to use the skills he had:

“I had the idea – OK, he must have waited table at times, or actually been a waiter, so I got him coming up to the hatch and giving out meals to people (...) He would take a plate of food over, but then he would start talking to the service users and you would need to call him back to give another because the other food was getting cold. But he was back in his restaurant role, sort of making sure the customers are happy.”

may enjoy participating in basic cooking skills, e.g. peeling apples.”

3.19. St Martin’s also found it was able to use the SATP model to support people with dementia better. Box 3.3 presents a case study of using the approach to understand the history and interests of one such client.

3.20. As with most of the projects, this was work that was continuing to evolve and it was recognised that there was considerable potential for development, particularly through wider involvement of families, friends and the community.

3.21. The Cambridge Care Company similarly reflected on experiences with a skills approach bringing people together for mutual benefit, sometimes in unexpected ways:

“We have found that two service users in particular have made a friendship from helping each other from one service user doing the other’s garden. They are getting to know each other and would like to socialise with each other and look forward to seeing one another aside from the gardening. It is really great that the person who is very good at gardening is getting the chance to learn further skills and do something he enjoys.”

And

“Other things that we did not necessarily plan have also happened. A service user who likes car boot sales bought a keyboard one weekend and her support worker is able to play and is teaching her. This may have happened anyway, but we feel that having an awareness and being involved with the project has encouraged staff to get involved and think more about their skills and how they can share them.”

3.22. Sue Ryder Care was using the SATP approach in services for people with dementia and neurological conditions, and saw the potential to work with clients and their family members to look at rekindling areas of interest:

“It’s about their skills and hobbies that they had, and how we could regain them (...) so that they feel they’re confident and it’s something that they could carry on maybe at home.”

3.23. The approach had met with mixed results, particularly when people had advanced
Box 3.4 Supporting people to recover their skills at Sue Ryder

“We have had real great successes with a gentleman who used to be in a band, and we got a volunteer with a guitar and they played (...) he plays a guitar, and then they brought him music and they were doing it together.”

“[So we did some simple things] like potting plants and then selling them at Valentine’s Day to make money for the café. So they did it for a purpose as well as like the hobbies that they’ve always done together (...) And one woman commented ‘I’m forgetting my husband has dementia, you know, because I’m doing the stuff that we used to do’.”

“One lady used to be a manicurist] and she’d lost the will to do anything with her own nails and it was really funny because we’d even struggle to get her into the café and it was like ‘Oh well, let’s talk about what you used to do and about your skills.’ And then she started telling us and it was amazing. And now she is bringing her nail varnishes in and not only does she want someone to do her nails properly, she wants to do everyone else’s! And the only time she’ll have a shower is when she comes to our service. And her husband says it’s funny how she can’t remember anything else in the week but as soon as he says ‘Right, we’re going out’, she says ‘Is it Synergy Day? I’ll take my nail varnishes’ (...) It’s the only day that she’s motivated and the only day that he actually sees her smile.”

Dementia and it was hard to engage them. People tended to move on from the Synergy Café day service provided by Sue Ryder and to move into care homes. However, for people with less advanced dementia or with neurological conditions, there had been some notable achievements. Box 3.4 presents a number of such case studies that illustrate the successful application of the SATP model.

3.24. Before embarking on the SATP programme, Sue Ryder Care had undertaken work within their service on personalisation and saw that the SATP approach would fit well with the philosophy of personalisation, but also challenge the service to work differently, as the project lead described:

“[In the past] a lot of the time it was a lot more group activities if I’m really honest you know, and a lot of it would be your standard, like your bingo. You would have music but a lot of it was just general reminiscence and there wasn’t a lot of like personalisation as in, you know, what they wanted to do or what they could do but that they need that little bit more support (...) But now it’s more about what they can do with us but also what they might be able to still do at home with that little bit of support from us as well.”

3.25. Focusing on people’s skills and having a conversation with them about their earlier life and interests had stimulated the service to rethink its approach, and to absorb a skills focus as part of their everyday mainstream practice:

“which I think is brilliant, it’s a better way of working.”

3.26. The approach had also challenged family carers and other relatives to think differently
about the person needing support:

“I think that the thing for us was making the carers, especially the carers to really think how they look at life with that person with dementia (...) you know, rather than they can’t do this, they can’t do that, you know.”

3.27. This shift in approach had been reflected in the assessment paperwork in use by Sue Ryder Care so that in future people would be asked about their skills and interests in order to better support them. This approach was also being used to help people to recover life skills, such as in helping with the washing up, and making sure that “they’ve got a purpose.”

3.28. Skills development was also being addressed by Wirral MBC as part of a day service run for people with physical and learning disabilities, particularly in enabling them to access sports and leisure activities. In the past people had taken part in sports within the day service building, but new sports groups were established and – in keeping with the wider objectives of personalisation and social inclusion – staff who would normally support people at the day centre were asked to support people in attending the leisure centre. People had gained social skills and confidence, and were also using their newly acquired skills to participate more actively in the wider community:

“The swimming session has also been shown to have an impact on individual wellbeing. For example, CJ who is socially isolated and apart from attending [day centre] twice a week has not been out and about in the community for some time. Being at the swimming and sports session has given him a sense of community presence and reduced his social isolation along with improving his mobility and general wellbeing.”

And

“JL’s confidence has grown and she has decided on occasion that she does not want to take part in the morning disabled swimming session but would like to try water aerobics or one of the dance sessions. JL has been supported and encouraged to follow her interests and often takes an active part in these open community sessions.”

SATP and assessment

3.29. Several of the projects were linking SATP to their model of assessment, but two in particular had made significant changes; these were Suffolk County Council and Jewish Care.

3.30. Suffolk County Council was already addressing many similar ideas in developing an asset-based approach to adult social care and had titled their model ‘Supporting Lives, Connecting Communities’ (SLCC). In common with many other councils, Suffolk had been trying to find a better way to manage approaches from people seeking social care support. A customer call centre service had been in place which dealt with
calls with minimal discussion or inquiry, for example:

“So, if somebody phoned and requested some support at night time, the stock answer was we don’t do night time support’. So it was looking at the request without going outside of that.”

3.31. The main purpose of the front of office contact with the public was to signpost people elsewhere. Without sufficient knowledge of a person’s circumstances it was impossible to know what their support needs might be and whether they could be supported in ways that enabled them to maintain their independence. A change of approach has led to calls now being dealt with by care professionals (social workers, community care practitioners, etc.):

“And their role is really to get underneath the call, so if someone was given that scenario [night time support request], they want to know a lot more about what has created that request.”

3.32. The prime focus is still on trying to “prevent someone needing ongoing or long term support”, but to do so by directing people to appropriate interventions including occupational therapy, assistive technology, reablement, etc. These discussions do not involve judgments about whether or not someone meets eligibility criteria for adult social care, but rather “what’s the best way to help them resolve their current situation?” The skills around the person approach enabled the council to find a way through the multiple layers of process that had been impeding a focus on the individual and were causing the system to grind to a halt:

“We were looking for a way to understand what that conversation entailed. So the social worker, for example, picks up the phone – what needed to change, or did anything need to change, culturally: the language, the terminology, the thinking behind inclusive responses. So again it dovetailed with that thinking. And the Skills Around the Person bid helped us to look at some tools maybe, different ways of thinking, to shift the culture, and particularly the local authority role within that.”

3.33. The ‘asset-based conversations’ began to emerge from the new approach, but it was recognised that what was happening between practitioners and people seeking support was not supported by assessment paperwork and processes that tended to be deficit-based and focused on what people couldn’t do for themselves. Developing a ‘Short term enablement plan’ (STEP), and putting a support plan on the Care First recording system were developments that “lend themselves more to that sort of positive discussion.”

“We had a bit of a mantra (...) about removing that professional overly bureaucratic (...) what we’re saying is get rid of the paperwork, get rid of all that and we’re going to have a conversation and a relationship if you like, and talk about what’s the best way to offer you support. And it’s not with a menu of services, and you’re leading on it - the customer, the person, is leading on it where possible.”

3.34. The asset-based conversation approach led to the development of a workbook around planning outcomes and managing risk. This was the basis for a two-day training course for staff to understand the asset-based model, but the support
planning toolkit is also available from the council’s website.20 The ideas and prompts in the toolkit were described in these terms:

“Questions like what support have you got, what friends have you got, is there anything that you enjoy doing?”

“So, sort of positive type questions to make them think a bit wider.”

“What are the good days compared to the other days?”

3.35. For social workers and other staff working with the ‘Supporting Lives, Connecting Communities’ model, the difference is not just about prompting people with questions about their preferences and aspirations, but about responding creatively:

“One of the things that the staff like about this model is that they can be innovative and, you know, use all sorts of (...) like a solution-focused model, it’s not about carers and respite and things like that (...). We’ve used lots of tablets, notepads, sort of thing for people just so that they can, even if they don’t want to go out, they can actually have choice about their shopping.”

3.36. Suffolk Council had also recognised that the SLCC approach provides a foundation for responding to the new requirements of the 2014 Care Act:

“And I think the SLCC model does support a lot of what the Care Bill is trying to achieve, so I think we’re part of the way there (...) Because there’s also a requirement in the Bill as it stands at the moment to provide, if people don’t fit our eligibility criteria, to provide information to support them with their immediate needs and prevention. So that is very much the SLCC model.”

3.37. As we have commented previously in this document, the SATP model is highly relevant to current and emerging policy agendas in adult social care, and the experience of Suffolk highlights some of the practical implications of incorporating the model into assessment processes.

3.38. Jewish Care is a health and social care organisation supporting the Jewish community in London and the South East. The organisation was involved with both components of the SATP/EoL programme; we will explore the end of life work later in the paper, but here we highlight the approach to skills around the person within assessments. The existing approach to assessment was ‘pulled apart’ in order to focus more clearly on the individual:

“I think now the main difference is really about taking that whole person’s journey – what’s important to them, what they’d like to achieve. Really delving into who that person is and identifying that, but also working with the people they’re working with, working with their family, with their carers, working with the other professionals and organisations that are involved.”

3.39. The difference that the approach makes was described by a manager:
“I think from my observation when my team ask me to sign off an assessment, what I’ve noticed is it’s very much I’m reading that person’s story, their life story. As opposed to – before it was very much tasks – you know, finances, care packages. But this is the story of that person and what it means for them. So I’ve seen that change.”

3.40. The change of approach has entailed issues of trust and expectations being explored more thoroughly than previously, and to examine what people want to get out of the process themselves. Indeed, the organisation no longer speaks of ‘assessment’ but of ‘consultation’:

“We’re trying to move away from the concept of this is an assessment. This is a discussion, a consultation with you, and your views are important (...). By giving them the opportunity to voice what is important to them (...) to have a platform of who this person is and what they want you know. They’re not an older person who’s retired, they’re a person of history (...) And one of our concepts is ‘meaningful lives’ and it’s about identifying for everyone what’s meaningful for them and being able to have a discussion around that.”

And

“I think it’s more about the conversation that we’re having with the people that we’re working with, I think the skill set has changed; the way people are going into it – so it’s a much more holistic experience rather than a question and answer session. Who is the person you’re working with, rather than what is their need?”

3.41. As well as changing the approach to assessment, Jewish Care had explored ways of drawing on the skills of the people they were supporting to enhance those of staff members. This included, for example inviting people to contribute to training meetings by sharing their experiences of living with conditions such as MS or Parkinson’s.

Conclusions
3.42. This section has provided an overview of the approaches and outcomes of projects participating in the SATP programme. The projects are diverse in many respects, including the organisations in which they are based, their client group focus, and their particular project objectives, and they have had similarly varied experiences and achievements. The purpose of this report is not to identify projects that have ‘succeeded’ or ‘failed’, but to explore the experiences of projects in interpreting and applying SATP, and to collect illustrative stories and case studies. The SATP programme was deliberately non-prescriptive and rather than directing projects in how to operate or what products were required, it provided a stimulus by posing some questions about what difference might result from a starting point that looked at the skills and experiences of people needing support, and how these might be developed in ways that would enhance wellbeing and promote personal aspirations. In many respects the underlying ideas and objectives were consistent with models of person-centred planning and personalisation, but the particular focus on skills was a distinguishing feature.

3.43. The concepts of SATP are in some respects very simple, but as the above analysis has demonstrated, engaging with the ideas of skills assessment and development
can have profound consequences. Many of the projects reported experiencing major changes with routine systems and processes (notably around assessment), and also identified organisational and cultural transformation that has – in many instances - been profound. There have been many surprises—whether in rediscovering the previous skills and lives of people being supported, or of those working with them. Equally, the opportunities for developing new skills and shared interests were often unexpected and could have major positive impacts on people’s wellbeing and quality of life. Even services that had well established person-centred practices found the SATP approach elevated them to another level and challenged assumptions and practices. In particular, the focus on what people can do rather than on what they cannot has been especially powerful in changing the nature of the conversation and engagement with people needing care and support.

3.44. The organisational and cultural changes that were widely reported are important, and mean that the benefits of the new model of working are likely to be sustained and not simply dissipate as the project ends. Indeed, project leads repeatedly referred to their continued ambitions for the approach and their plans for future developments. There was obvious value in the meetings of the two learning sets and projects benefited from exchanging information and sharing experiences. The wider relevance of the projects to the current adult social care policy agenda has been discussed above. The programme would seem to be particularly pertinent to the reforms that will be required to eligibility and assessment in supporting the implementation of the Care Act (2014). A new Think Local Act Personal (TLAP) Partnership Agreement\(^{21}\) has been published for the period 2014–17, and the relevance of the SATP work to the ongoing transformation of personalised care and support is evident (see Figure 3b below). In particular, the experience of the programme should inform the focus on building community capacity and on:

“Developing strategies that recognise and build on the resourcefulness of people, carers, families and community groups and develop their capacity to lead and influence.”\(^{22}\)


\(^{22}\) ibid p3
3.45. Figure 3b TLAP’s Definition of Personalisation

3.46. The draft guidance and regulations on the implementation of the Care Act similarly emphasise that assessment should explore what else – other than care and support - might help in meeting outcomes, and “should consider the person’s own strengths and capabilities, and what support might be available from the wider support network or within the community.” SATP offers an asset-based model to begin to inform such an approach.

3.47. The programme is also directly relevant to objectives of enabling choice and control, and tailoring support. SATP is a co-production model which is focused throughout on the individual at the centre of the process. Skills for Care is a member of the TLAP partnership and will want to seek opportunities to share learning and insights from the SATP programme both nationally and regionally, and to contribute to building the evidence base around community capacity building.

3.48. We turn now to examine the experience of the programme component exploring the application of SATP to end of life care and support.

23 Department of Health (2014), Care and Support Statutory Guidance, p70.
4. Skills around the person and end of life

Introduction

4.1. The fourteen SATP/EoL projects were briefly introduced in section 2 above. The organisations participating in the programme included: care and health service providers; community groups; training providers; arts and creative media companies; timebanking; social housing providers; and hospices. The graphics presented in appendix 3 below illustrate the diversity of the projects and their initial thoughts at the start of the programme. Some of the key themes included:

- People lack confidence and skills to have difficult conversations about death and dying.
- Services with little experience of dealing with death face particular challenges, but have contact with people and their daily lives and are well placed to make a difference.
- People need to be able to access information and support in a range of ways.
- The myths about death and dying can be dispelled.
- Some groups of people are particularly marginalised from the processes of death and dying (for example, people with learning disabilities).
- Carers need support when their loved one dies, and also have a lot of knowledge and expertise they can share with others.

4.2. All of the projects were – in different ways – looking at how they could enable people to have conversations about death and dying, and whether in doing so they could equip people better with the skills and resources to have the sort of death they might want. Some of the projects had prior experience with death and dying, but for others this was new territory and there was considerable uncertainty about how to approach the subject.

4.3. Several of the projects recognised that end of life has become both highly professionalised and medicalised, and part of the challenge was to enable people to take back control and ensure that they could shape things the way they wanted.

4.4. Below we adopt a cross-cutting thematic approach to analysing the projects and their experiences in bringing a skills around the person model to end of life care.

Difficult conversations

4.5. How to initiate and complete ‘difficult conversations’ about death and dying was a theme that recurred across all the projects. Without such conversations, death remains a taboo and people’s wishes are unknown. Being able to structure conversations can be empowering and creates the space for people to explore their fears as well as their hopes. These were topics that the projects explored together in
the programme’s two learning sets, and with input from the National Council for Palliative Care (NCPC). The Dying Matters Coalition was established by NCPC in 2009 to “promote public awareness of dying, death and bereavement.”

“Talking about death doesn’t bring death closer. It’s about planning for life. Without communication and understanding, death and terminal illness can be a lonely and stressful experience, both for the person who is dying and for their friends and family” (Dying Matters24)

4.6. Many projects recognised that they needed to find a technique or process through which to initiate conversations. Clearly, this is a sensitive area that needed to be approached carefully. N-Compass North West described their uncertainty about how to begin (“We didn’t quite know how to start the conversation”), and their decision to hold a will-writing day as a starting point:

“On the premise that people coming to write wills are already thinking about end of life; they’re already thinking about what to put in place when they die, so they might be really up for having conversations. And they were.”

4.7. In exchange for support with writing a will people were asked to respond to a questionnaire with five questions:

- How would you go about finding out information about end of life services in our area?
- How do you feel about talking about end of life matters?
- How would you want to help someone facing the end of their life?
- What would stop you helping someone at the end of their life?
- What would you need to help you feel more confident?

4.8. Respondents indicated that they were more comfortable and less emotional talking about such matters with people who were not family members. While people were generally responsive to the idea of helping someone facing the end of life, they were also worried about not knowing what to do, for example:

“I would try to contact other agencies. I also think that sometimes you do not know what to do.”

And

“I would be scared of doing something wrong and not having the skills to do what was required, and then I would feel guilty if I could not respond quickly enough.”

“I want more knowledge about what’s available and the full facts about the health condition. I wouldn’t want to do any harm and I would want to do what they want.”

24 http://dyingmatters.org/overview/why-talk-about-it
4.9. On the basis of these preliminary discussions N-Compass was planning to work with Dying Matters during Dying Matters Awareness Week (12–18 May 2014) to do further work with the community:

“I think I might do a pop-up shop (...) It’ll be about providing information to give people confidence (...) Lots of people in the community gather information from various different sources (...) So I think there’s a whole lot of, I don’t know – not taboos and not myths, just misconceptions that people think about, that they need information to dispel.”

4.10. Looking for opportunities to initiate natural conversations about end of life was also a focus of the project undertaken by Cheshire Living Well, Dying Well (LWDW) where a decision had been made to base the project in libraries. The project was also unique in locating the idea of helping people to “live well, age well, grieve well and die well” as a mainstream public health issue (a subject to which we return later in the paper):

“The programme is innovative and it’s all around how do we look at motivating and assisting people to start to consider, talk about and plan for their future, for getting folder and for end of life as well and how they communicate their wishes.”

“To me the libraries were a natural choice because we need to be looking at how we get this message into the community and the libraries are the hub of the community. And when I consulted within them and explained about the programme, a lot of what they said to me is that the cohort of people – or ‘the regulars’ as they described them that come in, the rapport and the relationship with those individuals is already really well developed and these kind of issues do come up around bereavement, and people are coming to the library to look for books on bereavement or for advice on writing a will or Power of Attorney, or how to communicate their wishes. So there’s already dialogue that takes place.”

4.11. Work took place with library staff to deliver some training sessions and increase staff confidence around the issues. This included exploring the barriers to raising the subject of end of life, concerns of staff over introducing the subject, but also helping to identify triggers and indications that people might want to have a discussion.

4.12. For some projects the ‘difficult conversations’ were more challenging because of familiarity in a small community. Ulnes Walton is a community group where the project coordinator observed:

“...the Community Group were reluctant to work on end of life issues as we did not feel we had the skills to work on such a sensitive subject.”

And

“Over half of the group are in their sixties or seventies, and it’s quite an emotive subject because they have relatives and friends who are dropping like flies almost and it’s a very difficult subject to bring up with somebody elderly.”
4.13. Organisations that are providing care and support and may have experience in supporting people at the end of life, still have to find ways of having the conversations. Jewish Care described working with their care teams to give staff the confidence to “have those open-ended conversations”:

“And people I think are quite scared to start the meaningful conversation. ‘What happens if I upset them?’ They are frightened to upset the other person, but then how much is that about their own fear.”

4.14. In some situations there are also cultural or faith considerations that create impediments to open discussion about death and dying, or a worry that the organisation will become wholly focused on palliative care, for example:

.....the fear of the organisation is that it will become a hospice – you know, there is this extreme fear, these extreme thoughts about what’s going to be the image of this organisation if we start talking about death.”

4.15. Jewish Care worked with its Palliative Care Support Team to lead five support groups to map the current skills and knowledge of staff supporting people approaching the end of their lives and their families. Feedback from participants six weeks after the focus groups reflected on changed practices, as the comments in Box 4.1 highlight.

**Box 4.1 Conversations about death & dying in Jewish Care**

“I ask staff, when appropriate, about how they feel about the subject of death (...) and try to encourage them to speak to each other and people in their care about end of life, so they feel comfortable with the subject.”

“I am more aware of what questions to ask and what to ‘look for’ when speaking to a referrer/client (...) I am more confident when speaking to callers on the phone regarding palliative care and end of life issues.”

“It has made me much more aware about planning for the future and how important it is and we should discuss openly about end of life care.”

“Raising issues to do with end of life is always a delicate matter. It is difficult to determine whether others are able and willing to face up to the fact of death and the practicalities that surround it, and if not, whether that is sufficient reason to avoid the topic altogether.”

“I am more aware of picking up on end of life advance wishes (...) I am able to have discussions with clients, staff and colleagues around advanced wishes which is very positive as sometimes this has not been discussed or thought about before.”
4.16. As a result of the Skills for Care project, Jewish Care concluded:

“We have seen a ‘taboo’ subject becoming visible and somewhat more comfortable to discuss, whereas before it felt hidden.”

4.17. Day centres for people living with dementia had begun to change their admission paperwork “to document meaningful conversations about an individual’s wishes and preferences” before they lose mental capacity. A list of helpful phrases had also been adopted “to assist beginning a sensitive conversation.”

4.18. A very different style of project was that undertaken by Spare Tyre, a well-established participatory arts charity that is experienced in “using and making theatre that enables voiceless communities and individuals to share and celebrate their untold stories.” The ‘Village Green’ project worked on a particular estate in Roehampton (Wandsworth, London) in two phases. The initial outreach phase took place around a gazebo set up on a green area of the estate, and people were encouraged to visit by the offer of tea, cake, and plants in exchange for their thoughts about themselves and the estate. People were also asked to identify the skills that they would be willing to exchange with other people in the community, and these pledges were captured on postcards displayed around the gazebo (see Fig 4a The ‘Village Green’, Roehampton Estate).

4.19. The second phase (after a four week interval) took place under the canopy of a tree on the green, with the aim of engaging people in talking about death and identifying the skills available in the community to support people at such a time.

4.20. Initiating the difficult conversations was easier than it might otherwise have been given the earlier phase of work that Spare Tyre had undertaken on the estate, and the trust and rapport they had been able to establish with residents. An older person had also recently died on the estate, so people were more aware of issues around death and dying and perhaps more inclined to have the conversations. The aim was to talk about death and to discover what skills there were in the community to support people at such a time:

“We asked a range of questions: Did they have a wish list before they died? What were their support needs? Was there life after death? Was there a special memory? Who did they need to talk to about their wishes?

Our creative process led us to having boxes on the table labelled: wish, support, afterlife, memory and music (...) They sang for us and allowed us to record their voices. We became the listeners for a community.”

25 http://sparetyre.org/about/about-us
Fig 4a The ‘Village Green’, Roehampton Estate

Fig 4b The ‘post-boxes’ for end of life thoughts, Roehampton Estate
4.21. In a final phase of the project Spare Tyre tested out the idea of an internet radio station, Roehampton Radio. Pilot episodes were created that included recorded interviews and discussions with people living on the estate, together with music tracks chosen by the residents. One episode was based specifically around discussion about death. Support from the local authority has been obtained to allow Roehampton Radio to continue to develop and to provide a platform for photos from the estate, stories and discussions.

4.22. The Spare Tyre team described the process and conversations with the Roehampton residents very positively, and although the subject matter was serious and sad at times, engaging with the residents was also light and uplifting:

“[many of] the conversations about end of life have been like hilarious, like really funny, like really active. This is mainly with people at the club rooms; we haven’t started talking with the younger group about it but the people there are a lot more resilient and humorous than they’ve been given credit for.”

And

“I think it was really interesting – I thought actually the younger people, and I guess we’re talking about kind of like you know, under 35s, would probably not want to talk [about death]. But they had some profound stuff to say around it really.”

4.23. A project operated by social housing provider Gentoo adopted a range of innovative and informal tools and techniques to facilitate the difficult conversations around death and dying. Gentoo had worked with Skills for Care previously in developing community skills and social capital within neighbourhoods, but the focus on EoL matters took them into new territory. As a provider of sheltered accommodation and extra care housing, Gentoo was not unaware of death and its staff have EoL level 3 qualifications. The project was seen as an opportunity to have difficult conversations but in a relaxed and informal context. As the project lead described:

“We’re a housing provider (...) it’s not about delivering palliative care, because we don’t do that. It’s more about the conversations that we have with people in terms of helping them plan their end of life wishes and getting people to realise that the reality is perhaps you do need to think about your advanced care decisions.”

26 http://sparetyre.org/watch-and-listen/mixed/roehampton-radio
4.24. Rather than approach the subject in ways that might seem morbid, it was decided to establish movie afternoons (with free choc ices, popcorn, etc.), starting with a showing of The Bucket List\textsuperscript{28} (a film about two terminally ill men who set off on a road trip to fulfil their to-do list before they die).

“We said – just come along and watch a film, we just said it’s light-hearted, it’s about life, it’s about laughter and friendship. That’s how we marketed it.”

“There was a staff member in each of the viewings and people just naturally started to talk about it (...) We wanted to keep that momentum so we started to view other films, the likes of ‘Cocoon’, ‘The curious case of Benjamin Button’, ‘The Notebook’, that all touch on dying or dementia. And so it sort of sows the seeds to have people think, well – you know – what would I do in that situation, or what would I like?”

4.25. Twenty-seven film afternoons took place across five venues, with more than 250 recorded attendances. A series of workshops was then developed under the banner of ‘Life – do it your way’. The workshops included personal bucket lists; memory boxes; dancing and humour (see flyer reproduced below). The focus of the workshops was described:

“So we had one workshop which was about the bucket list, and that was about thinking about the time that you’ve got left and what you want to achieve; if you wrote a bucket list, what would be on it? Then we also had a workshop ‘this is my life’, so a memory box workshop (...) if this is a box of your life, what would go in it? the photographs, the people who matter to you; is there a song that you would associate with it, is there any particular moment in your life that you’re really proud of, that you’d want people to remember? We also did a workshop called ‘dance like there’s no one watching’, and that was tap dancing – a local group of older people and it was just a bit of fun, bit of a giggle you know (,,,) highlighting to people that your life is not over, there are still things that you can do. If you’ve got mobility problems, then sit down, you know, those sorts of things, overcoming those barriers. And then we had fun workshops – ‘always look on the bright side of life’, and that was a bit of a sing-along.”

\textsuperscript{28} http://www.imdb.com/title/tt0825232/
4.26. Subsequent work through the project saw the development of a memory book (based around the ideas of the memory box workshop). The book has a number of sections such as about me; my early life; my fondest memories; thing I’d like you to know about me; the people who matter most to me; these are a few of my favourite things; my bucket list, and when my time comes.
As the project lead explained:

“The idea is we want to sit down with people and help them plan their final wishes, so their funeral wishes, making their choices known, sort of things like organ donation, advanced care decisions, the practical tasks associated with dying and death (...) But we’re also wanting to use it as a bit of a reminiscing book as well, because if you want people to come along and you say you know ‘come and plan your funeral’ you’re probably not going to get a great amount of people who will come along!”

4.27. Getting people involved in social situations and participating as a group paved the way to talking about more difficult topics “and it’s just a natural conversation.” Particularly for people who had some involvement with the project from the beginning (e.g. watching the The Bucket List film), moving on to more explicit discussion about death was less of a shock. The project was continuing to evolve and an event was planned for May 2014 that would include a “Before I Die” wall (see Box 4.2). It was also intended that printed copies of the ‘This is my Life’ book would be rolled out and made available, and it was planned to establish a support group or ‘Death Café’ within an extra care housing scheme.

“So I want to leave the community with a Death Café or a support group or some sort of thing, the memory book project, and then a worker who can help facilitate all of those sorts of things.”

29 http://beforeidie.cc/site/blog/category/walls/
30 http://deathcafe.com/
Box 4.2 The ‘Before I Die Wall’

Candy Chang is a New Orleans artist who lost a loved one and struggled with the grief and depression. When she eventually came through this time she found value in contemplating death; she wanted a reminder and she wanted to know what was important to the people around her. In 2011 she got permission to paint the side of an abandoned house with blackboard paint and stencilled ‘Before I die I want to...’, and left bowls of chalks for people to add their own wishes in the 80 blank spaces which were filled by the next day with people’s many and varied hopes and desires.

Posting photos of the chalkboard brought an influx of requests from people wanting to do their own versions. She created a the http://beforeidie.cc/ site with resources to support people doing their own walls, and these have now gone global with at least 500 Before I Die Walls in 30 languages and more than 60 countries. She has published a book documenting the walls (see http://candychang.com/before-i-die-the-book/).

The story of the Before I Die wall is told by Candy Chang on TED talks.

“Preparing for death is one of the most empowering things you can do; thinking about death clarifies your life. Our shared spaces can better reflect what matters to us as individuals and as a community. With more ways to share our hopes, fears and stories the people around us can not only help us make better places; they can help us lead better lives.”

http://www.ted.com/talks/candy_chang_before_i_die_i_want_to

4.28. The final project that we focus on in this section is a timebank. Somersham timebank had worked with Skills for Care around community skills development and was also involved in the SATP/EoL programme (working with CHS group, providing housing and support across Cambridgeshire, and the Cambridgeshire Timebanking Partnership). Moving the timebanking model into EoL proved challenging, partly for logistical reasons (a timebanking coordinator resigned), but also because of the difficulties of raising the subject of EoL in a sensitive way within the timebank. One person who had been identified who would have welcomed EoL support from the community subsequently moved into a hospice before anything could be established. However, the approach was still being actively developed. Box 4.3 presents a case study highlighting the role of timebank members in supporting two people approaching the end of their life in the community.
Box 4.3 Somersham timebank’s first EoL referrals

An elderly couple (Brenda 85 and Ken 88) were put in touch with the timebank by a dialysis nurse at the local hospital. Ken has had a stroke and has care staff visiting 4 times a day; he can use the stairs and sleeps upstairs. Brenda has dialysis three times a week and also has a heart condition which prevents her using stairs and she sleeps in the sitting room. Brenda had become increasingly depressed about her condition and situation, and was in final stages of renal failure.

A timebank coordinator visited on a regular basis and took cakes made by timebank members “which they have really appreciated and shows them that someone is thinking about them.” Visits were also organised by a young timebank member and her three-year-old daughter, which were particularly appreciated by Brenda and Ken who are effectively housebound and have no interaction with children.

Brenda told the coordinator that the timebank is “better than any medicine” in supporting them. By working with a specialist in EoL care the timebank was learning more about Brenda’s health problems and how the timebank could help in the final stages of her life.

4.29. It is likely that the flexibility of the timebank model will increasingly enable members to engage in supporting people as they face end of life situations. However, this is also likely to be something that is a natural part of the exchange of time and skills rather than something that is separately developed. For example, Brenda had donated a box of chocolates as a raffle prize for bingo night, and “the timebank enabled them to feel they could contribute something back to the community.” If timebank members are providing befriending support (and practical help) to other members, over time this is likely to evolve into supporting people remaining in the community to the end of their lives.

Information, skills and knowledge

4.30. Identifying and addressing gaps in skills and knowledge about death and EoL issues (both of professionals and the public) were central concerns of all the projects in different ways. N-Compass described an initial ‘mapping and gapping’ exercise in which they identified what was available locally and what was absent. Consultation with hospice professionals revealed consensus over the key skills needed in end of life care (symptom recognition, communication, compassion and a holistic approach), while also indicating crucial skills gaps in the same areas. Comments made in a focus group included:

“Lack of confidence just to be alongside patients and families and not to medicalise a perfectly natural part of life.”

And

“There are still skills gaps in communications, symptom recognition, how to support families and what to do if a patient lacks mental capacity.”
4.31. Care2Care Training also explored people’s knowledge and awareness about EoL and used four targeted questionnaires for people being supported, carers, care staff and managers. For people being supported and carers the conclusion was clear, as the project leader described:

“It really boiled down to that people just did not know where to go (...) Who is responsible for organising care? Who can support us and how do we do it?”

4.32. Some people also described very poor experiences of waiting too long for assessments and services to be organised in EoL situations, and not knowing what to do if they were dissatisfied with the process. Care2Care produced a simple flowchart to help people find their way through local services:

“I’m happy because it’s something that can be helpful to people to prevent, or at least minimise, you know, the horribleness, the horrible things that people experience at sad times.”

4.33. It was also believed that there would be value in using the flowchart in staff training:

“It’ll also be a good way of assessing staff themselves, you know, my staff’s abilities and confidence.”

4.34. The focus in Ulnes Walton’s project was similarly on providing a source of information for people who might need to know about EoL and care and support available. The preamble to the guide explains its purpose in these terms:

“Being given the news that you or someone you love and care for is nearing the end of life may be distressing and frightening. You can often feel very alone and as if there is nowhere to turn. Finding your way through the health and social care systems can also be very difficult. However, there are many sources of help and this booklet is designed to support you to find assistance. It is also designed to help you make choices.”

Developing skills

4.35. Skills for People is a user-led voluntary organisation supporting disabled people to be in control of their lives and included in their communities. It is still not unusual for people with learning disabilities to be excluded from any involvement with death and dying, as the Skills for People project lead commented:

“There are still a lot of myths around that people with learning disabilities shouldn’t be told about people dying, and attending funerals and things like that.”

And

“People with learning disabilities, we know from national reports, receive inconsistent end of life care. They are often excluded from conversations about death and dying, whether their own death or of those close to them.”
4.36. Enable Care and Home Support (a not for profit organisation providing care and support for people with learning disabilities) made a similar point: “[there is] growing recognition that learning disabled people often have ‘poor death experiences’ and are disenfranchised during death, dying and bereavement processes. Such issues can only be addressed by enabling carers to overcome their own perceptions about death and dying and challenging misconceptions about people with learning difficulties in general.”

4.37. Skills for People wanted to explore whether care staff had the skills and knowledge to support people with learning disabilities at the end of life, particularly considering that such support will not be a routine experience for care staff, and gaps in skills may only become apparent “when they are put in a situation which may require them to provide support to someone at the end of their life.” The role of care staff can be especially important for people with learning disabilities who may lack family members or friends to support them.

4.38. Local service providers (across the North East where Skills for People operate) were asked to complete an on-line survey via the North East Third Sector Network. Eighteen responses were received which indicated:

- Organisations providing support to people with learning disabilities are more open to and want to provide end of life care if at all possible.
- Senior staff in organisations are likely to have received additional training in palliative care and EoL support.
- Additional support from palliative care specialists gave teams greater confidence to support someone in their own home.
- Support staff are not always aware of available tools and resources on EoL.

4.39. Follow up discussion with staff teams was undertaken by Skills for People to explore issues in greater depth. Box 4.4 (page 42) describes the importance of support staff being involved in EoL planning and being able to advocate on behalf of people in such situations.
Box 4.4 Best Interest Decisions

“From the interviews and the workshop it was clear that organisations and support staff are very familiar with the Mental Capacity Act and the principles of ‘Best Interest Decisions’, this was part of their core training. They agreed that ‘Best Interest Decisions’ played a key role in getting the correct support from external organisations. This meeting was the catalyst for engaging with the health professionals. ‘Do Not Attempt Resuscitation’ were also discussed at these meetings with the family and the support team. They were very clear that best interest decisions are crucial when people do not have the capacity to consent. They believed that the staff team being involved in the process had helped both the family and the support team to influence the outcome for the person with learning disabilities who was at the centre of the discussion.

One staff team did say that when some health professionals visited the person in their own home they may not always be supportive of the decisions. It was important to them that they were supported to challenge those who did not follow it through.”

Skills for People (2014), Community Skills and End of Life Care, report for Skills for Care, p23.

4.40. The project leader reflected on the positive conclusions from the workshop:

“Very positive; quite uplifting in a way because I think these people are really committed to this. They really wanted to do it for the person because, you know, they knew the person well and had looked after them for quite some years and (...) they all said the thing that you underestimate always how much time it will take, how difficult it is both emotionally and physically. It’s a draining experience looking after somebody who’s dying. And they said you don’t realise until you’ve been through it just how demanding it is; but then they said they’d do it all over again because they felt that it was such a worthwhile experience to see that person die somewhere they wanted to die, with people around them that they knew and loved.”

4.41. Equipping care staff with the necessary skills is critical to whether or not they feel able to support someone in an EoL situation. Particularly when care staff are encountering death relatively rarely:

“They’re frightened, and by giving them a little bit of extra support they can do anything. And it’s just that initial fear, and it’s that fear that often results in people going into hospital because the staff think I can’t do this; I don’t know how to do this. Where giving that extra support and knowing who to contact and knowing which health professionals to get in touch with is such a key thing.”

4.42. As we have mentioned previously in this report, the established model of person-centred working in learning disabilities services can be especially helpful as a foundation for EoL, and this was recognised by Skills for People:

“If [care staff] have got a good value base and good person-centred approaches and planning then, that in itself can support end of life care.”
4.43. The Enable Care & Home Support project emphasised their experience of fighting to get EoL support and hospice care for clients with learning disabilities. Box 4.5 highlights the difficulties.

Box 4.5 Learning Disability & Palliative Care

“Today somebody else has been refused access to (...) well, the local hospice has said they’re not geared up to meet the needs of somebody with a learning disability (...) they’re saying they can’t cope with him. How can a hospice not care for the gentleman that’s dying just because he’s got a learning disability?! (...) It’s not about his learning disability, it’s about his palliative care (...) his symptom control is no different to anybody else’s, and he needs the same pain relief.”

“There were some groups we contacted (...) that didn’t know how to work with somebody with a learning disability, they had never even thought of it.”

“And again – there’s the bereavement services – but there is nothing for people with a learning disability.”

“There were clearly gaps in knowledge and skills resulting in exclusion and a lack of additional support. For example, the local hospice ran a bereavement group but did not feel able to support someone with a learning difficulty, and a Prostate Cancer support group had never considered people with learning difficulties attending, or alternative means of communication such as pictorial information.”

4.44. Enable adopted a case study approach to explore skills and attributes of staff team members, and of people being supported, their family members and key professionals around them. The exercise underlined the general willingness of the community to engage with people with learning disabilities but “a definite knowledge and skills gap.” Work was planned to develop a downloadable app that people could use to support them in enabling people to “have a quality of life until the end of life.” The project also examined the merit of using a SATP approach to enable staff to meet mandatory training requirements in a person-centred way:

“The concept of skills around the person is what really lit my fire! Because I think, you know, staff have to do certain bits of training and sometimes it’s a struggle to get them to come to training. And you regurgitate – or you’re in danger of regurgitating – the same sort of stuff, you know. Now, if you worked it around the person (...) you can do lots of things based on that and I think that would have much more meaning to the team.”

4.45. Using a case study approach to focus mandatory training is an innovation that Enable plans to continue developing. While recognising that it might not be a total solution, but certainly it was a technique that seemed to have considerable potential:

“To get people through that amount of training that you have to do, and you look at things like e-learning packages and all the rest of it, and I’m not saying there isn’t a place for all types of learning, I wouldn’t say that at all, but I just think if you’ve got a staff team for a day and I’m concentrating on the individual and what sort of things are needed to support that, you’d easily cover lots of stuff.”
4.46. This aspect of SATP was not specifically focused on EoL, but could encompass it. Interestingly, the work being undertaken by Hft to support SATP (see section 3 above) had also recognised that innovative approaches to training (including joint training with people being supported and with their carers) could address mandatory requirements in much more engaging and stimulating ways that were genuinely person-centred and skills focused.

**Social inclusion**

4.47. Addressing social inclusion and engaging people with their communities was a recurrent theme across many of the projects addressing EoL, and we have highlighted several instances of this. However, a few projects particularly illustrate the relevance of this dimension. Imaginarium Seed was the second of the arts-based companies participating in the SATP/EoL programme. The company provides social, emotional and educational development and describes itself in these terms:

“Our approach is simple, we help people rediscover their creativity and imagination, and in doing so empower them to create a better world for themselves and the people around them.”

4.48. ‘Friends of Hainworth’ focused on an estate in Hainworth Wood (Bradford Metropolitan District Council) and was concerned with integrating older residents within the community. The estate had a history of fragmentation and dysfunction, over many years, with a lot of animosity between the residents of older people’s bungalows and the younger people. The older residents had become more isolated and anxious, particularly since the removal of a warden service:

“A lot of the people in the bungalows are very fearful because a man had died and been left undiscovered for three days. So this had just rippled fear through the bungalows, of this idea of feeling so alone; we’ve got no wardens, we’re scared to go out of doors, we don’t know anybody.”

4.49. Imaginarium set about making a DVD, available at http://vimeo.com/76756780, with the objective of bringing the community closer together:

“So the film making was going to be the vehicle to get people on board and say ‘Let’s celebrate something good about this community.’ And basically the brief I gave to them was that what we’re going to do is we’re going to find a need in our community and then we’re going to fill it; we’re going to serve it, we’re going to serve that need.”

4.50. The DVD enabled people to share their stories and transformed the way people perceived each other, as the project coordinator described:

“So we showed the DVD and the impact it had on the community was absolutely huge, and the feedback that we got from people was — everybody was saying ‘I didn’t know that was on our doorstep.’ ‘I just didn’t know’ (...) and other feedback that got me was a lot of people saying ‘I’ve never even thought of old people before’ (...) so there was a lot of really honest feedback from the people in the community.”

31 http://www.imaginarium-seed.com/
4.51. The idea of ‘Friends of Hainworth’ emerged from the process and engaged local residents as volunteers in a friendship group to support older members of the community through a four strand strategy (see Box 4.6). The friendship group has continued to grow and includes elderly residents as volunteers themselves, and intergenerational contact has emerged as a valued feature. Some local authority funding has been obtained to support a community development worker continuing to support the group.

4.52. Compared with many of the projects, the skills focus and concentration on EoL was less evident in the Hainworth initiative. Supporting older people in the community was seen by the project in some ways as synonymous with meeting “the needs of those in the community who are in the end stages of life” simply because of their age. Nonetheless, the development of substantial community resources and social capital has been achieved and provides a valuable platform for further initiatives.

Box 4.6 Friends of Hainworth Wood

“Knock: Friends of Hainworth Wood want to be simply that, friends. We want to enjoy the company of our neighbours and community and would love to pop in and have a good chat over a cup of tea. If you would like to find new friends and would enjoy a weekly visit, please call the friends line and let us know, as we would love to pop in and meet you.

Call: Join our daily phone chain with a quick phone call to let a neighbour know you are well, and check to see they are OK too.

Care: The Hainworth Community Centre offers a Tuesday morning luncheon and Thursday morning craft group with lots of activity, laughter and a chance to meet new people.”

Help: Whether it is sheet ice preventing you from leaving the house, a snow pile up or any other major obstruction, please feel free to call the friends line and we will happily arrange a team of Friends to pop down and help clear the problem.”

4.53. The project run by St Michael’s Hospice, Hereford, was the only one in the SATP/EoL programme to focus exclusively on supporting carers (mainly family members caring for and supporting relatives at the end of life), although support for carers was a component of all the projects in some way or another. St Michael’s established a CARING group:

C - Confidence
A - Ability
R - Resources
I - Information
N - Nurturing
G - Group
The intention was to develop a programme of learning, development and support for family members and friends caring for or supporting someone with a life-limiting or life-threatening illness. Enabling carers, who are typically isolated, to benefit from mutual support can be seen as an important aspect of social inclusion. The project leader described the objectives of the seven week programme:

“We’ve run it once a week, primarily to try to build the group as a group. Because part of our aim has been very much about looking not only at what they can learn together, what they can learn from us, but what they can learn from each other, how they can support each other; and how we can help them hopefully build into a little compassionate community.”

4.54. This objective appears to be successful, and not only have carers acquired new skills and knowledge, but people have established mutual support networks and at least one group was continuing to meet informally in each other’s homes.

4.55. In addition to providing practical information and advice, the course helped people to acknowledge what they are doing as carers and the impact it has on them “in a way that also enables them to seek help for it.” Various resources include a DVD pack with three films under the banner of ‘Living to the End of Life’ that was made for St Michael’s Hospice and launched in Herefordshire before being made available to hospices nationally in 2011 (through Help the Hospices).

4.56. Part of the reason for establishing the CARING group was recognition of the particular difficulties facing carers in rural areas, but also because much local support had been on parent carers, with much less attention on adults supporting adults. The CARING project set out to design a training programme that could be used repeatedly, albeit with a flexible structure to allow input from participants and reaction to the needs of each group. Enabling the group members to become connected to each other in ways that continue beyond the seven weeks of the programme was seen as a particular strength, as the report on the project reflected:

“This is, for some, the most helpful element of the facilitated sessions – that we enable the group members to become a group that can sustain itself in the future. From our perspective this has been a highly rewarding and motivating aspect of the project, which we would hope to continue in the future with other similar groups.”

4.57. The decision to establish the CARING programme arose from the hospice’s informal support work with family members of people referred to the hospice over the years. It was apparent that carers often had not been given vital information or support at an appropriate time:

“And the family carers would say things like, ‘Oh I only wish I knew this earlier’, or ‘If I’d only known I could have asked for this help before’ (...) and that kind of struck quite a chord with us (...) as part of our desire to take our whole services more broadly in terms of offering care much earlier in these processes, it seemed logical that we should extend that work across the family carers as well.”

32 http://www.silvaproductions.co.uk/projects/st-michael-s-hospice-hereford-living-to-the-end-of-life-4
33 http://www.helpthehospices.org.uk/
This reflects the wider shifts taking place in the hospice movement, as the project leader commented, in the past hospice care was almost exclusively focused on the last couple of weeks of life and was primarily for people with cancer:

“We’ve moved an enormous way from that model to a situation where from St Michael’s we would discharge home around about 45% of our inpatients on an average month, and that’s because what we’re looking to do – we’re looking to help people more, early in the disease process. We’re looking to support them more effectively to enable them to get the most out of their lives. And of course, in order for them to do that we need to provide better support for family carers.”

The work being undertaken by Cheshire Living Well, Dying Well has been discussed previously; however, it was the explicit decision to approach the project from a public health perspective which was particularly distinctive and which also is relevant to any consideration of social inclusion and participation. The essential focus of the approach was to bring an awareness of death, dying and EoL throughout the life course:

“...not just when we are at end of life, or we get a diagnosis or a prognosis and we’re in crisis; but how do we help to make this a mainstream public health issue that we talk about alongside diet, alcohol, sun cream, etc?”

An ‘opportunistic’ approach was adopted to embed Living Well, Dying Well messages within the libraries, which was thought to have worked because some of the libraries had identified this as their year of Health and Wellbeing so were already predisposed to looking at ways they might promote messages about health and wellbeing to the community. The project worked with library staff to develop their understanding of what a ‘brief intervention’ in public health terms could look like in terms of Living Well, Dying Well:

“So there was a lot of discussion around actually what we mean by a ‘brief intervention’ in public health terms, looking at the sort of questions that they could ask and how to notice those triggers and also how to notice to step back as well.”

By approaching the topic from a public health standpoint, the project started from the idea of ‘healthy engagement’ with the concepts of death and dying, so that people have a level of preparedness and resilience if and when the time comes that they need to think about dying. The project was one way to ‘start chipping away’ and having those thoughts and discussions about personal wishes:

“I don’t think it is the right time when you are bereaved, when you’ve lost somebody, you’re trying to deal with all that. To then start to think about you at that time (...) it’s just not the best time. The best time is to do it actually while you’re still healthy and while there is a bit of distance (...) and then if you are at end of life or in crisis, you’ve started it already.”

Box 4.7 presents some of the reflections of the Cheshire project coordinator on the potential for the work to become more mainstream within a public health agenda and what that could look like.
Skills around the person

Conclusions
4.63. In this section we have described and analysed the experience and outcomes of a wide range of projects that engaged with Skills for Care to explore the concepts of skills around the person and end of life care. The richness of innovation was evident with many projects adopting unusual and imaginative approaches.

4.64. The recent and ongoing focus on improving end of life care, particularly following the National End of Life Strategy and the establishment of the care pathway, has arguably done much to raise awareness of the need both to improve care and to ensure that communication is open, honest and appropriate. Such objectives are unlikely to be fully met without a much greater openness about death and dying in the wider culture. As the experience of many of the projects reported here has indicated, having ‘difficult conversations’ can be demanding and uncomfortable; however, finding ways to do so can be empowering and liberating.

4.65. None of the projects reported that they had been unable to achieve what they set out to do, and in many instances the outcomes of the projects were unexpected and more fruitful than had been anticipated. Almost all project leaders conveyed their enthusiasm for what they had been able to do and their aspirations to continue to develop and expand the approach in one way or another.

Box 4.7 EoL as a public health issue

“My ambition for the programme would be that it just continued, that we’d get it completely embedded locally as a public health issue, that is cross-cutting. And then it’s continually on the radar of all the different partners and community organisations, and that we can really try to look at this as something through the life course, and to bring end of life right upstream (...) Because it’s linked to all parts of life, so all conditions and health statuses. And there’s a strong link to dementia, there’s a strong link with emotional resilience, there’s a strong link with care and community capacity.

There’s quite a negative perception often in society about getting older and I think we need to challenge that as well as part of living well, and bringing thinking about dying well as part of that (...) and transition and change through life (...) how can we adapt those skills and help people realise that they’ve got that skill within them to do that. It’s conversations around end of life, conversations about getting older – it’s human knowledge; it’s not medical knowledge.”
4.66. Initiating conversations was often the starting point to safely address myths, fears and misconceptions about death and dying. Doing so typically equipped people with skills and resilience, and this was true both for staff providing care and support, and for the wider public. The idea that death and dying should be seen as everyone’s business is powerful. If it is regarded solely as the province of ‘experts’ and ‘specialists’, this can disempower others. Projects that sought to increase the knowledge, skills and understanding of care staff who were not routinely involved in end of life situations (but were likely to encounter them at some point) highlighted the growth in confidence and the readiness to resist pressures to admit people unnecessarily to hospital care when their stated preference was to remain at home.

4.67. Far from being a morbid or depressing programme of work, the experience of the projects demonstrated that opening sensitive conversations was often a prelude to rich and vibrant discussion and engagement in communities. Furthermore, as the experience of Gentoo and Spare Tyre demonstrated in particular, people were very willing to engage in creative approaches that allowed them to explore their own beliefs and wishes and empowered them to take control of their futures.

4.68. The willingness and capacity of people to support others in EoL situations was also evident, whether as care staff, as family carers, or as friends and neighbours. The social capital that exists in communities is considerable, although often latent and unharnessed. People are concerned about ‘doing the wrong thing’ around people who are approaching the end of life, but with the right support they are able to recognise and develop their own skills to provide mutual help and assurance. Bringing communities together around specific activities or shared endeavour can be enormously enriching and provide the foundation for further development, understanding and engagement. As the programme demonstrated, even in communities that have a troubled history or lacked cohesion, focusing on skills development and enabling people to share their experiences has been transformational.
5. Overview and conclusions

5.1. Throughout the report we have drawn heavily on qualitative evidence and have enabled the voices of people working on and participating in the projects to be heard. From the outset, it was not so much intended that the programme would result in definitive ‘how to do it’ toolkits, but that they would highlight a range of models and practice that appear to have merit and that are worth sharing more widely and scaling up.

5.2. The programme did not seek to dictate a right or wrong way of conceptualising SATP and suggested simply that it could be worthwhile to invert many traditional approaches to assessment or care planning and instead to begin with a focus on the skills, aptitudes and resources of the person themselves. This has proved to be a liberating and stimulating starting point that has enabled projects to interpret the remit very freely and to follow widely divergent approaches.

5.3. The programme produced many surprises for participants and the opportunities for sharing experience through the learning sets was invaluable, allowing projects to exchange ideas and to learn from each other. A key purpose of writing this overview report is to enable wider dissemination of the findings from the programme and to encourage further expansion of the underlying ideas and their application.

5.4. The findings from the programme have been presented throughout this report; however, we conclude by highlighting the major messages and emerging conclusions.

- The concept of skills around the person (SATP) has proved to be a valuable model for considering the knowledge, experience and attributes of people needing care and support and of those supporting them.

- Enabling people to maintain or develop their skills at any stage of life and despite disability can be enriching and empowering.

- The current and emerging policy agenda consequent to the Care Act 2014 seeks to promote people’s independence and wellbeing.

- The SATP approach is a tangible way of addressing the transformation agenda in adult social care and putting people’s needs, talents, skills and goals at the centre, and enabling people to make their own decisions and develop opportunities.

- End of life care policy and practice builds on the 2008 National End of Life Strategy and underlines the importance of the six steps of the care pathway.

- Work by Skills for Care on the core competences and principles for health and care workers has highlighted the contribution of a wide range of workers in supporting the daily lives of people nearing the end of their lives—this is not just about palliative care specialists.

- SATP is a person-centred and co-produced model that is non-prescriptive but is based around skills mapping and skills development understanding and processes.
Developing and applying the model requires significant organisational and cultural transformation, particularly in shifting from a deficit model of need to an asset-based approach.

Hidden and latent skills and talents of care and support staff are frequently overlooked and unknown; skills mapping enables these to be identified and maximised.

SATP encourages people to challenge risk-averse practices and consider the balance of positive risk taking and safeguarding.

SATP has potential application in informing staff recruitment and ensuring better matching of care and support staff with people they support in order to maximise achievement of aspirations and shared interests.

SATP can also be used to shape joint training and development opportunities to allow shared learning and skills development between care and support workers and people who need support. SATP provides an invaluable lens through which to model mandatory training components in innovative ways.

SATP blurs the boundaries between people being supported, staff and volunteers in the area of skills development. There are opportunities for everyone to share and learn from each other. People’s histories and rich life experiences are rediscovered and valued, and people with dementia are able to reconnect with some of their life story and experience.

SATP provides a model for genuine personalisation and individualising care and support rather than a standard offer of activities that may be of little interest or relevance to people.

SATP enables people to gain social skills, self-esteem and confidence and to participate more fully in the wider community.

Incorporating SATP into assessment changes the focus and enables an ‘asset-based conversation’ to take place and unpacks the life story of each person.

The SATP model has much to offer continuing work in adult social care. The new TLAP Partnership Agreement emphasises the contribution of community capacity building and developing strategies that recognise and build on people’s resourcefulness.

People are apprehensive about initiating ‘difficult conversations’ around death and dying, but without these death remains taboo. Many projects developed techniques or processes to establish and manage such conversations in non-threatening and informal settings.

Some of the most innovative approaches to SATP/EoL emerged in projects that were not involved in mainstream care and support. Engaging people in workshops and enabling them to share their life stories was especially productive, particularly if the activity had an enjoyable and social component.

All the SATP/EoL projects identified and addressed gaps in skills and knowledge around death and EoL (whether of care and support workers or of the wider public).
Some people (particularly those with learning disabilities) are more likely to be marginalised or excluded from high quality EoL support and palliative care because of lack of skills and understanding of staff.

Equipping care and support staff with skills to continue supporting someone to the end of their life can avoid unnecessary and inappropriate hospital admissions.

Social inclusion objectives can be promoted and encompassed by SATP/EoL approaches, and people can be supported to develop the skills and confidence to create their own compassionate communities.

Finally, approaching EoL within a public health agenda has enormous potential to bring death and dying awareness and understanding into the mainstream of health and wellbeing.

5.5. The SATP and EoL programme has generated a considerable body of innovation, and creative endeavour. A willingness to experiment and see what might work characterised the programme and owed much to the enthusiasm and commitment of individual project leads. The provision of a small amount of seed funding by Skills for Care was invaluable in giving projects the space and opportunity to explore areas of interest. Most projects are continuing to develop the work they have begun and have been inspired by the achievements in their own projects and in the wider programme.

5.6. There is much in the programme that should be shared and widely disseminated. The underlying principles of the SATP model are deceptively simple but have considerable capacity to challenge established models of working and assumptions about people’s capacity and abilities. The resourcefulness of individual people and of their communities is substantial but often unrecognised. The programme has demonstrated repeatedly the opportunities to harness skills, experience, aptitudes and passions, and to do so in ways that promote individual aspirations, enhance independence and maximise autonomy. In meeting the demands of the Care Act 2014, there are major opportunities to draw on the experience of the SATP programme to meet new duties around the provision of information and advice, and to deliver asset-based approaches in supporting people to live their lives.
Appendix 1

The SATP projects

Cambridge Care Company
The Cambridge Care Company is a home care provider supporting around 130 people in the Newmarket and Haverhill area of Cambridgeshire.

Hft
Hft is a national charity, providing a range of services from home support, day opportunities, residential and supported living services for people with learning disabilities. Hft supports approximately 2,500 people across England and employs more than 3,000 staff.

Jewish Care
Jewish Care is the largest health and social care provider supporting the Jewish community in London and the south east, supporting more than 7,000 people in day care, home care and residential services.

St Martin's Centre
St Martin's Day Centre provides care and support for older people in Cambridge at risk of social isolation. The centre also provides volunteering opportunities for people who find mainstream work difficult or are trying to rejoin the workforce.

Star Support
Star Support is a small organisation in the West Midlands providing Personal Budget support services and developments to Councils, Health organisations, people who use services and carers.

Stockport Council
Stockport Adult Social Care is committed to developing coproduction and used the SATP model to find ways of breaking down barriers between 'service land' and the wider communities in which people live and should belong.

Sue Ryder Care
Sue Ryder is a leading provider of end of life care and complex neurological care. The organisation supports people to remain in their own homes through a range of non-residential services and opportunities.

Suffolk County Council
Suffolk County Council Adult and Community Services provides care and support for adults and is transforming the model of response under the objectives of ‘Supporting Lives, Connecting Communities’ which promotes independence and the development of community resources.
**Thera Trust**
Thera supports people with a learning disability to live in their own homes in the community. Thera supports approximately 1000 people in 19 counties. The SATP project focused on Thera East in Essex and Suffolk.

**Wirral Metropolitan Borough Council**
The Department of Adult Social Services in Wirral MBC provides support to around 11,000 people each year. Co-production with people who use services, local people and the community is a core objective.
Appendix 2

The EoL projects

Cambridgeshire Timebanks
A number of timebanks operate in Cambridgeshire, enabling people to exchange their knowledge, help and skills in return for time credits. Timebanking also creates opportunities to bring communities together.

Care2Care
Care2Care training provides training and consultancy in health and social care in Yorkshire, Derbyshire and Nottinghamshire.

Cheshire LWDW
The Cheshire Living Well, Dying Well Partnership is supported by St Luke’s Cheshire Hospice and Macmillan Cancer support and provides multi-agency support for the Cheshire LWDW public health programme.

Enable
Enable Care and Home Support (ECHS) is a not for profit organisation originally established in 1990 to facilitate the closure of a long stay hospital (Whittington Hall). ECHS provides a range of care and support to more than 350 people with learning disabilities mainly in the Derbyshire area.

Gentoo
Gentoo is a major housing provider in the North East. The project was undertaken by the Older People’s Team which aims to provide more life choices and greater opportunities for independent living.

Housing 21
Housing 21 is a major provider of retirement housing and is the UK’s largest non-profit care provider.

Imaginarium Seed
Imaginarium Seed design and run arts-based projects aimed at enhancing social, emotional and educational development.

JackDawe
JackDawe provides specialist home care support to people with dementia and their carers for Nottingham City Council.
Jewish Care
Jewish Care is the largest health and social care provider supporting the Jewish community in London and the south east, supporting more than 7,000 people in day care, home care and residential services. Jewish Care had two projects with Skills for Care working on both the SATP and EoL parts of the programme.

N-Compass North West
N-Compass operates across the North West of England to make a positive difference and enhance life opportunities for adults and young people needing care and support.

Skills for People
Skills for People is a user-led voluntary organisation working in the North East and supporting disabled people to be in control of their own lives and to be included in communities of their choice.

Spare Tyre
Spare Tyre is a participatory arts charity with extensive experience of using and making theatre to enable voiceless communities and individuals to share and celebrate their untold stories.

St Michael’s Hospice
St Michael’s Hospice is a major provider of palliative care education and training in Herefordshire that provides educational opportunities to encourage learning and confidence in all aspects of caring for and supporting patients and their families.

Ulnes Walton
Ulnes Walton is a village in Lancashire which has an active community group that focuses on reducing social isolation of elderly residents.
Appendix 3

Graphic facilitation by Pen Mendonça

Organisations set up by older people for older people may lack confidence around End of Life.


Focus on Housing

Gentoo

60% of people are over 50

Community-based

Belief that older people can & do contribute (including as grandparents)

Often well placed to know about support people at end of life.
CARE 2 CARE, SHEFFIELD

- Focusing on care homes & nursing homes
- Staff had end of life training but many lacked confidence
- It can be difficult in services where people rarely die
- Issues for carers include fear of doing the wrong thing, little or no support, stress, fear, and having to deal with conflicting advice
- Who will take care of her when I die?

ULNES WALTON

- Representatives of small, local community groups come together to make things better, work on projects & fund raise
- We help people to know what help is out there & what they may be entitled to
- Not just signposting people but connecting people & following up
- Many older people do not use the internet & need other kinds of support & information
- W.I. are one of many groups who jolly people along & get them to stay active
N-COMPASS (North West)

Wanting to dispel the myths about death & dying & help people have conversations

Family

Community

Person-centred

Working with a hospice & Lancaster University

Have mapped services & supports within an area:
- health & social care
- role of faith groups/coffee morning/befriending

It's been medicalised
People don't know how to talk with children about this

Trying to change this discourse

Now working with community groups, hospice volunteers, end of life network

We really learnt a lot from doing the Skills work before & made great connections

On communication awareness raising
Skills around the person

IMAGINARIUM with Hainworth Community

- A fractured community
- Drug & alcohol problems
- Social & family problems
- Isolated 'community' of older people dying alone

Grassroots group want to improve things for local people

- No pub
- No school
- No church or post office

Using film to give older people a voice & promote intergenerational solutions/connections
We began by looking at the skills of the team.

Now we are focusing on the skills needed in the community so that people with learning disabilities can access existing support. i.e. does the cancer support group know how to include & support learning disabled people?

St. Michael's Hospice (Hereford) Living Well Project = not just focusing on crisis

A big geographical area with isolated rural communities

Lots of older people move here (limited networks)

Lots of sheep!

Financial help with mobility, health issues etc.

Supporting carers practically & emotionally

Hospice at Home
Nottingham City Council

Helping people who use services & staff across the workforce to use music at the end of life

**SOUNDTRACK**

**WHAT MAKES YOU FEEL LIKE DANCING?**

**WHAT MAKES YOU FEEL SAD?**

Important to connect music to individual's life history

Using music in a person-centred way with people with dementia

CD & booklet of memories for family

**THINKING ABOUT THE USE OF MUSIC IN THE MOMENTS BEFORE / AFTER DEATH**

**TRAIN THE TRAINERS**

**NEXT STEPS:**

**USING MUSIC & SOUND IN STORY-TELLING**
Skills around the person

Cambridgeshire Timebanking Partnership

An hour of time for an hour of time

Encouraging community-led developments that come about as a result of timebanking

Timebanking projects in rural communities & city settings

Organisations can now join as well as individuals:

Nature Reserve
Barclays
Timebank

A local experience of timebanking led to corporate project with wider benefits

Stories of individuals, families where the network they have gained through timebanking has been of benefit during/ following hospital admission

Working with housing association to look at timebanking approach within their schemes

END of LIFE
Cambridgeshire Timebanking Partnership

An hour of time for an hour of time
EXCHANGING KNOWLEDGE, SKILLS, HELP...

Encouraging community-led developments that came about as a result of timebanking
Timebanking projects in rural communities & city settings

Organisations can now join as well as individuals:

- NATURE RESERVE
- BARCLAYS
- Timebank

A local experience of timebanking led to corporate project with wider benefits

Stories of individuals, families where the network they have gained through timebanking has been of benefit during/following hospital admission

Working with housing association to look at timebanking approach within their schemes

END of Life
Skills around the person

Gathering stories from older people & recording them

Playing them back to community members & inviting them to comment & add

Challenges including work across local authority departments that don’t have the same understanding/culture.

Why is it that communities here feel isolated & alienated from each other?

On going learning from people with dementia, women with experience of violence & adults with learning disabilities.

This work needs to be intergenerational & include issues around sudden death & younger death.

It's really rough there.

But the people are fantastic & there is loads of green space!
Skills for People

Supporting people with learning disabilities to speak up & have control in their lives etc...

People with learning disabilities are often not told what is happening when a loved one is dying

Some don't even get the chance to participate & grieve at a funeral.

WHAT WILL I SAY?

Paid carers often feel that they lack the skills/confidence to support people at the end of life

Tools are often difficult for people to use & understand, may list details or names but not explain what needs to happen

Working with support workers & managers to find out what they think is needed

Focus of tools & training often about funerals, sometimes person-centred
Skills around the person

St. Lukes (Cheshire) Hospice

Living Well
Dying Well
Programme & Partnership

Help us to have those difficult conversations about death & dying

Helping other people to understand the implications of not planning for death & dying

Helpful with:
- Older peoples network
- Librarians
- Centre for Independent Living (disabled people)
- Volunteers

Challenges for public health:
- Stop smoking and live longer!
- We are all going to die one day so let's talk
- Fair enough

Trying to 'normalise' death & dying

Funeral & financial planning

Music for my funeral

A load of rubbish

Hospice staff can struggle to talk about death in their own lives despite doing it at work.
Skills around the person

**SKILLS 4 CARE PROJECT**

**Yorkshire & Humberside**
- Improving education around death in care homes
- Reducing the numbers of people having to die in hospital

**Limited training**
- For care home managers & deputies
- 500 care homes receiving training from a range of organisations

**Housing 21**
- Even when people do have the skills they can find they lose confidence when it comes to end of life
- Working in different areas across the country

A lot of energy has been spent helping health & social to work well together

Promoting networks, helping people to discuss & learn together

**E-learning**
- Resources available

**Death & bereavement**
- But what do people need before this?

**Communication**
- Training with managers, GPs & frontline staff

**Language is important**
Skills around the person

Jewish Care

I want to die here, with you by my side

Community-based support
Work within our care homes

This work links to our work on the Skills Around The Person Project

A challenge: Negotiating splits within Jewish community & beliefs around death

Promoting person-centred approaches to end of life

Improving the skills, knowledge & confidence of staff

Enabling staff to pass their skills & knowledge on...

Reciprocal training

Finding less intimidating approaches & ways of having conversations
On the following pages are some questions and a story to help you begin to identify and map the skills that already exist in your communities, and to think together about how these might be valued and developed in ways that benefit everyone.
What Skills are in Our Communities?

Who else can help us identify skills, qualities & experience?

What things can we count or record?

What skills do we need or want to develop?
What would help value and grow these skills?

<table>
<thead>
<tr>
<th>Our thoughts and ideas:</th>
<th>What needs to happen to value &amp; grow skills at an individual level?</th>
<th>Who can we share these ideas with?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals, Families &amp; Friends</td>
<td>What needs to happen to value &amp; grow skills at a group or neighbourhood level?</td>
<td></td>
</tr>
<tr>
<td>Neighbourhoods &amp; Groups</td>
<td>What needs to happen to value &amp; grow skills across the whole community?</td>
<td></td>
</tr>
<tr>
<td>Whole Communities</td>
<td></td>
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</tr>
</tbody>
</table>
Even though she was dying, she helped me make plans for my future, and I helped her stay at home until the very end. I hadn’t realised how many skills I had gained through being a carer for so long.

They asked me to help other carers who might be worried about their loved one’s final days. They even got me to speak at a meeting set up by local residents who wanted to celebrate how great our community is.

I made new friends, joined Timebank and a club. Some people from a care home were at the meeting. They were surprised at how much was happening locally. We worked with them to find better ways for those they support to really be part of our community.
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