



Gofal Cymdeithasol **Cymru**  
Social Care **Wales**



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# Development of a strategic plan for care and support at home

Literature review



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### **Introduction**

- 1.1 This rapid review aims to provide a broad overview of the key messages emerging from the evidence on home care and to signpost examples of innovative practice.
- 1.2 Drawing on research, policy and practice literature, the paper summarises the main themes around domiciliary care workforce, person-centred, relationship-based care, outcomes-focused services, specialist services, integrated care, commissioning, and characteristics of the home care market.
- 1.3 Given the range of the thematic areas investigated, and their complex and multifaceted nature, the review provides a selective discussion of some of the topics that have emerged and signposts some models of innovative practice currently developed and implemented in the UK.

### **Workforce**

- 2.1 The Welsh Government has earlier this year held a consultation on how to improve the quality of domiciliary care in Wales, by having a positive impact on the recruitment and retention of domiciliary care workers. While findings are yet to be published, as part of this programme a study has been conducted examining current issues with recruitment and retention of domiciliary care workers and the extent to which these factors impact upon the quality of care (Atkinson et al., 2016). The research study comprised a literature review and qualitative data collected from seven local authority commissioners, 32 registered domiciliary care managers and 41 domiciliary care workers using telephone interviews and focus groups. In the section that follows findings from this evidence review together with findings of a recent SCIE review of the evidence on social care workforce (unpublished) for the broader context will be briefly outlined.

### **Workforce size and characteristics**

- 2.2 'The role undertaken by domiciliary care workers is both responsible and skilled. Domiciliary care workers generally work independently and unsupervised, using their discretion and autonomy. Domiciliary care workers support individuals to live at home by focussing on promoting their well-being. This can include assisting with household tasks, such as cooking and cleaning, assisting with personal care, accompanying clients to see their GP or other medical appointments, and

assisting with other activities to support people to live as independently as possible. Domiciliary care workers also undertake more specialised activities such as working with people with dementia and administering medication' (Wales. Welsh Government, 2016).

- 2.3 It is estimated that approximately 19,500 domiciliary care workers are employed in Wales, delivering around 260,000 hours of domiciliary care a week to 23,000 service users. The rate of turnover in the domiciliary sector is around 32% and vacancy rate of around 6% (Wales. Welsh Government, 2016). UKHCA however estimate that 26,100 people are employed in the domiciliary care sector in Wales, with 21,100 employed in the independent/voluntary (Howat et al., 2015).
- 2.4 Data analysis for the UK suggests that females account for 80% of the workforce. In terms of the ageing profile, over half care workers are aged over 40, more than 25% over 50 and only a third are aged 30 or under.
- 2.5 The demand for social care services and care labour is growing in the context of significant demographic changes and the growing incidence and large prevalence of complex, long term conditions. 'The ageing population means over a quarter of the population in Wales is aged 50 plus. Those aged over 65 are expected to increase from around 600,000 in 2013 to 900,000 in 2037 and the number of over 85s is growing at an even faster rate (Age Cymru, 2015). Wales also has a higher proportion of people aged 85 plus compared to the rest of the UK (StatsWales, 2012).' Population growth and demographic profile projections indicate that the supply side of social care is struggling to keep pace with demand. The data indicates that across the UK over half a million new care workers/home carers will be needed by 2022 (Howat et al., 2015).
- 2.6 The literature suggests that the gap between labour demand and supply is exacerbated by a widespread perception that a career in the social care sector is as unattractive due to working conditions, low pay, lack of job security, lack of career progression opportunities and the overall low status of the profession.

### **Training and qualifications**

- 2.7 The literature acknowledges the role of training and qualifications in ensuring the delivery of high quality care but also suggests that the current provision of training in the social care sector is unsatisfactory. 'Problems with poor quality training and a lack of high quality apprenticeships are not unique to the Care Sector, but are more pronounced' (Kingsmill, 2014). Qualifications Wales recognises that the current coverage of certain key aspects of learning for different areas of work, including dementia care and domiciliary care requires strengthening and has committed to revise the qualification framework (Qualifications Wales, 2016).
- 2.8 Findings from a recent survey of more than 1,000 care workers employed by councils and private firms across the UK suggest that workforce receives inadequate training and this can leave care users in significant discomfort and

vulnerable to infections. Of the homecare workers surveyed who regularly carry out the following tasks: almost six in ten had received no training in how to attach or change a convener catheter; more than half had not been shown how to perform stoma care; more than four in ten had not received training in how to change a catheter bag; and more than a third hadn't been showed how to carry out peg feeding. Almost a quarter of staff administering medication had received no training, despite some of them distributing drugs such as liquid morphine and insulin (Unison, 2015).

- 2.9 In addition, with the rise of the personalisation agenda and the drive “to help people to help themselves” and to support people to live independently ‘higher-level skills being required for care assistants in general, with an emphasis on communication and influencing skills’ (Howat et al., 2015).
- 2.10 ‘Concerns have also been raised in respect of qualifications, both level and uptake (CCW, 2010). In Wales, a service provider must ensure at least half its workforce holds a minimum Level 2 relevant qualification; all care workers taking up a new role in social care must complete an induction training programme within 12 weeks; and apprenticeships are increasingly promoted as a skills development mechanism (Kingsmill, 2014). The Qualifications and Credit Framework Health and Social Care Diploma Level 2 (QCF2) qualification requirement (originally National Vocational Qualification Level 2, NVQ2) was embedded in the National Minimum Standards established by the Care Standards Act 2000. At the time of the 2000 Act, over 80% of The UK workforce held no relevant social care qualification (Gospel and Lewis, 2011). The evidence raises concerns about the value of QCF2 qualifications and whether they can adequately provide the knowledge and skills for an increasingly demanding profession. Concerns refer both to the level of the qualifications, deemed to be too low, and the vocational nature of QCF2 qualifications designed to assess practical skills rather than expanding underpinning the knowledge and the essential relational, ‘soft’ skills required in care work.
- 2.11 In response to these concerns, the recent report by Qualifications Wales (2016) proposes ‘that any main domiciliary care qualification should be at Level 3 rather than at Level 2, in the context of the higher level of responsibility required when operating in the more isolated contexts of domiciliary care.’
- 2.12 Some commentators argue however that knowledge and training alone may not be sufficient in instilling a sense of competence in care workers. Muller and Sullivan (2016) found that ‘a positive attitude towards people with dementia, and stronger intentions to implement person-centred care strategies, predicted a greater sense of competence to provide care, whereas knowledge and training, commonly believed to be important contributors to sense of competence in dementia care, did not predict this outcome.’ They argue that ‘investing in strategies that address staff attitude and encourage person-centred care could influence sense of competence, and by extension, dementia care’.

- 2.13 The literature indicates that there are limited opportunities for progression and career development in the care sector, due to the flat hierarchies within provider structures and the lack of financial incentives and career progression pathways. In addition, the workforce with a strong motivation to work in the frontline may be disinclined to take on managerial roles.
- 2.14 The evidence acknowledges the role played by supervision and management in ensuring the workforce is supported but recognises the challenges for ‘the domiciliary care sector where there is a high incidence of lone working’.

### **Pay and job security**

- 2.15 Frontline roles within the care sector are generally perceived as low-status, low-skills jobs. This is reflected in the rates of pay, with most workers being paid at or around the National Minimum Wage. Low wages impact directly on the ability to recruit and retain staff particularly in the context of other sectors, including retail, being able to offer higher pay. ‘Recent ONS data (Kirton, 2015) shows that unemployment in Wales, at 6.4%, is now around pre-recession levels and that pay has performed relatively strongly in retail as opposed to the more constrained public and associated sectors. Social care pay rates risk falling further behind other competitor sectors.’
- 2.16 In addition, domiciliary care workers across the UK routinely do not receive pay for travel time. ‘Only 21 per cent of English councils now require employers to pay home carers for travel time, although this is an increase from the 7 per cent recorded in 2014. In Wales two of the nation’s 22 councils now require travel time payments for home care workers compared to none in 2014’ (Unison, 2016). There is general agreement in the literature and among commentators that the introduction of the National Living Wage will add further pressures to an already fragile sector, unless additional funding is provided.
- 2.17 There is a lack of conclusive evidence on the positive causal relationship between pay levels and improved care quality. However, the research highlights the importance of ensuring staff feel valued and able to progress. Carr (2014) argues that ‘working conditions and organisational culture are essential parts of the overall approach to ensuring low-paid staff feel valued and satisfied, recruitment and retention of talented staff is maximised, and the continuity of care associated with quality is maintained.’
- 2.18 Domiciliary care is also characterised by high levels of job insecurity and a substantial proportion of zero-hours contracts. There are not specific figures for Wales but the data for the UK suggests that 56 per cent of domiciliary care workers in the independent sectors are on zero-hour contracts. Other sources estimate even higher levels, 70 per cent or 80 per cent. Rubery et al. (2015) warns that ‘labor shortages are likely to persist as long as workers are required to adapt to a regime of fragmented time and to work more hours than are paid, even at pay rates close to the national minimum wage’.

2.19 Furthermore, a recent report on the use of zero hours contracts in devolved Welsh public services, drawing on a literature review, survey of organisations involved in the delivery of public services and qualitative fieldwork with stakeholders, found that 'respondent organisations reported that they employed over 25,000 people on No Guaranteed Hours Contracts, though in many instances, these individuals were also employed on substantive permanent contracts alongside this'. 44% of the Welsh public service organisations that took part in the survey admitted using NGHCs (including people employed on a zero hours, hourly-paid, on-call, casual or bank basis). Over a third of them said they used agency workers and 23% used self-employed or freelance workers. While unable to provide specific figures for the domiciliary care sector in Wales, the report acknowledges that 'the use of NGHCs to employ domiciliary care workers in particular has been the subject of much media attention of late amid concerns that those providing care to some of the most vulnerable in society are themselves in poorly paid and insecure employment. Earlier research has suggested that 'zero hours contracts are the dominant employment model' in that part of the health and social care sector'. 'Both stakeholders and the literature pointed to a growth in the contracting out of home care services by local authorities, more often than not, linked to the financial pressures they have been facing over recent years' (Burrowes, 2015).

### **Worker motivations and occupational status**

2.20 The evidence suggests that care workers are attracted to a career in the care sector because of the working time flexibility; the opportunity to work with people; contributing to positive outcomes for service users; making a difference; and values. 'This supports a view of care work as vocational but tends also to position it as women's work, particularly for older women who have cared for children or older relatives'.

2.21 The perception of care work as a low-status occupation is associated to low pay levels and low entry requirements, but also to the nature of the work and the belief that is essentially a female profession. The evidence base suggests that practice designed to improve the skills and qualifications needs to recognise the complexity of care work, reflect the relational, interpersonal aspects of the job and develop and value a broader range of skills, including 'soft skills'.

### **Recruitment, retention and good recruitment practice**

2.22 'The top four recruitment difficulties in domiciliary care are (overwhelmingly) pay, the nature of care work, local labour market competition (e.g. retail) and travel costs (where workers are unpaid for these) (Rubery et al., 2011)'. Zero-hour contracts, limited career progression options, low status of the occupation and sector's poor reputation further exacerbate the difficulties in attracting skilled workers.

- 2.23 Poor working conditions and low pay also negatively affects retention of care workers, particularly in the domiciliary care sector and indeed there is evidence that turnover is less pronounced in the residential sectors where wages and working times are better (Rubery et al., 2011).
- 2.24 There is limited evidence on good recruitment practice. Employers use a range of methods to advertise vacancies and recruit, including word of mouth, local press and increasingly online sites and the social media. The literature suggests that Job Centres may be an ineffective way to recruit care workers, generating a high volume of job applications including from applicants who do not intend to embark on a career in social care. Recruitment agencies on the other hand are deemed to be costly and ill-equipped to identify suitable candidates.
- 2.25 Value-based recruitment is emerging as a recruitment practice particularly suitable to the vocational nature of care work, although strong evidence of its effectiveness on either quality of care and recruitment and retention is lacking. There is however some evidence that this approach can lead to the selection of suitable candidates (Goode, 2014). Other studies have shown a positive impact on retention, with one study suggesting an improvement in turnover rate by 5.6% when value-based recruitment methods are used. Findings from a recent survey of social care organisations employing approximately 27,000 people revealed that values based approaches to recruitment and retention are widely used (74% of participating organisations) and where comparisons could be made the majority of participants (72%) felt that staff recruited through this route performed 'better' or 'much better' than those recruited via traditional methods (Consilium, 2016).
- 2.26 Staff performance was rated in relations to the following measures: sickness absence; punctuality; skills required for their role; and overall. In addition, 'approximately three quarters of employers stated that staff employed through a values based approach to recruitment and retention performed either 'better' or 'much better' than people recruited through 'traditional' approaches in terms of a wide range of care values', including compassion, respect, empathy, treating people with dignity and integrity. Two thirds stated that communication performance was also better in staff recruited through a values based approach.

### **Career pathways**

- 2.27 There is general agreement in the literature that the lack of career progression options within the care sector has a significant impact on turnover rates. There are approximately 19,500 domiciliary care workers in Wales but only 630 domiciliary care managers in the Care Council for Wales register. While a range of other managerial/supervisory roles are available, overall the care sector and care providers are characterised by a 'flat' hierarchical structure. This is especially true for small and medium size enterprises, which are most frequent in the care sector.
- 2.28 While the evidence indicates that career pathways in the care sector are few and ill-defined, it is also acknowledged that the fragmentation of the qualification

landscape makes it difficult for care workers to understand how their qualifications relate to professional roles and pay structure (Kingsmill, 2014). Qualifications Wales is planning to strengthen the qualification framework to ensure 'learners moving between settings, for example between residential and domiciliary care, should be able to take only those elective elements of the qualification that are required to top up their existing core elements. Elements should be able to be separately certificated and, where relevant, funders of learning should be encouraged to support as flexible a system as possible'.

- 2.29 In addition, some evidence suggests that the overemphasis on national qualifications may create an unnecessary barrier to promotion for experienced workers and may be ineffective if not counterproductive in the care sector, which is characterised by a flat employment structure (Warwick Institute for Employment Research, 2014). Furthermore, while often managers view qualifications as a means to raise the company profile and retain staff, for employees professional development may be a way to enhance their chances to move to a new job and leave the company.

## **Person-centred, relationship based care**

- 3.1 The concept of person-centred care has gained increasing prominence in both health and social care research and practice. It reflects a shift from profession and service led approaches to a model of care that places patients/service users at the centre, addressing their wider needs, and enabling them to participate in the choice, design and delivery of their care. The concept however lacks a single agreed definition, is multifaceted and variably used in the literature to refer to a range of key principles and practical approaches to care. A number of correlated terms are employed either conterminously or contextually and together provide a richer vocabulary that perhaps better captures the nuances and complexities of the personal-care approach. These comprise personalisation and user choice, relationship-centred care, user-oriented care, mutuality, experience based co-design, and outcomes-focused care.

## **The quality of the evidence**

- 3.2 While there is a growing emphasis in person-centred approaches in both policy and practice, the evidence on its effectiveness is limited. 'Considering the vast amount of published literature on this topic, there is relatively little evidence presented about the effectiveness of practising in a person-centred way. It seems the shift towards person-centred care that is evident in this review is as much due to philosophical considerations (belief in the equality of the service provider-user relationship, belief in the expertise of the client and their rights to make their own decisions about their health care) as it is to evidence-based practice' (Dow, 2006).
- 3.3 This assessment is echoed in a more recent scoping review of the literature on person-centred practice in social care for disabled adults and older people with severe and complex needs. The review found that thirty-five papers advocated

person-centred support for people with complex needs, but no well-supported evaluation evidence was found in favour of any particular approach to delivering this. The strongest evaluation evidence indicated the effectiveness of a multidisciplinary specialist team for young adults; intensive case management for older people with advanced dementia; a specialist social worker with a budget for domiciliary care working with psycho-geriatric inpatients; and interprofessional training for community mental health professionals. The dearth of robust evaluation evidence identified through this review points to an urgent need for more rigorous evaluation of models of social care for disabled adults and older people with severe and complex needs' (Gridley, 2014).

### **Principles of person-centred care**

- 3.4 While peer reviewed evidence on the effectiveness of person-centred care as a comprehensive and well-defined approach is limited, practice and policy guidance is being developed to support its implementation. Current guidance offers an indication of how this emerging practice, and its value, may be understood in its various components and expressions and how it may be achieved. For instance, the Health Foundation proposes that person-centred care comprises four principles: affording people dignity, compassion and respect; offering coordinated care, support and treatment; offering personalised care; and supporting people to recognise and develop their own strengths and abilities to enable them to live and independent and fulfilling life (Health Foundation, 2014).
- 3.5 In its guidance on the delivery of person centred care for people with dementia, the Care Council for Wales (2011) borrows a definition developed by Professor Dawn Brooker (based on the work of Professor Tom Kitwood) and known as the VIPS framework. This is expressed as: V for Valuing – unconditional valuing of the person regardless of their illness; I for Individualised - treating the person as an individual; P for Perspective - looking at the world from the person's perspective; and S for Supportive - providing a positive social environment in which a person can experience well-being throughout life (Rowett, 2010).
- 3.6 An earlier literature review on person-centred health care links it to the concept of partnership, encompassing the following principles: getting to know the patient or client as a person (holistic approach as well as individual approach); sharing of power and responsibility (patient or client as expert in their own health, sharing of decision making, information, the idea of common ground); accessibility and flexibility (of service provider as a person and of the services provided); coordination and integration (consideration of the whole experience from the point of view of the service user); having an environment that is conducive to person-centred care (supportive of staff working in a person-centred way and easy for service users to navigate) (Dow, 2006).

### **Guidance on person-centred home care**

3.7 NICE (2014) sets out what person-centred approach to home care for older people involves:

- 'Ensure services support the aspirations, goals and priorities of each person, rather than providing 'one size fits all' services.
- Ensure support focuses on what people can or would like to do to maintain their independence, not only on what they cannot do. Recognise: that people have preferences, aspirations and potential throughout their lives, and that people with cognitive impairment and those living alone might be at higher risk of having unmet social care-related quality of life needs or worse psychological outcomes.
- Ensure people using home care services and their carers are treated with empathy, courtesy, respect and in a dignified way by: involving people and their carers in discussions and decisions about their care and support; agreeing mutual expectations; always respecting confidentiality and privacy; providing a reliable service that people and their carers can trust; regularly seeking feedback (both positive and negative) about the quality and suitability of care from people using the service, including those who do not have a carer or advocate.
- Prioritise continuity of care by ensuring the person is supported by the same home care worker(s) so they can become familiar with them.
- Ensure there is a transparent process for 'matching' care workers to people, taking into account: the person's care and support needs, and the care workers' skills, and if possible and appropriate, both parties' interests and preferences.
- Ensure the person using the service, and their carers (if the person has involved them in their care), can direct the way home care is delivered. This is so that the person's safety, comfort, independence and sense of security are always promoted.'

**User preference, choice and quality of life**

3.8 It is not surprising that given the multifaceted and composite nature of the person-centred approach to care and the range of definitions available, research studies have tended to focus on particular aspects of person-centred care, looking for instance at the implications or impact of user or carer experience, user choice, user/carer-care worker relationship, self-care, personal budgets, shared decision making, user-directed care, user and informal carer strengths, user and carer outcomes (the latter will be discussed in the next section).

3.9 Drawing on and summarising early evidence (outside the scope of this review), NICE guideline supporting evidence analysis concludes that 'person-centred care relies on addressing a person's wider needs, by commissioning services that can

improve quality of life (e.g. leisure activities: Henderson 2006, evidence level + citing Patmore, 2005) and that address explicitly the priorities and aspirations defined by the person using the service (Gethin-Jones, 2012b, Part Two, evidence level +). Bowers (2006, evidence level –) noted that services provided by volunteers can be particularly outcome-focused as volunteers start with the task that needs completing rather than the time available. A number of papers noted that person-centred care ensures the person is treated with respect, courtesy and in a dignified manner, with their confidentiality ensured (CSCI, 2006; evidence level +; Manthorpe and Stevens, 2010; evidence level +).’ NICE full guidelines provides an ampler and critically appraised evidence base on the effectiveness of person-centred home care.

- 3.10 Within domiciliary care, service users’ ability to exercise choice may impinge on a number of aspects of the care provision. McCaffrey et al. (2015) identified six salient service features that characterise consumer preferences for the provision of home-based support service models. These included: choice of provider, choice of support worker, flexibility in care activities provided, contact with the service co-ordinator, managing the budget and saving unspent funds’.
- 3.11 There is some evidence that involving patients in the decision making leads to lower demand for emergency services and higher compliance with treatment; patients are more likely to be satisfied with the service they receive and tend to choose less invasive treatments; they are more likely to adopt healthier life styles; and staff satisfaction also tends to improve as a result (Health Foundation, 2014). However, the literature cautions that ensuring people play a more active role in the decisions about their care is a complex process. ‘A number of factors facilitate older adults’ decision and capacity to become involved in the coordination of their care, including their perceptions about how their condition impacted their everyday lives, and availability of intrinsic resources, tangible resources, and social network. Low perceptions of control over health and lack of such resources constrain their involvement.’ Hence a need for practitioners to use a language that emphasise ‘psychosocial experiences in addition to medical symptomatology. They may also provide targeted support for patients with limited facilitating factors to promote involvement at multiple stages of the care coordination process’ (Ruggiano, 2015).
- 3.12 The role played by the social context and networks as enablers of service users’ participation in decision making is echoed in other studies. For instance, ‘Seddon and Harper (2009, evidence level +) reported that care managers identified the importance of enabling older people living in their own homes to maintain community connections and draw on existing community facilities. To be effective, support needs to be underpinned by a person-centred approach which takes into account individual preferences and priorities, and is organised locally to where older people live (National Institute for Health and Care Excellence, 2015).
- 3.13 Furthermore, a systematic review of consumer-directed care for older people found that that consumer-directed care approaches have the potential to empower older

people. 'Older people reported varying preferences for consumer-directed care with some demonstrating limited interest. Clients and carers reported good service satisfaction. Research comparing user preferences across countries or investigating how ecological factors shape user preferences has received limited attention. Policy-makers and practitioners need to carefully consider the diverse contexts, needs and preferences of older adults in adopting consumer-directed care approaches in community aged care. The review calls for the development of consumer-directed care programmes offering a broad range of options that allow for personalisation and greater control over services without necessarily transferring the responsibility for administrative responsibilities to service users' (Ottmann et al., 2013).

### **Relationship-based care**

- 3.14 The evidence often contrasts the person-centred approach with task-oriented care. Using a non-participatory, observational method, Kazemi and Kajonius (2015) have attempted to assess user-oriented care along ten process quality indicators targeting the acts of caregiving (i.e. task focus, relation focus, involvement, time-use, body language, autonomy, respect, warmth, encouragement, and information) in two elderly care settings, home care and nursing home. Their findings show that aspects of caregiving that emphasise the relationships between care workers and the service users are positively associated with a whole range of other person-centred quality indicators. On the one hand the observations revealed a 'negative correlation between task and relation foci, that is, the more the care worker adopted a task focus, the less was the relation focus'. On the other hand the study found that 'variables most strongly associated with relation focus were involvement, warmth, and respect in both settings. Whereas all these associations were positive, involvement, and warmth were negatively associated with task focus. Respect was not significantly associated with task focus. The same held for body language, that is, whereas body language was positively associated with relation focus in both care settings, no statistically significant relationship was found between body language and task focus'.
- 3.15 NICE (2014) assessment of the strength of evidence on the effectiveness time spent conversing with service users finds that 'there is moderate evidence from one UK secondary data analysis (Henderson 2006 + citing Patmore 2005) that good quality practice allows time for the workers to complete the required tasks as well as having time to chat or help with household task (such as washing up or pet care). Moderate evidence from one UK mixed methods study (Gethin-Jones, 2012b, +) showed that service users reported benefits as a result of being able to form a relationship with their care workers. In a UK qualitative study (Ekosgen, 2013, +), self-funders highlighted the importance of building trust, a positive relationship with their care workers, thus ensuring continuity of care. Continuity of care – to build positive relationships - was also noted in McNulty & Patmore (2005, evidence level +).'

- 3.16 Ensuring care workers are given sufficient time to complete their work is a critical indicator of person-centred, relationship-based care. NICE (2014) however finds that ‘there is good evidence from two UK surveys (Angel, 2012, +; UNISON, 2012, +) and two UK mixed methods studies (Gethin-Jones, 2012b, +; PCC, 2012, +) and one UK secondary analysis study (Henderson, 2006, +) to suggest that care workers felt the service they offered was compromised due to 15-minute and 30-minute appointment, or appointments being booked too closely together. Users reported feeling ‘rushed’. These findings are further corroborated by a recent study of people’s experiences of receiving care services in their home. Based on 240 responses from older people or their carers the study shows that overall people value their home care service and recognise its importance in keeping them as independent as possible and enabling them to live at home. However, ‘many respondents raised concerns about rushed visits, unpredictable and variable timings of care and missed visits; nearly half of respondents felt there was insufficient time and/or carers’ approach or skill level resulted in care needs not being met; service users rated the attitude and approach of staff overall as good and felt they were treated with dignity and respect but a high number of respondents made reference to poor communication and poor attitude of some care staff; there was a high recognition of lack of skills and training among some care staff; many respondents highlighted the need for the same care workers to visit regularly; overall support and effectiveness from the service generally received positive commentary’ (Healthwatch, 2015).
- 3.17 Critically, the relational aspects of person-centred care not only impact on user-services’ perception of the quality of care but also on staff job satisfaction. A meta-analysis of five doctoral thesis on the role of empathy between the older person receiving support and the paid home-care worker revealed conflicting feelings among care workers. ‘Most experienced frustration when they were not able to express empathy in their working practices. Empathy was typically hindered by lack of time, care workers’ own needs, and inflexible home care systems. However, a key element of the job-satisfaction reported by care workers appeared to be its empathic nature. Most care workers perceive encounters with older people as opportunities to respond empathically rather than indifferently’ (Strandberg et al., 2012). Similarly, examining the impact of person-centred care on caregivers in nursing home settings, a systematic review tentatively concludes that person centred care has been shown to have positive effects on a number of dimensions of caregivers’ job satisfaction (Pol-Grevelink, 2012).

### **Personal budgets and direct payments**

- 3.18 The literature on person-centred care often discusses personal budgets and direct payments as means to achieve personalised services and encourage user service choice. ‘A PB is an amount of money allocated to an individual, based on an assessment of needs. Underpinning PBs are the principles that individuals should know the amount of the budget and plan its use to optimise outcomes. PBs can be taken as cash direct payments; held by a local authority or another third party account; or as a mixture of the two’ (Baxter, 2013). At 31 March 2015 the number

of adults receiving direct payments in Wales was 4,463, a 7.6% increase on previous year.

- 3.19 'Direct Payments' (DP) is a service user-implemented scheme in which the individuals assessed as needing personal, social or health-related care services are given cash payments, allowing them to 'buy in' services they require'. Evidence suggests that 'service users are generally satisfied with most aspects of the scheme; however, difficulties still exist around provision of information, support, user responsibilities and public awareness' (McGuigan and et, 2016).
- 3.20 However, the strength and quality of the evidence is sometimes contested, occasionally leading to increasingly polarised views. A number of studies suggest that PBs do not deliver better outcomes for less money and argue that where better outcome do occur, better funding levels are a factor (Slasberg C. & al., 2012).
- 3.21 Arguably, however, many current accounts of direct payments and personal budgets 'are based on an imperfect understanding of the principles at stake; on a failure to apply the same burden of proof to the old system as well as the new; on prior attitudes to state services and to current social care; and on a potentially limited adherence to more traditional forms of evidence-based practice' Glasby J., 2014). Slasberg C. & Beresford P. (2015) offer an additional interpretive lens for the success of direct payments, arguing that it is better understood 'as a triumph for needs-based planning, but carried out in a person-centred way' rather than as the triumph of consumerist notions of choices.
- 3.22 If there is mixed evidence that personal budget objectives are achieved in practice 'this is especially so in respect of older people who are less likely to accept a personal budget and more likely to be dissatisfied with their experience of using one' (O'Rourke G., 2016). In addition, 'most councils are finding significant challenges in implementing personal budgets with older people, in particular in achieving good numbers while also being confident that they are making a positive difference' (TLAP & SCIE, 2012).
- 3.23 However, Routledge M & al. (2015) drawing on the 2013 and 2014 National Personal Budget Surveys and informed by the Personal Budgets Outcomes and Evaluation Tool (POET), and other research, argue that there is evidence to support the view that older people do experience positive benefits from having a personal budget, although these are not as marked as for other groups. They also note that there is typically lower level of resources available to older people in their personal budgets leaving less scope for personalised outcomes. Factors linked to positive outcomes, and which are to an extent now incorporated into the IPC programme, include: getting help to plan the budget; feeling their views were included in the support plan; the council making all aspects of the personal budget process easier; getting third party support with a personal budget; using a personal budget flexibly on community and leisure activities rather than on formal services; and employing a personal assistant.

- 3.24 Drawing on a survey of local authorities' senior managers, older people and carers, Woolham J. (2015) found that while personal budget had the potential to give more choice, control and independence to older people, take up was low due to a lack of suitable services and information, low expectations and the stress of arranging care at a time of crisis. Informal carers of older people with direct payment also reported higher levels of stress, possibly associated with the responsibilities of organising and managing the care services.
- 3.25 In addition, while there are significant geographic variations in older people's take up of PBs, the 2014 National Personal Budget Survey shows that the impact of the scheme on this demographic group is overall modest, with older people less likely to report positive impact in terms of increased control, improved mental health, and users' ability to buy services and support. However, the evidence also shows that resources available to older people are typically low and may not fit their requirements, access to information and options is inadequate and there is little support to plan and use personal budgets (Routledge M., 2015).
- 3.26 Similarly, Rabiee P & Glendinning C. (2014) find that the level of choice and control older people using Council-managed PBs 'felt able to exercise to tailor home care services to their personal needs and preferences was restricted to low level choices. Other choices were constrained by the low levels of older people's PBs and council restrictions on what PBs can be spent on. Older people's understanding of limitations in public funding/pressures on agencies and their reluctance to play an active consumer role including willingness to 'exit' from unsatisfactory care arrangements appeared to further challenge the potential for achieving greater choice and control through council-managed PBs'.
- 3.27 Looking specifically at the costs and benefits of personal budgets for older people, Woolham J. & Benton C. (2013) concluded that 'compared to younger adults, older people did not greatly benefit from possessing a budget on the outcome measures used, but costs were higher for budget holders across all care groups. These findings support evidence from an earlier study (Glendinning et al., 2008) and raise important questions about the suitability of PBs as a means of achieving personalised services for older people and the implications for social work practice.' Woolham J. et al. (2015) however suggest that these concerns may be addressed at policy level through a renewed emphasis on person-centred care, rather than personalisation.
- 3.28 Equally, an evaluation of direct payments in residential care trailblazers shows modest positive outcomes. A few service users and families acknowledged that DP had allowed them access to a care home or to activities that had not been previously available to them. The findings also show that the costs of implementing the scheme were high compare to the modest outputs (Wittenberg R., 2015).

- 3.29 A key issue emerging from the literature is whether the use of PBs for older people may lead to an increased risk of certain types of abuse, including financial abuse. However, there does not appear to be strong evidence to suggest higher levels of safeguarding referrals among people using personal budgets, although 'in three councils studied in depth there was a statistically significant higher proportion of referrals for financial abuse and abuse by home care workers among people using PBs' (NIHR School for Social Care Research, 2014).
- 3.30 The evidence of positive impact of personal budgets in people with mental health care needs is stronger. Indeed, personal budgets have been shown to support recovery thinking and to mobilise suitable resources in mental health settings. Crucially, the research shows that this is better achieved through co-production and peer-supported processes of assessment and planning (Tew J., 2015). A systematic review of the effectiveness of personal budgets for people with mental health problems found that positive outcomes included greater choice and control, quality of life, service use and cost-effectiveness. However, the review also highlighted the methodological limitations of the studies reviewed and suggested that there is an evidence gap in terms of high quality research (Webber M., 2014).
- 3.31 'A key factor enabling personal budgets to support empowerment and recovery was reported to be the quality and continuity of the professional relationship', suggesting that external factors such as organisational culture and processes significantly impact on the success of PBs (Hamilton S. & al., 2016).
- 3.32 Similarly, a recent qualitative study on outcomes from personal budgets in mental health found that 'most participants identified positive outcomes across domains interconnected through individual life circumstances, with mental health and wellbeing, social participation and relationships, and confidence and skills most commonly reported' (Larsen J. & al., 2015).
- 3.33 Impact on carers – Larkin M. (2015) found that just over half of the sample of carers she interviewed felt their relationship with users had been enhanced by the personal budget arrangements. Three quarters reported positive outcomes, such as feeling happier, healthier and having more control over their lives. An independent evaluation of the 2005-2007 individual budgets pilot (IBSEN) arrived to similar conclusions, suggesting that 'that the receipt of the budget was significantly associated with positive impacts on carers' reported quality of life and, when other factors were taken into account, with social care outcomes. These outcome gains were achieved despite no higher costs being incurred to the public purse, thus suggesting that IBs for service users are cost-effective for carers' (Jones K. & al., 2014).
- 3.34 There is however evidence that inadequate funding and restrictions on how personal budgets/direct payments may be used can inhibit choice and control (Morris J., 2014). These are limitations that the IPC programme intends to address and evidence is needed to ascertain whether the programme is successful in tackling them.

## Successful outcomes-focused service delivery and innovation

- 4.1 The shift from service-led to person-centred models of care has been accompanied, and strengthened, by a growing emphasis on outcomes-focused care. This shift represents a move away from needs-led, task-orientated service provision. In this context, outcomes refer to a whole spectrum of goals, priorities and preferences users expect care services to meet and deliver. This implies that services not only need to adapt flexibly to the specific circumstances of each user but also reflect their preferences in the way outcomes are achieved and services designed.
- 4.2 'Outcome' refers to the impacts or end results of services on a person's life. The Social Care Institute for Excellence provides this definition of outcome: 'outcome-focused services therefore aim to achieve the aspirations, goal and priorities identified by service users – in contrast to services whose content and/or forms of delivery are standardised or a solely determined by those who deliver them. Outcomes are by definition individualised, as they depend on priorities and aspirations of individual people (Glendinning et al., 2006).
- 4.3 There is limited evidence on the effectiveness of outcomes-focused approaches to home care. Assessing the advantages of a goal-oriented approach from a health care perspective, Reuben et al. (2012) argue that this approach 'frames the discussion in terms of individually desired rather than universally applied health states'; 'simplifies decision making for patients with multiple conditions by focusing on outcomes that span conditions and aligning treatments toward common goals'; and 'prompts patients to articulate which health states are important to them and their relative priority. Thus, patients can be in control when treatment options require trade-offs (e.g., better symptom control at the expense of potentially shorter life span). Such trade-offs are currently made, for example, when patients choose to receive hospice care and decline aggressive treatment of their medical conditions'.
- 4.4 Gethin-Jones (2012) examined the effectiveness of outcome-focused home care on subjective wellbeing of older people (N=40). The study found that 'at 18 months, older people in the outcomes-focused group (N=20) reported improved concern scores (p 0.00) and significant improvement in their subjective wellbeing (statistical data not reported) when compared with older people in the time-task group (N=20). The study also revealed 'that contact time reduced in the outcome-focused group (n=4) and increased in the time-task group (n=4) and that the time-task group was 17 per cent more expensive.' Overall, the findings indicate that 'service users' subjective well-being improved due to the ability of outcome-focused care to provide consistency, flexibility and most importantly the ability of the service user to form a relationship with the homecare workers providing their care'.

- 4.5 Parsons et al. (2012) found that the use of a goal facilitation tool in assessment of an older person's needs on referral for homecare leads to significant improvements in health-related quality of life. 'This may be through a higher proportion of individualised activities tailored to a successful identification of the person's goals'. The study intervention group involved participants completing a goal facilitation tool with assessors to identify rehabilitation outcomes.
- 4.6 NICE (2014) analysis of the evidence suggests that 'there is supplementary good evidence from one UK mixed methods study (Glendinning et al, 2008b, +) to suggest that the different definitions and meanings of 'outcomes' among health and social practitioners to be a main barrier to implement integrated outcomes-focused day services. Facilitators included good and trusting relationships with external partners working together to meet the needs of individual older people.'
- 4.7 A research study on whether the use of outcome-focused homecare improves the subjective well-being of the familial carers of older people with dementia shows that 'familial carers expressed an improvement in their subjective well-being and that of their older family member, who appeared more settled as a result of this model of care' (Gethin-Jones, 2014).

#### **Examples of outcomes-focused innovative practice**

- 4.8 As outcomes-focused approaches to home care are gaining currency and innovative models are starting to be developed by local authorities, some initial evidence on their effectiveness is emerging.
- 4.9 Bolton (2015) for instance offers a brief evaluation of two outcomes-focused approaches to domiciliary care: the Helped-to-live-at-Home service in Wiltshire and the 'local offer of support' in Hertfordshire.
- 4.10 Helped to live at Home is focused on enabling people to retain or regain independence. 'In the model, the outcomes are initially determined between the assessor and the customer. These outcomes are then put to the provider who agrees with the customer how they will be delivered through a support plan. The payment is then calculated through a combination of a pre-set fee level for each described outcome and the detail of the support plan. There is no specific reward as such for delivering an outcome. However, if a provider delivers an outcome earlier than was anticipated, they are still paid the full amount' (Bolton, 2015). The introduction of this model of outcomes-focused domiciliary care, which includes provision of reablement services, resulted in 'about half of the customers in Wiltshire needed no further care help from the domiciliary care providers within six weeks. A further cohort of customers needed no further care delivered within a six month period.'
- 4.11 Hertfordshire uses a 'lead model', where a lead provider is responsible for the provision of domiciliary care in each district but is able to sub-contract care to existing local providers. The council set the outcomes a person wants to achieve,

and these are checked to ensure that they are being met at care reviews. When providers are able to demonstrate they have reduced the need for domiciliary care, they are paid at a rate of 50% of the hours saved for the equivalent of 12 months.

Further details are available at:

[https://ipc.brookes.ac.uk/publications/John\\_Bolton\\_Outcome\\_Based\\_Commissioning\\_Paper\\_April\\_2015.pdf](https://ipc.brookes.ac.uk/publications/John_Bolton_Outcome_Based_Commissioning_Paper_April_2015.pdf)

[https://ipc.brookes.ac.uk/publications/Wiltshire\\_Council\\_Help\\_to\\_Live\\_at\\_Home\\_IPC\\_Report\\_April\\_2012.pdf](https://ipc.brookes.ac.uk/publications/Wiltshire_Council_Help_to_Live_at_Home_IPC_Report_April_2012.pdf)

## **Specialist areas of service provision: dementia and end of life care**

### **Dementia**

#### **Demographics**

- 5.1 'Around 850,000 people live with dementia in the UK, 45,000 of whom are Welsh residents. The vast majority (almost 95%) of those living with dementia are over the age of 65. There are, however, approximately 2,500 people under-65 in Wales who have dementia. Dementia also has an interesting gender profile: two thirds of people with dementia are women. The latest data suggests that dementia or Alzheimer's is now the biggest single cause of death amongst women in England and Wales, having surpassed different forms of cancer for the first time' (Living with dementia in Wales, 2016; Dementia UK update, 2014). By 2021, the number of people with dementia across Wales is projected to increase by 31% and by as much as 44% in some rural areas ((Living with dementia in Wales, 2016; Dementia UK update, 2014; National Dementia Vision for Wales). In Wales it is estimated that the average rate of dementia diagnosis is 42.9%, with an estimated 25,000 people living with dementia without a diagnosis (Marie Curie Cancer Care, 2015).
- 5.2 'Between 2003 and 2013 the percentage of deaths from dementia and Alzheimer's disease in England and Wales rose from 4.7% to 12.2% for women and from 2% to 6.2% for men' (Living with dementia in Wales, 2016; Dementia UK update, 2014). Most people with dementia want to die at home, which for many will mean the care home where they normally live. Figures for Wales suggest that over half of deaths with dementia as the underlying cause occur in care homes. The palliative care needs of people dying with dementia need to be better understood and effectively provided for in the community, including appropriate levels of support in nursing and residential care homes (Living with dementia in Wales, 2016; Dementia UK update, 2014).

#### **Dementia care in Wales**

- 5.3 Living and dying with dementia in Wales (2015) sets out in some detail the current barriers to dementia care in Wales, across care settings. Barriers are linked to identification and planning, inequality of access and the quality of care experienced by people with dementia. More specifically, the barriers identified and discussed in the report include: lack of timely and appropriate diagnosis; lack of recognition of dementia as a terminal condition; failure to identify dementia as a cause of death; ineffective advance care planning; access to palliative care; access to hospice care; access to funding; discrimination; inconsistency in care standards in hospitals; inappropriate hospital admissions; lack of continuity of care; poor pain management; inappropriate interventions, including aggressive treatment; failure to adapt practice to reflect the different nature of dementia; and lack of support for carer.

### **Dementia and home care**

- 5.4 Evidence suggests that older adults with dementia living at home experience higher quality of life, ADLs, and social connectedness compared with those living in institutional care (Nikmat, 2015). Using a systematic approach, Dawson (2015) reviewed the evidence on what works to support home care for people with dementia. From a database of 14599 potentially relevant papers the study evaluated 131 publications. The review found that key to an effective domiciliary support is flexibility and responsiveness of services, moving away from task oriented and time limited care.
- 5.5 The research points to the role domiciliary care plays in transition from hospital to home, particular in the context of end of life care for people with dementia and recommends that people with dementia should be supported to remain in a familiar context, and carers fully involved for best outcomes. 'Routes to improving current provision include the development of more appropriate forms of assessment, the need for more tailored support and the effective coordination of services' (Dawson, 2015).
- 5.6 Dawson (2015) evaluates the evidence on a whole range of community services, programmes and schemes that are either intended or could potentially support domiciliary care. The review identifies a research gap in relation to the uptake of self-directed care by people with dementia and finds some evidence of people reluctance to write advance care plans. The review found little focused evidence on the impact of rapid response, programmes attending people in crisis at home.
- 5.7 The use of an integrated multidisciplinary approach is supported by the literature, as a way to meet the multifactorial needs of complex dementia-related conditions. The evidence suggests that joint working can improve the standard of care, promote more holistic service provision, and encourage collaborative learning. Some papers however caution that multidisciplinary services may require specific, appropriate commissioning and that integrated may increase demand for services but not necessarily clinical outcomes (Dawson, 2015).

- 5.8 Dawson's review also evaluates the state of evidence on prevention and reablement in the context of home care for people with dementia. The review identifies a growing body of evidence on non-medical, cognitive interventions. While suggesting that more research is needed, the review found moderate evidence that cognitive rehabilitation impacts positively on 'language skills, communication and other activities of daily living'. Citing a study by Ballard & al. (2011) the review suggests that the evidence is strongest for cognitive stimulation therapy. Computer-based cognitive interventions are also found produce positive benefits and have the potential to be tailored to individual needs and there is some evidence that reminiscence therapy may slow the rate of decline in cognitive functioning. The review highlights the potential role of outdoor and physical activity as part of a rehabilitation approach, although strong evidence is not available.
- 5.9 The bulk of care needs of people living with dementia are met by family carers (UKHCA, 2015) and indeed 'the main cost drivers of dementia are informal costs due to home based long term care and nursing home expenditures rather than direct medical costs (inpatient and outpatient services, medication) (Schaller & al., 2015)'. Examples of support intervention for carers include respite and day services. Dawson (2015) found the evidence on the value of day services and respite services to be inconclusive. While showing that the caregivers do to an extent perceive benefits for themselves and their relatives, it also indicates that significant numbers of people with dementia are reluctant to use day services. Reasons given by potential users include concerns about meeting new people, losing independence and being institutionalised. Challenging behaviour and high levels of physical care needs are found to be responsible for the substantial drop-out rates.
- 5.10 A Preliminary Analysis of Dementia in Wales (2010) arrived to similar conclusions, stating that while day centres do provide valued support 'not everyone liked day centres and these appear to be one of the main provisions for people in the early stages of dementia. For people who don't like centres or for people in more rural and isolated communities other opportunities need to be available' (Care and Social Services Inspectorate Wales, 2010). Another study however suggests that 'cognitive impairment is associated with accessing more hours of respite and day centre care but fewer hours of other formal care services. Additionally, the likelihood of support from an informal caregiver increases when a client becomes cognitively impaired' (Vecchio, 2016). This would indicate a growing need for innovative respite programmes to support informal caregivers in the future. Tretteteig et al. (2016) drawing on the findings from their review of the literature argue that the effectiveness of these services depend on how well they meet the specific need of service users. They conclude that 'as a respite and support service, day care centres have the potential to give family carers (FCs) a feeling of safety and relief, reduce the caregiver's burden, and increase their motivation towards their role as caregivers. These outcomes depend on the quality of treatment, and how the service meets the FC's needs for flexibility, support, information, and responsibility sharing'.

- 5.11 Dawson (2015) also examines the evidence around direct support for informal carers, who play a critical role in ensuring people with dementia can remain at home. The review found strong evidence on the positive impact of support groups, particularly in terms of improved psychological wellbeing and mental health. Coping strategy based support is also shown to benefit the mental health of carers and to improve the quality of life of people with dementia. In addition, the evidence acknowledges the role of training and education support for carers but recommends 'a user-centred approach on the basis that information can increase as well as reduce problems for carers.' (see Cooper, 2012).
- 5.12 While strong evidence on the impact of the use of technology in the context of dementia care is lacking, the research suggests that innovations in this area 'hold promise for improving safety at home, reducing care burden and reducing overall costs of home-based dementia care' (Dawson, 2015). A study on the use of 'of advanced electronic tracking, communication and emergency response technologies, namely, an extended safety and support (ESS) system for people with dementia (pwd) living at home' found that 'carers noted that pwd were more independent than previously on those occasions when they engaged in outdoor activities. Staff considered that nearly half of pwd could remain living at home due to the ESS, compared with a third amongst carers. In total, 50 per cent of carers felt it was justified to equip their relative with an ESS without their explicit consent, compared to one in eight staff' (Magnusson, 2014).
- 5.13 'Care recipients' ADL impairment was associated with caregiver outcomes, but only before resistiveness (Fauth and et, 2016) to care (RTC) was entered into the models. RTC frequency significantly predicted caregivers' overload, captivity, and depression. RTC appraisals predicted overload and captivity. Conclusion: RTC is common in persons with dementia residing at home, and RTC has more negative association with informal caregivers' well-being than assistance with ADL. Adding RTC frequency and appraisal items to standard ADL measures may better estimate caregivers' needs and risk, and identify.
- 5.14 The increasing number of people with dementia means more demand for both informal and formal sources of care. Developing interventions such as case management, which enhances the co-ordination between different agencies involved in community care, might offer the support necessary to cover some of the needs of people with dementia and their carers. A review of the literature on case management approaches to home support for people with dementia revealed that 'found benefits at six months and 18 months but not at 12 and 24 months. However, when only studies which were clearly focused upon delaying institutionalisation or prolonging the period of community care were included we found a reduction in institutionalisation at 12 months. Some studies examined the benefits of case management in terms of reduced hospital length of stay, and there was evidence to suggest that it might increase at six months. Some studies indicated that case management was more effective at reducing behaviour disturbance at 18 months, reducing carer burden and depression and improving carer well-being at six months and social support at 12 months. Case

management increases the use of community services but there was some indication that overall healthcare costs may be reduced in the first year. Some studies reported that case management was no more effective than usual care in improving patient depression, functional abilities or cognition. There was not enough evidence to clearly assess whether case management could reduce the length of time until people with dementia were admitted to care homes' (Reilly, 2015).

- 5.15 Echoing some of the themes explored in research studies and highlighted in the evidence review, a recent UKHCA report on driving quality and innovation in dementia and home care outlines a framework for policy and practice. The report sets out practical actions for change, including: championing homecare as the key facilitator of dementia care and information; delivering a personalised approach focused on outcomes for the individual; giving greater flexibility for homecare providers to innovate and shape care with and for the individual; recognising and realising the value of homecare to reduce risk and lessen the negative impact of dementia progression; prioritising homecare as a cost effective form of intervention; ensuring sufficient time to deliver the care people with dementia need, in the way they want; developing consistent and reliable homecare services and training; helping providers to implement and experiment with technology; and developing research on care, as well as cure.

### **Examples of innovative practice**

- 5.16 It is beyond the scope of this review to provide a detailed summary of the whole range of current innovative interventions in dementia home care but the UKHCA report does offer a good selection of innovative, good practice examples (Dementia Health and Care Champion Subgroup on Homecare, 2015). The example focus on key areas of intervention, including: timely intervention and support; combatting loneliness and boosting health; support and respite for family carers; developing the homecare workforce and staff recruitment; person-centred approach; integration and working in partnership; technology and adaptations; and innovative commissioning of homecare by local authorities and CCGs.

<http://www.ukhca.co.uk/pdfs/DementiaHomecareDrivingQualityInnovation.pdf>

Additional initiatives and best practice models of domiciliary care for people with dementia are outlined in Improving Domiciliary Care for People with Dementia: a provider perspective. They focus on service delivery, workforce development, and multi-agency working / links.

<http://www.ukhca.co.uk/pdfs/Ukhca-domiciliary-care-final-report.pdf>

### **End of life care**

#### **Demographics**

- 5.17 The End of Life Care Annual Report 2015 sets out the scene of end of life and palliative care in Wales. The report shows that: 'each year around 32,000 people

die in Wales, around 250 of these are children and young people. This equates to 88 people a day. More than half of these die in hospital; the Office for National Statistics predicts that the number of deaths in Wales will increase by almost 10% to around 35,000 by 2037; of the 32,000 people who die each year over 20,000 are aged 75 or over; the majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia; about 39% of deaths occur in people's usual place of residence, either at home (22%) or in a nursing/care homes (17%). 56% of deaths occur in NHS hospitals; investment over the past few years has allowed Wales to provide 7-day specialist services to ensure that there is a service across Wales available to give advice to those professionals caring for patients in their homes, in hospices and in hospitals across Wales on a 24/7 basis; it is estimated that 75% of people dying have some form of palliative care need. This would mean that of the 32,000 people who die in Wales each year, about 24,000 will have palliative care needs' (Welsh Government, 2015: Together for Health: the End of Life Care Annual Report 2015). The report also shows that 'since 2007-2008, the percentage of people dying in their own home has increased from 19.8% to 22.6% and in a care home from 12.3% to 16.6%. At the same time the percentage of people dying in hospital has fallen from 62.6% to 56.2%' (Welsh Government, 2015).

### **Home as preferred place for end of life care**

5.18 A Sue Ryder survey of people's preferred place of death and the outcomes people value at the end of life shows that around two thirds of people wish to spend their final days at home. The polling shows 63% of people said that this would be their preferred place of care in their final days, while 28% wish to die in a hospice, 8% in a hospital, and only 1% want to die in a care home' (Wood, 2013). The characteristics most commonly associated with home include: being surrounded by your loved ones (83%); in familiar surroundings (83%); being surrounded by your personal things and/or your pets (60%); being in a calm and peaceful atmosphere (50%); and having privacy and dignity (46%). However the report also indicates that people's first priority for the end of life is to be free from pain and discomfort, an outcome people mainly associate with residential and hospital care (with only 27 per cent only feeling that home was a place where they would be free from pain during their final days).

5.19 The report suggests that outcome preference, rather than place preference, should inform policy and practice. Indeed, the survey results indicate that preferred place of death changes over different stages of illness as people's priorities and preferred outcomes change. The findings show that 'the proportion of people opting for hospice care rises from 4%, to 17% to 28% in the final year, weeks and days before death respectively. The proportion of people opting for dying at home falls from 91% to 75% to 63% over the same time frame' (Wood, 2013). Glass (2016) echoes these findings and argues that although most people say they would prefer to die at home, in some situations the nursing home can be a satisfactory choice, particularly if hospice is involved' (Glass, 2016).

5.20 The quality of end of life hospital care however remains patchy. The 2015 National Survey of Bereaved People VOICES survey (England) shows that the percentage of people whose relative or friend died in hospital and that rated hospital care as outstanding, excellent or good is significantly lower than that of those who died in a care home, hospice care or care at home. A total of 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital (Office for National Statistics, 2016).

### **Effectiveness of home-based end of life care**

5.21 We identified a Cochrane systematic review on home-based end of life care (Shepperd, 2011, updated 2016). The authors acknowledge that there is widespread support for models of care that better serve the needs of patients at the end of their life, but found little evidence supporting the effectiveness of home-based end-of-life care. The review was only able to identify four trials, and no new study was included in the 2016 update. The data shows that people receiving end-of-life care at home are more likely to die at home while it remains unclear whether home-based end-of-life care increases or decreases the probability of being admitted to hospital. The review found that ‘admission to hospital while receiving home-based end-of-life care varied between trials.’

5.22 There are however examples of programmes that appear to improve discharge rates for people who preferred to be cared at home. For instance, to facilitate individuals' preferred place of care, a large acute hospital in northeast England implemented a pilot project to establish a nurse-led Macmillan Palliative Care Discharge Facilitator Service. An evaluation of the service revealed that the ‘discharge Facilitator Service acted as a reliable resource and support for facilitating the fast-tracking of end-of-life patients to their preferred place of care (Venkatasalu, 2015).

5.23 Shepperd (2016) also found that people who receive end-of-life care at home may be slightly more satisfied after one month and less satisfied after six months but evidence on whether home-based end-of-life care reduces or increases caregiver burden is inconclusive.

5.24 The review show that ‘patients receiving end of life home care reported greater satisfaction than those in the hospital group ( $P = 0.02$ ) at one-month follow up (Hughes 1992). This difference disappeared at six months follow up, which may reflect a reduced sample size due to the death of a number of these patients. Brumley 2007 reports similar findings, with greater satisfaction reported by those receiving end of life home care at 30 days (OR 3.37, 95% CI 1.42 to 8.10) and no evidence of a statistically significant difference at 60 days (Brumley 2007)’ (Shepperd, 2016).

5.25 In terms of satisfaction of care givers of patients receiving end of life home care, the review found that one study ‘reported higher satisfaction compared with care givers in the control group at one-month follow up (Hughes 1992). This difference

disappeared at six months, which may reflect a reduced sample size. At six months follow up, care givers of patients in the end of life home care group who had survived more than 30 days reported a decrease in psychological well-being compared with care givers looking after patients in the control group. Grande 2004 found no statistically significant difference between groups for care giver bereavement response six months following death' (Shepperd, 2016).

### **Coordinated end of life care**

- 5.26 A person who is dying at home may receive support from a range of health and social care staff, including: GPs and their out-of-hours services, district and community nurses, healthcare assistants, specialist nurses (cancer care or palliative care) providing hospital or hospice services at home, ambulance paramedics, occupational therapists, social workers, and domiciliary (home) care workers. SCIE review of the evidence on dying well at home (2013) discusses at length the state of evidence around coordinated home-based end of life care.
- 5.27 The key messages include: there is no evidence of good liaison and support of people dying at home by specialists in specific diseases who are hospital based although some patients attend hospital outpatient appointments; end of life care in the home is led by GPs and much of it is provided by district nurses; there is some evidence that GPs are reluctant to discuss the patient's dying status; risk adverse GPs tend to transfer patients to hospital; hierarchical nature of the relationship GPs-nurses create tensions; out-of-hours GPs cover remain problematic; there is some evidence that community nurses are not always aware of what their role involves although other studies indicate that they feel they play a central role in providing palliative care and coordinating service; nurses' considerable workload is highlighted as a problematic, with their tasks varying at different stages of illness; there is some evidence that while health and social care home care workers can make a significant contribution to patient and family carer support, there is limited availability of home care services, lack of continuity of care, time constraints, lack of flexibility and poor communication with other services; there is some evidence that Rapid Response Teams and Discharge Community Link Nurses Teams improve the rates of home deaths; hospice at home programmes are valued by GPs and patients but an evaluative study raises concerns about the quality of the service; there is some evidence that users and carers value the support received from hospice day care (Social care Institute For Excellence, 2013).
- 5.28 Multidisciplinary teams increasingly play a critical role in ensuring effective collaborative care for people dying at home and necessary support for carers. The evidence suggests that 'that encouraging practitioners to share past experiences and foster common goals for palliative care are important elements of team building in interprofessional palliative care. Also, establishing a team leader who emphasises sharing power among team members and addressing the need for mutual emotional support may help to maximise interprofessional teamwork in palliative home care' (Shaw, 2016).

## **Costs of dying at home**

5.29 In their review of home-based end of life care, Shepperd (2016) concluded that healthcare costs are uncertain, and no data on costs to participants and their families were reported. Results from a study of the societal costs of home and hospital end-of-life care for palliative care patients in Ontario CA show 'no significant difference in total societal costs between home and hospital death patients. Higher hospitalisation costs for hospital death patients were replaced by higher unpaid caregiver time and outpatient service costs for home death patients. Thus, from a societal cost perspective, alternative sites of death, while not associated with a significant change in total societal cost of end-of-life care, resulted in changes in the distribution of costs borne by different stakeholders' (Yu, 2015). SCIE review of the literature on end of life care at home (2013) however found that although there is limited evidence on costs, that which does exist suggests that dying at home is less expensive than dying in a hospice or hospital (Social care Institute For Excellence, 2013).

## **Home-based end of life care guidance**

5.30 SCIE has produced a guide to help enable people who want to die at home to do so and improving the quality of care they receive. It is aimed at practitioners, managers and commissioners supporting people with end of life care needs across the health, social care and housing sectors (Dying well at home: the case for integrated working, 2013). The guide, drawing on the evidence, makes a number of specific recommendations for good practice focusing on: choosing to die at home; dying a good death; meeting carers' needs; coordinated care: health and social care and housing; accessing equipment and services; costs of dying at home; and commissioning.

## **Examples of good practice**

5.31 Dying well at home: the case for integrated working (2013) outlines a number of good practice examples, covering: befriending services; training domiciliary care workers; the Gold Standard Framework; home from home services; palliative care; clinical coordinated care; the Midhurst Macmillan Specialist Palliative Care Service; culturally appropriate care by the community; care bundle; services for older carers; and community intravenous therapy teams.

A detailed descriptions of the interventions can be found at:

<http://www.scie.org.uk/publications/guides/guide48/>

## **Integrated care: joint working between health and social care**

6.1 Integrated care is defined as a single system of needs assessment, service commissioning and care provision. Integrated services are designed around the needs of individuals providing the best opportunities to improve people's health and wellbeing and helping to bring financial sustainability (NHS Confederation and

et, 2016). 'In Wales, there is increasing recognition within Government policy of the potential value of integrated service models in providing a more proactive approach to older people's services, seeking to protect what can be fragile independent living via community based models of care that are person centred and delivered within the person's usual place of residence' (Health and Wellbeing Best Practice Innovation Board, 2013).

### **The determinants of effective integration**

6.2 The evidence suggests that the factors that positively impact on the integration of health and social care include: 'clarity of strength of purpose - having a shared vision, culture and values that deliver person centred services based on shared outcome frameworks; collaborative leadership at all levels, with expert change management skills and the ability to drive cross sectoral working; a culture of learning and knowledge management, that seeks to support the sharing of best practice, improvement and service development across organisational and sectoral boundaries; a supportive legislative/policy environment that seeks to create the environment within which integrated services can develop; integrated management structures, incorporating the use of joint appointments, with unified leadership and joint governance arrangements and accountability; trust based interpersonal and interprofessional multidisciplinary relationships across sectors, building on the strengths and unique contribution of each partner; appropriate resource environments and financial models seeking to ensure collaborative financial models, including the need for pooled budgets; comparable IT and information sharing systems that facilitate ease of communication; unified performance management systems and common assessment frameworks; and collaborative capabilities and capacities, with all practitioners being skilled in integrated working and management' (Health and Wellbeing Best Practice Innovation Board, 2013).

6.3 For the NHS Confederation (2016) the keys to successful health and care integration are: shared commitments; shared leadership and accountability; and shared systems. Shared commitments support approaches which focus on what is the best outcome for citizens and communities; are designed around individual and the outcomes that are important to them; and support prevention. Shared leadership and accountability support governance arrangements that transcend organisational boundaries are collaborative; are locally owned; and are underpinned by a clear, long term vision. Shared systems involve information and technology being shared across agencies and individuals; joint commissioning; and integrated workforce planning and development (NHS Confederation, 2016).

### **Models of integrated care**

6.4 Evidence from case studies shows that interventions in integrated care broadly fit into three main areas of focus: prevention; care coordination and emergency admission avoidance; and discharge and reablement (Richardson, 2016).

- 6.5 Specifically, integrated care models that may directly interplay with home care provision are described as: care planning and care coordination to help people manage their health day to day across the range of health and care settings; case management as a collaborative process of assessment, planning, facilitation, coordination, evaluation and advocacy for options and services to meet the comprehensive needs of individuals and families; rapid response teams, providing a short-term service that enables people to stay home during a time of crisis with an aim of avoiding unnecessary admission to hospital; reablement services, designed to enable and maintain a person's ability to remain at home independently, sometimes through appropriate interventions delivered in community settings; joint assessment and discharge facilitation; integrated health and care teams by developing multidisciplinary teams across health and social care boundaries; care at home and virtual wards involving schemes specifically designed to ensure patients can be supported at home with regular monitoring instead of being admitted to hospital or a care home; and falls prevention, working with people to build their stability, confidence, and reduce falls and may involve home modification (Richardson, 2016).

### **Examples of good practice**

- 6.6 There is a wealth of literature and case studies of innovative models of integrated care and their interplay with domiciliary care. Ham (2013) provides an overview of integrated care in Wales and identifies examples of good practice. These include the Gwent Frailty Programme, described as largest single exploration of integrated care delivery in Wales, which began by focusing on earlier discharge of such patients and on providing alternatives to emergency hospital admission. Wyn Campaign, Cardiff and the Vale of Glamorgan provide wrap-around services for frail older people, including facilitated discharge, an alternative falls pathway for ambulances, in-reach support to care homes to prevent admission, improved case management for people with long-term conditions, and targeted step-up responses for frail older people. Hywel Dda Health Board has developed joint health and social services provision for people in Carmarthenshire and has now broadened its services to embrace four elements of redesign for out-of-hospital care. Full details of the programmes, including lessons learnt, barriers and enablers are available here:  
[http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/integrated-care-in-northern-ireland-scotland-and-wales-kingsfund-jul13.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/integrated-care-in-northern-ireland-scotland-and-wales-kingsfund-jul13.pdf)
- 6.7 LGA (2016) draws key learnings on integrated care provision from seven localities. The case studies examined include: Tower Hamlets programme, which from an initial focus on primary care transformation has now extended to public health and community health and mental health; Torbay, which largely focused on the older population and chronic diseases with community health and social care as the main providers, and now also incorporates primary and acute providers; Pennine Care's RAID model, which addresses people with mental health issues, working with secondary and community care; Salford, Leeds and Nottingham City, which address a wide spectrum of need, including older people and those with chronic

diseases, focusing on primary, community and social care; Northumberland has focused on the frail elderly at high risk of admission via primary care and the community through locality integrated networks (3 per cent of population). The report suggests that the impact of these interventions include: reduction in emergency admissions; prevention of chronic diseases; and reduced cost growth and several outcomes related to discharge facilitation (Richardson, 2016). A full outlines of examples of practice are available at:

[http://www.local.gov.uk/documents/10180/7632544/L16-49+Journey+to+integration\\_v05+amend+pg+9.pdf/5b2e8a96-f1ac-4894-9031-b93459193cee](http://www.local.gov.uk/documents/10180/7632544/L16-49+Journey+to+integration_v05+amend+pg+9.pdf/5b2e8a96-f1ac-4894-9031-b93459193cee)

Additional examples of health and social care integration projects, and their impact on reducing avoidable hospital admissions, reablement and timely hospital discharges, smoother transitions, and better use of resources, are available at:

<http://www.skillsforhealth.org.uk/images/resource-section/service-area/integrating-health-and-social-care/Project%20Summary.pdf>

Approaches to integrating housing and care services are been developed in a number of localities. An outline of case studies and good practice examples is available at:

<http://www.local.gov.uk/documents/10180/6869714/L15-435+A+home+is+much+more+than+a+house/df3048c6-63b8-4419-8dcb-afee2a275f69>

The remainder of this section outlines the key findings from a quick scanning of the evidence on two approaches to integrated care: integrated health and care teams (multidisciplinary teams) and reablement services.

### **Integrated health and care teams**

- 6.8 The evidence consistently shows that integrated care more broadly, and in particular when delivered through multidisciplinary teams, produces a number of positive effects in relation to a broad range of outcomes, including: patient-centred outcomes, process quality, use of healthcare resources and costs.
- 6.9 Comparing integrated care interventions with usual care in their meta-review of integrated care programmes for adults with chronic conditions examining 27 systematic reviews and meta-analyses, Martinez-Gonzalez et al. (2014) found 'beneficial effects of integration of care on several outcomes, including reduced mortality, reduced hospital admissions and re-admission, improved adherence to treatment guidelines and quality of life.' Similarly, Hickman L. et al. (2015), examining how multidisciplinary team intervention can optimise health outcomes for older people, conclude that 'the tailoring of treatment, underpinned with clear communication strategies can reduce emergency department re-admission rates, mortality and functional decline of older people.'

- 6.10 According to Stokes J. et al. (2015), assessing the effectiveness of case management for patients in primary care 'at risk' of hospitalisation and in particular older people with multi-morbidity, the evidence shows that the effectiveness of case management may be increased when delivered by a multidisciplinary team, and when a social worker is involved.
- 6.11 More specifically, exploring system characteristics associated with higher and lower increase in unplanned admission rates in those aged 85 years and over in six sites in England, Wilson A. and colleagues (2015) found that 'the most striking difference between improving and deteriorating sites was not the presence or absence of specific services, but the extent to which integration within and between types of service had been achieved.' They recommend maximising integration, leadership and adopting a system-wide approach to reconfiguration.
- 6.12 The critical role played by co-ordinated care interventions to support enhanced hospital discharge safety is highlighted by Waring J. and colleagues (2015), who note that 'hospital discharge involves a dynamic network of interactions between heterogeneous health and social care actors, each characterised by divergent ways of organising discharge activities; cultures of collaboration and interaction and understanding of what discharge involves and how it contribute to patient recovery.'
- 6.13 Evaluating a number of interventions aimed at reducing resource utilisation in acute care and which employ multidisciplinary approaches to assessment and treatment of patients, Monitor's Moving healthcare closer to home: financial impacts (2015) finds that well-designed schemes can deliver benefits in the long term. They are likely to have clinical outcomes that are equal to hospital care and sometimes better, reduce hospital admissions and provide access to care that would not have been available through acute care services.
- 6.14 Drawing on current evidence and setting out the key priorities for commissioners to help transform the care system, the King's Fund supports the provision of care co-ordination through integrated health and social care teams, arguing that 'improved care co-ordination can have a significant effect on the quality of life of older people and people with multiple long-term conditions (Addicott R. et al., 2015).
- 6.15 Similarly, the Commission on Improving Urgent Care for Older People (2015), setting out the principles for redesigning services that better meet the needs of older people, supports greater use of multidisciplinary and multi-agency teams, both hospital and community based, suggesting that for frail patients 'there is evidence that comprehensive geriatric assessment – underpinned by a multidisciplinary approach – leads to better outcomes.' For instance, examining the impact of the Westminster Falls Service, which provides a multidisciplinary falls risk assessment and targeted intervention for people referred following a fall, or who are at risk of falling, the Commission on Improving Urgent Care for Older People reports that people followed up a year post-discharge reported 60 per cent reduction falls, 55 per cent fewer fractures, 92 per cent fewer A&E admissions,

and an 80 per cent reduction in GP appointments compared to the year prior to intervention.

- 6.16 The literature identifies a number of factors supporting interdisciplinary collaboration, particularly between social workers and health professionals including: acknowledgement of colleagues' expertise, recognition of roles, positive level of communication and mutual respect (Gabrielova J. & Velemiski M., 2014). Theoretical differences, varying professional perspectives, lack of knowledge and poor communication, on the other hand, are barriers to effective integrated care team work.
- 6.17 For Mackie S. & Darvill A. (2016), who critically examined existing evidence on factors that enable the successful implementation of integrated health and social care and effective integrated team work, key enablers are: co-location of staff, communication, leadership, resource and capacity, national policy framework and information technology systems. Crucially, they observe that 'the opinion that integrated teams take a number of years to become established and start realising the benefits of an integrated care approach is widely acknowledged.'
- 6.18 The evidence on the cost-effectiveness of integrated care team work and multidisciplinary teams is limited and inclusive. According to the King's Fund, assessing the cost-effectiveness of coordinated care provided through integrated health and social care teams, the 'impact on costs and cost-effectiveness is less easy to predict and is likely to be low in the short term given the upfront investments required. However, health systems that employ models of chronic care management tend to be associated with lower costs, as well as better outcomes and higher patient satisfaction' (Singh and Ham 2005, in Addicott R. et al., 2015). In their meta-review of systematic reviews on integrated care programmes, Martinez-Gonzalez et al (2014) also found little evidence for a reduction in direct or indirect costs. Similarly, in their systematic review on the effectiveness of inter-professional working for older people living in the community, and specifically examining integrated team work, Trivedi D. and colleagues (2013) conclude that overall 'there is weak evidence of effectiveness and cost-effectiveness for IPW, although well-integrated and shared care models improved processes of care and have the potential to reduce hospital or nursing/care home use.'
- 6.19 However, in their financial impact analysis of models designed to keep patients away from hospital and based on principles of integrated and multidisciplinary care Monitor (Financial impacts, 2015) suggest that these schemes are 'likely to reduce the rate of expenditure growth by substituting for – or at least delaying – the need for investment in new acute hospital facilities.' Monitor estimate that similar schemes running at scale would need to cost around £350 for an average entire patient intervention to cost less than treating patients in acute setting but warn that 'a scheme can take up to two to three years to reach its intended scale.'

## **Reablement services**

- 6.20 A guide drawing on approximately 10 studies and 2 randomised controlled trials found good evidence that reablement 'improves service outcomes (prolongs people's ability to live at home and removes or reduces the need for standard home care)' (SCIE, 2013).
- 6.21 In an evaluation of the effectiveness of reablement services (NHS Benchmarking Network, 2015) outcomes found that 76.1% of patients in receipt of reablement services improved; 15.7% maintained their condition, and 8.2% deteriorated. The evaluation used data collected in 2015.
- 6.22 The results of research into a 6 week reablement programme in Glasgow found that 'a sizeable proportion of service users went on to be independent in the community and most were able to sustain this over a period of time'. In addition, the study also found that 'service users who had moved onto mainstream home care were mostly on reduced care packages (Ghatorae H., 2013).
- 6.23 An Australian comparison of the home-care and healthcare service use and costs of older Australians randomised to receive a restorative or a conventional home-care service (Lewin G. et al, 2014) found 'restorative clients used fewer home-care hours, had lower total home-care costs'. In addition they were also 'less likely to have presented at an emergency department or have had an unplanned hospital admission.'
- 6.24 In the results of a survey of 13 local authorities in Scotland, 12 responded to a question about the average reduction in care hours by the end of a reablement service. However, the reduction in care hours reported varied from 20% to 19%. Suggested reasons for this included, different eligibility criteria for the service, process in place around goal planning, and the role of occupational therapists (Joint Improvement Team, 2013).
- 6.25 Local evidence indicated that by the time they were discharged from reablement services between 50–90% of older people (depending on the LA concerned) needed less or no support than when they initially contacted the service. Local evidence also revealed that many of older people's personal outcomes were met (NIHR School for Social Care Research, 2013).
- 6.26 Although not as strong as for service outcomes, there is 'moderately good evidence that reablement improves outcomes for users in terms of their ability to perform daily activities or improving morale' (SCIE, 2013). A study of older adults found that a '12-weeks home-based reablement program was found to improve ADL ability among older adults regardless of whether they had received help' (Winkel A. et al, 2015).
- 6.27 An earlier study (Wilde A. et al 2012) which explored the views of 34 service users and 10 carers from 5 established reablement services in England 'found clear evidence that interviewees felt that they had benefitted from re-ablement services'

(Wilde A. et al 2012). However it also found that the benefits of re-ablement were reduced 'if users failed to understand the aims of the service, or if the service failed to provide support with activities or outcomes that were particularly important to the service user or carer.'

- 6.28 However, in relation to improving outcomes for people with dementia, SCIE found a lack of evidence regarding the effectiveness of reablement, (SCIE, 2013) The skills and professional mix of staff is one factor that can impact on the effectiveness of reablement services, in particular the literature highlights the importance role of Occupation therapists (OT) in reablement services. A literature review into the effectiveness of occupational therapy interventions for older people in social care services found 'a high level of user satisfaction was identified once timely occupational therapy services were received' (Boniface G., 2013).
- 6.29 Drawing on a large prospective longitudinal study carried out in 2008-2010 (Newton C., 2012) identified that motivation was a key to the success of reablement. The study concludes 'that reablement staff should be trained to identify personal goals with service users and use task'.
- 6.30 Other factors that can impact of reablement services include the type of scheme, ie whether it has a selective or inclusive intake; flexibility of re-ablement period and package, signposting to other services; culture of independent providers; training for home care support workers; specific service or culture across the organisation (Joint Improvement Team, 2013).
- 6.31 There is no systematic review focusing specifically on the effectiveness and cost effectiveness of re-ablement'-based interventions, though one is in progress (Cochrane A. et al, 2013).
- 6.32 However, Monitor report that 'there is robust evidence that reablement schemes reduce ongoing care needs. Studies estimate that social care packages required by patients of reablement schemes tend to be about 60% lower than those of equivalent patients who are not referred to a reablement scheme'. (Monitor, MHCH: financial impacts, 2015).
- 6.33 SCIE (2013) reports on the findings of a SPRU/PSSRU cost effective analysis study which found, that although reablement has higher set up costs, 'savings of up to 60 percent in the costs of subsequent social care provision among the reablement group'.
- 6.34 An Australian comparison of the home-care and healthcare service use and costs of older Australians randomised to receive a restorative or a conventional home-care service (Lewin G. et al, 2014) found 'restorative clients used fewer home-care hours, had lower total home-care costs'. In addition they were also 'less likely to have presented at an emergency department or have had an unplanned hospital admission.'

6.35 In another Australian study to examine the evidence for the long term cost effectiveness of home care reablement found that people 'who had received a reablement service were less likely to use a personal care service throughout the follow-up period or any other type of home care over the next 3 years. (Lewin G., 2013). This was 'associated with median cost savings per person of approximately AU \$12,500 over nearly 5 years.'

## **Commissioning**

### **Social care commissioning in Wales**

7.1 The evidence provides a mixed picture of current commissioning practice in Wales. Between July 2013 and January 2014 the Care and Social Services Inspectorate Wales conducted a review of how well local authorities commissioned social care in Wales. The review looked at governance and strategic planning; prevention and early intervention services for people with dementia; supporting people in the community; supporting people with complex needs; and engaging service users and carers. The review found that in response to the demographic challenges and financial constraints local authorities are looking a new models of care delivery, moving from residential to domiciliary and extra care and building resilience in the community. The report however suggests that there is a lack of evidence of the financial benefits of these models and little understanding of community's needs and strengths on which to build resilience (Care and Social Services Inspectorate Wales, 2014).

7.2 While local authorities in Wales have introduced mechanisms for specifying quality and outcomes in the spot procurement process, 'inspectors found evidence that local authorities commissioning practice is not sufficiently focused on the quality of care provided and people's quality of life. Inspectors saw contracts for dementia care that were limited to a functional care role attending to physical and practical tasks. Furthermore, training for care providers on providing care to service users with dementia is inconsistent. Thus the standard of care provided can be poor as the carers focus on the tasks to be accomplished in a short time and not the quality of care given to the service users' (Care and Social Services Inspectorate Wales, 2014).

### **Outcome focused commissioning**

7.3 Commissioning is the process by which people needs in an area are assessed and services are designed to achieve appropriate outcomes. The public, private or third sectors may all be involved in the provision of domiciliary care services (Bolton, 2015). However, while Lucas and Carr-West (2012) detected a renewed interest in in-house provision by local authorities, there is evidence that 'some councils see themselves as a 'commissioning organisation' and are either divesting all of their directly provided care to the private or voluntary (not-for-profit) sector or are creating new models of care that are separate to the formal council

structure' (Local Government Association, LGA Adult Social Care Efficiency Programme, 2014).

- 7.4 The evidence on person-centred, outcomes-focused and integrated home care underpins and informs much of the UK policy and good practice guidance on commissioning and much of the literature on social care and domiciliary care commissioning focuses on personalisation and outcomes. It is argued that given the fragmented domiciliary care market and the risks of market failure in Wales, 'a move to commissioning outcomes rather than outputs would be beneficial. Current processes for commissioning and monitoring against set time allocation are bureaucratic, expensive and counterproductive in achieving outcomes. Furthermore, this also offers a win-win opportunity for providers to pay their staff more as a result of fewer hours being required to achieve outcomes (Association of Directors of Social Services, 2016).
- 7.5 However, 'time and task driven commissioning, as remains the norm across Wales, directly opposes the notion of outcomes based support, in addition to the key principles underpinning the Social Services and Wellbeing Act 2014 (UKHCA, 2015). 'Translating outcomes into contractual arrangements with providers is an important challenge for care services. When providers are paid by the hour, it gives them a false incentive to maximise the number of hours they spend with a service user, rather than promoting their independence, and supporting their recovery where possible' [...]. Besides being counter-productive for the individual, this is also financially inefficient' (Lucas, 2012).
- 7.6 Bolton (2015) proposes a framework for the commissioning of efficient and cost-effective outcomes-focused domiciliary care. It comprises three objectives, on which both providers and commissioners should agree. These are:
- Objective 1: To build a set of services that respond quickly to older people in crisis and ensure that at least 50% need no further care after a six week period and a further set of people require little or no care after a year's assistance (discharge care support services). Performance Indicators: Low delayed discharges from hospital. High rate of reablement offered that enables older people to need less or no care after the help that has been offered.
  - Objective 2: To ensure that older people in the service are helped in the most cost effective way with a stable and trained workforce that can help them live as independently as they are able. To this end the service will combine the effective use of contact hours with the use of equipment to help meet someone's needs. Performance Indicator: Low average costs per head for domiciliary care packages.
  - Objective 3: To have a service which has a strong focus on helping older people to remain in their own homes. Performance Indicators: Low admissions to residential care. That the transaction costs between the

providers and the commissioners are kept to a minimum for both parties. If the NHS is involved in commissioning the service – lower admissions to acute hospital for this group and lower readmissions for those supported through discharge’.

### **Joint commissioning**

- 7.7 Dickinson et al. (2013) have produced a substantial research study exploring joint commissioning in health and social care. The study comprises an extensive literature review and an evaluation of five case study sites which all have which all have different types of joint commissioning arrangements in place.
- 7.8 ‘There are at least three different discourses of joint commissioning in the wider literature that outline and underlying theory or rationale of what this is and the types of practices that might be associated with this way of working.’ Specifically, joint commissioning is understood as an approach that can promote prevention, empowerment and efficiency. Overall, however, the review found that there is a lack of high quality evidence ‘with much of literature comprising opinion pieces or the voices of those who have been involved in leading these types of initiatives’ (Dickinson, 2013).
- 7.9 The case study analysis found that those involved in joint commissioning were unable to identify a clear set of practices that could be associated with joint working. Enablers of joint commissioning however included: formalised structures; pooled budgets; lead commissioning arrangements and integrated teams; co-location; integrated assessments; and service user and carer involvement (Dickinson et al., 2013).
- 7.10 Dickinson et al. found inconclusive evidence on the impact of joint commissioning. Nonetheless, better joint working was highlighted among the outcomes, facilitating better inter-professional and inter-organisational collaboration. There was also evidence of efficiency and improved productivity through the use of pooled budgets and hospital discharge teams, with an example of length of hospital stay having been reduced from an average of 108 to around 40 days. Some service users reported greater ease of access to services through co-location of providers, although this view was not consistent across sites.

### **Guidance on home care commissioning**

- 7.11 SCIE Commissioning for Older People (2014) guide sets out specific recommendations for each stage of the home care commissioning cycle: assessment, planning, contracting and monitoring (Social Care Institute for Excellence, 2014). These are summarise as follows:

#### **Assessment**

7.12 Commissioners should: develop their understanding of older people with complex needs and see them as people rather than as a series of individual needs; involve older people who use services and their unpaid and paid carers in designing services; understand the particular needs of older people within their local area and look at what provision already exists in the area; establish clear and unambiguous criteria for acceptance into domiciliary care services that are designed to address unmet needs.

## **Planning**

7.13 Commissioners should: develop values that inspire a positive attitude to home care such as flexibility and person-centeredness; design a clear plan of how to commission integrated services to improve the outcomes that can be achieved; work together with others, involving users and unpaid carers and encouraging health and social care staff to work together too; consider a single point of entry to services; investigate the role that assistive technology can play.

## **Contracting**

7.14 Commissioners should: use evidence-based intervention programmes; create diversity among providers; think about how effective provision can be achieved with existing staff; make sure that staff development and training are considered in the contracting model; embed an outcomes-based approach in the contracting process; contract with clear expectations regarding quality of care; have robust contractual arrangements in place and monitor outcomes.

## **Monitoring**

7.15 Commissioners should: move away from task-focused to outcomes-based commissioning; develop quality monitoring methods that place older people's views at the heart of assessing quality of care; think about the impact on carers when commissioning increases the number of care packages that people receive at home; pay attention to the extra needs of people from black and minority ethnic groups and other excluded groups.

7.16 The Commissioning Framework Guidance and Good Practice requires that local authorities in Wales and their health partners: develop their current visions into firm plans for service transformation; engage the public effectively in the debate about service transformation for adult social care; effectively integrate health and social care provision, and develop joint, coherent, and financially robust plans for the commissioning of services for people with dementia and their carers; include prevention and early intervention services within their joint overall commissioning strategy for adult social care; develop outcomes based commissioning strategies, with contract monitoring and review, focusing on the quality of care and outcomes achieved for service users; ensure that joint commissioning plans have appropriate governance arrangements and frameworks that professionals can operate within, including effective control and mitigation of risks to service users;

implement effective strategies that provide a wide variety of services that support carers; and evaluate the effectiveness and financial viability of new and alternative models of care for people with dementia (Care and Social Services Inspectorate Wales, 2014).

- 7.17 Commissioning for better outcomes (2015) sets out the standards for good commissioning of care services, which a framework for self-assessment and peer challenge. These include: person-centred and focused on outcomes; co-produced with service users, their carers and the wider local community; well led; a whole system approach; uses evidence about what works; a diverse and sustainable market; provides value for money; develops the workforce; and promotes positive engagement with providers (University Of Birmingham Health Services Management Centre, 2015)

### **Good practice examples**

- 7.18 SCIE guide includes a brief outline of 11 practice example, covering: services that rely on well-trained carers, are flexible and innovative; reablement projects; services that use relationship-based home care; end of life care package provided by multi-agencies coordinated by a community matron; volunteers providing learning opportunities to older people receiving care; joint working between health and social care; outcomes-focused Help to Live at Home; promoting assistive technology; local support for people with dementia (Social Care Institute for Excellence, 2014). A description of the examples is available at:  
<http://www.scie.org.uk/publications/guides/guide54/>
- 7.19 The National Review of Commissioning for Social Services in Wales 2014 highlights a number of good practice examples of innovation, focusing on: governance and strategic planning; prevention and early intervention services for people with dementia; supporting people in the community; supporting people with complex needs; and engaging service users and carers (Care and Social Services Inspectorate Wales, 2014). A brief description of the example is available at:  
<http://cssiw.org.uk/docs/cssiw/report/140416overviewen.pdf>
- 7.20 Bolton (2015) provides an initial evaluation of outcomes-focused commissioning and emerging practice, looking at the Helped-to-live-at-Home service in Wiltshire County and the local offer of support in Hertfordshire.  
[https://ipc.brookes.ac.uk/publications/John\\_Bolton\\_Outcome\\_Based\\_Commissioning\\_Paper\\_April\\_2015.pdf](https://ipc.brookes.ac.uk/publications/John_Bolton_Outcome_Based_Commissioning_Paper_April_2015.pdf)
- 7.21 Outcomes Matter: Effective Commissioning In Domiciliary care offers a number of case studies to illustrate progress against some of the key challenges. Case studies cover approaches to: incentivising providers to deliver against outcomes (including payment by results approaches); breaking down a time-task culture; sharing outcomes across organisational boundaries; shifting the emphasis away from cost and onto quality; working with service users to design services and establish outcomes; and supporting care users to make informed decisions.

## Care and support at home market and business sustainability

- 8.1 'The domiciliary care supplier market is difficult to analyse as it consists of a wide range of different providers providing different services. It is also very dynamic and changing. Unlike care homes which are fixed assets, agencies can start up, disappear, grow or shrink with relative ease' (Care and Social Services Inspectorate Wales, 2016).

### The domiciliary care market in Wales

- 8.2 The total number of adults receiving homecare in Wales at 31 March 2015 was 23,744. 'There were just over 60,600 adults receiving community-based services at 31 March 2015, 3,933 (6 per cent) less than the figure 12 months previously. The number of adults receiving homecare, day care, respite care, meals, equipment and adaptations fell in 2015, when compared to 31 March 2014. There were increases for supported accommodation, direct payments, adult placements and reablement' (Welsh Government Knowledge Analytical Services, 2016). According to UKHCA (2016), however, the total number of people using domiciliary care in 2014/15 was 47,300. The number of adults with learning disabilities receiving community and residential services at 31 March 2015 was 9,688, of which 8,390 were receiving community based support (Wales Welsh Government Knowledge Analytical Services, 2016).
- 8.3 Between 1 April 2014 and 31 March 2015 13.2 million home care hours were provided by local authorities in Wales. The total of hours directly provided by local authority staff decreased by 16 per cent compared to 2013-14, while there was an increase by 6 per cent in number of hours provided by the independent sector. In 2014-15 the independent sector provided in excess of 80 per cent of home care hours (Wales Welsh Government Knowledge Analytical Services, 2016). A comparison of data for the last week in September in 2013 and 2014 shows that there was a 4 per cent decrease in number of adults receiving up to hours of home care and a 5.8 per cent increase in the number of adults receiving 10 hours or more.
- 8.4 On the supply side, as of March 31 2015: 381 domiciliary care services were owned by an organisation; 41 services were owned by an individual; 7 providers had both domiciliary care and supported housing services; the largest provider owned 7 services; of 422 providers 320 only owned 1 service (75.8%) (Care and Social Services Inspectorate Wales, 2016). Crucially, the CSSIW reports that a number of multi-national companies are acquiring local agencies, although this is not always reflected in registrations as they tend to continue to operate as the pre-existing, separate agencies (CSSW, 2016). In 2015 the independent/voluntary sector delivered 81% of all local authority funded domiciliary care in Wales. The remaining 19% was delivered by local authority in-house teams (UKHA, 2016).

While no data is available as to which sector provides domiciliary care directly purchased by individuals in Wales, UKHCA estimates that this type of support is delivered exclusively by the independent/voluntary sector.

- 8.5 Agencies offer a range of services spanning from specialised support for learning disabilities and reablement to more generic services. 'Some provide dedicated supported housing services, while others provide care across a variety of services on a spot or block-purchase arrangements. Some agencies are also nursing agencies' (CSSIW, 2016). The CSSIW also registers an increasing number of home care agencies commissioned by the NHS to support long term complex conditions or provide hospital to home support (Care and Social Services Inspectorate Wales, 2016). The size of agencies varies from typically 20-50 workers in small private agencies through to over 200 workers in public sector services, suggesting that the workforce in domiciliary care in Wales is highly fragmented (Llewellyn, 2010).

### **Providers and market sustainability**

- 8.6 UKHCA (2016) provides a comprehensive picture of the domiciliary care market in the UK and Wales in particular, highlighting some of its vulnerabilities. Drawing on findings from a survey of domiciliary care providers, the report raises concerns about the stability of the UK market and highlights the impact of the pervasive underfunding of the sector. The report shows that '93% of providers trading with councils had faced a real-terms decrease in the price paid for their service over the last 12 months, 20% reported a decrease in the actual fees paid; 50% of providers who were aware of tender opportunities from their local authority had declined to bid on the basis of price; there was also evidence of pending market stability over the next year, 74% of providers responding to the survey said they would reduce the amount of publically funded care they delivered, estimated to affect 50% of all people they provide care and support to; and 11% of providers though they would have 'definitely' or 'probably' ceased trading within the next 12 months, while 38% of providers were completely confident that they would still be trading at the same time next year' (Holmes, 2016). The report indicates that 'between 2009 and 2015 the number of people receiving local authority funded domiciliary care in the UK decreased by 20%. Over the same period the hours delivered decreased by 6.8%'.
- 8.7 UKHCA Market Stability Survey (2015), which received responses from one or more providers based on 45% of councils in Wales, shows that 80 per cent of providers in Wales (compared to 74 per cent across the UK) said that they had requested a rate increase from the local council(s) to which they supplied services over the last 12 months. Across the UK, 'the overwhelming majority of providers (93%) reported receiving a real-terms decrease in the price they received from the councils with which they trade over the previous 12 months' (UKHCA, 2015 Market stability survey). In Wales, 60 per cent of providers either regularly or occasionally declined to accept new care packages due to the low price offer. The report notes that 'the reason for these decisions may not be purely financial, but may represent

providers' assessment that workers cannot complete the care safely (or with sufficient dignity) within the amount of time the council was prepared to purchase of behalf of the individual'.

- 8.8 86 per cent of suppliers providing to councils in Wales (and 80 per cent providing to self-funders only) were not confident they would be able to meet the costs of the National Living Wage (76 and 63 per cent respectively in the UK (UKHCA, 2015).
- 8.9 The introduction of the National Living Wage is expected to add additional pressure to domiciliary care providers. To contrast its negative impact, the Association of Directors of Social Services Cymru (2016) provide the following advice: make the procurement/tendering processes less bureaucratic and costly; apply consistent standards across local authorities boundaries; move to commissioning outcomes rather than outputs; changes in VAT status, to prevent current exemption penalising providers who are unable to claim back the VAT on related purchases; and provide additional funding. 'Without an element of additional funding there is a very real danger that local authorities will only be able to meet costs by reducing the number of care hours and placements that they purchase.'
- 8.10 ADSS Wales (2016) acknowledges that fees to homecare providers have been an issue in Wales for some time, noting that in 2015 'the hourly rates paid by local authorities in Wales varied between £11.67 to £16.24 per hour with only two local authorities paying rates that exceeded UKHCA's indicative minimum price of £15.74 per hour. It should be noted that this minimum price does not take account of the forthcoming increases in the minimum wage' (Association of Directors of Social Services, 2016).
- 8.11 These concerns and more broadly the state of the current domiciliary market in Wales are echoed by CSSIW. In their annual report they note that 'during 2015, concerns about domiciliary care provision were reported across the UK national media, particularly in relation to short visits, call clipping, lack of travel time between calls and the pay and conditions of staff, many of whom were on "zero hours" contracts. Two issues emerged in Wales which attracted particular concern and attention: the re-commissioning of domiciliary care services in Powys, and the introduction of dynamic purchasing by Cardiff Council' (CSSWI, 2016 improving...). With specific reference to service failures in Powys County Council, the report argues that the decision to reduce the number of suppliers from which service was procured (a four-fold reduction from the original 16 local providers) was somewhat misplaced. If the intention was to allow suppliers sufficient scale and capacity scope, the exposure to risks from provider failure was significantly augmented. A determining factor was the unwillingness of the workforce to move from family-led to larger providers (CSSIW, 2016).
- 8.12 Laing (2014) sets out the key characteristics of the adult social care market in the UK and its intrinsic vulnerabilities. These are:

- ‘Competitive on the supply side: (there are few council area in which any one provider controls 25% or more of the local care home market), and homecare supply is even more fragmented;
- Fragmented, with the four leading providers controlling 16% of the care home market nationally and 14% of the homecare market nationally;
- Limited economies of scale above about 25-30 beds at the individual home level, and there are also limited economies of scale at the organisational level from operating large portfolios;
- Mixed public / private funding: nearly all registered services (both care homes and homecare) have mixed funding from both the public sector (councils and the NHS) and the private sector (private individuals);
- Endemic cross subsidies: from private to public payers;
- Polarisation: local markets are highly polarised between affluent areas with high private pay demand and non-affluent areas dominated by publicly paid demand;
- Market power typically lies on the demand side in areas dominated by public pay, as local authority commissioners exercise monopsony power over the purchase of services (both older people’s residential and homecare) which are usually fulfilled locally;
- Risk to providers from councils’ market power: providers in areas with high exposure to public pay are at high risk of councils using their monopsony purchasing power to depress margins below a level necessary to sustain investment in either existing or new capacity;
- Highly regulated: providers have limited discretion over the main element of cost, which is staffing levels;
- Information deficit: the market is not fully transparent, with private-pay cross-subsidies to public-pay usually hidden, and there are poor information flows generally for typically once-in-a-lifetime purchasing decisions in crisis situations’ (Laing, 2014).

### **Factors that may influence organisational and market stability**

8.13 The Institute of Public Care (2014), focusing on England and mainly looking at residential care provision, have analysed the main factors that may influence organisational and market stability. The study suggests that organisations that are most likely to have the greatest financial stability are not for profit, large scale, housing providers who also provide care (Oxford Brookes University Institute of Public Care, 2014).

8.14 Geographical coherence is also important for care providers - attempting to cover wide geographical areas without a travel and time premium is equally financially risky for providers. ‘Therefore, companies that rapidly acquire new businesses without geographical coherence may be more at risk than others, particularly if the intention is to rapidly increase turnover before selling on’ (Oxford Brookes University Institute of Public Care, 2014).

- 8.15 In addition, 'many of the providers interviewed saw employment factors as one of the biggest threats to market stability', particularly in relation to levels of pay, the ability to recruit, the costs of agency workforce, high staff turnover, and the higher risks and impact of poor quality of care resulting from staff turnover and use of agency staff (Oxford Brookes University Institute of Public Care, 2014).
- 8.16 Fees, pricing and profitability are found to be affected by a number of factors, including: whether or not providers have large debts; the proportion of clients they have who are LA funded; the extent to which they provide services to people with learning disabilities (whose funding has not been cut back by LAs as much as services for older people); and the extent to which they provide services to CCGs. The report finds that many older persons domiciliary care providers 'say they are making very small profits, or even losses, and some are considering moving out of the market. Most providers state that they are rapidly seeking to bolster their organisation by developing the self-funders' market' (Oxford Brookes University Institute of Public Care, 2014).
- 8.17 The study identifies three features of the current care market that contribute to stabilise the market: 'an increase in the use of personal assistants offers wider choice and greater diversity and may bring some people to work in the care sector who would otherwise not have been attracted to it; there is an increasing involvement in care provision via extra care and a remodelling of sheltered housing by housing providers that is backed by a considerable asset portfolio; the diversity of care providers, funding and governance models makes the market more stable' (Oxford Brookes University Institute of Public Care, 2014).

### **Provider size**

- 8.18 The size of agencies varies from typically 20-50 workers in small private agencies through to over 200 workers in public sector services, suggesting that the workforce in domiciliary care in Wales is highly fragmented (Llewellyn, 2010). The evidence base suggests that larger providers may be able to deliver at sufficient scale and capacity scope (CSSIW, 2016) and that large scale organisations are afforded greater financial stability (Institute of Public Care, 2014). As Powys County Council case study shows, however, they are not immune from failure.
- 8.19 There is some evidence that small providers are better placed to provide flexible, innovative care. Needham (2015) find that 'micro-providers offer more personalised support than larger providers, particularly for home-based care; they deliver more valued outcomes than larger providers, in relation to helping people do more of the things they value and enjoy; they are better than larger providers at some kinds of innovation, being more flexible and able to provide support to marginalised communities; and they offer better value for money than larger providers. Factors that help micro-providers to emerge and become sustainable include: dedicated support for start-up and development, strong personal networks within a localities, and balancing good partnerships (including with local authorities) with maintaining an independent status. Inhibiting factors, on the other

hand, include a reliance on self-funders and the financial fragility of the organisation.

8.20 The report makes the following recommendations: commissioners should develop different approaches to enable micro-enterprises to join preferred provider lists; social care teams should promote flexible payment options for people wanting to use micro-enterprises, including direct payments; social workers and other care professionals need to be informed about micro-enterprises operating close-by so that they can refer people to them; regulators need to ensure that their processes are proportional and accessible for very small organisations; and micro-enterprises need access to dedicated start-up support, with care sector expertise, as well as ongoing support and peer networks' (Needham, 2015).

### **Approaches to domiciliary and social care market sustainability**

8.21 A Managed Change (2015) sets out an agenda for sustainable domiciliary care in Northern Ireland, outlining key features associated with successful, sustainable models of domiciliary care.

<http://www.hscboard.hscni.net/download/PUBLICATIONS/DOMICILIARY%20CARE/An-Agenda-for-Creating-a-Sustainable-Basis-for-Domiciliary-Care-in-NI.pdf>

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