



External Report

Commitment to Carers: The Carers' Voice Network

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1 Plain English Summary

In 2015-2016, Staffordshire University and a steering group of carers and health and social care professionals, supported NHS England in evaluating the ways in which examples of integrated care have led to changes for both carer representatives and professionals. Our findings indicated that when services work together, and professionals in those services communicate well with each other, this translates into carers feeling more supported and valued. Our first report also highlighted that many carers are placed under a considerable amount of daily and on-going stress in meeting the needs of those they care-for as well as looking after their own health and well-being. This was one of the most pertinent aspects of our first report, where carers had a 'voice' in sharing their experiences and concerns.

This earlier work subsequently grew into what has developed to be the Carers' Voice Network. The aim of this network is to hear the carers' voice and improve the health and well-being of carers, through ensuring that carers are able to share their experiences of care and support and drive improvements across the health and social care economy. Our objective was to obtain stories from carers across Shropshire, and Telford and Wrekin. Because of the sheer diversity of areas carers offer support, we decided to focus on four key areas within health and social care; these included: dementia, parent carers, young carers under 25 years, and forensic carers. Under these four working groups, we asked the Carers' Voice Network to submit stories of care and support to a secure email, where those stories were anonymised and submitted for analysis.

Our analysis involved reading carefully through every story, highlighting and summarising pertinent issues. After reviewing every story, a list of summary points (codes) were created and links between these points was made with other stories. We highlighted 13 areas, or themes, that helped to explain the complexities raised in each story across the four different areas of focus.

Across all areas, it was clear that carers found themselves in situations, providing care and support to loved ones, that they were unable to free themselves from. Consequently, carers reported experiencing considerable psychological and physical stress in caring for a relative with dementia; a child with a learning disability or accessing specialised children's services; providing care and support as a young carer under 25 years; or as a forensic carer having to negotiate not only systems of care but also the Criminal Justice System. The stress carers faced was due in part to the demands on their time, but also aspects such as securing funding to help them obtain temporary or enhanced care. Many carers were also of a working age, and it was clear that there were occupational challenges in them meeting not only their needs as a carer, but also earning a living and maintaining their sense of well-being and quality of life. Other findings indicated that effective communication between professionals and carers is vital, especially in ensuring that carers are included, involved, and empowered. The cared-for transition between services was also a concern for some carers, as was the way in which carers were able to access help and support and disclose their carer identity. It was clear for forensic carers, that there needs to be more specialised commissioning of forensic care services.

Recommendations are provided herein, and pertain to the need of greater awareness of carers, ensuring carer support, and continued integration of services.

2 Introduction

Carers form a “hidden army” (Oldman, 2014, p. 26) that operate resiliently in the background, providing care to loved ones and family. It goes without saying that the National Health Service (NHS) would succumb to immense operational, budgetary, and social pressures if it were not for the estimated 6.5 million people in the United Kingdom (Carers UK, 2015) providing unpaid care for friends or family members. “Carers are a hugely important asset to the NHS” (NHS England, 2014a, p. 5). Wigfield (2011) estimates £119 billion of savings carers make to the health and social care economy per year; equivalent to £18,473 for every carer in the UK. In Shropshire (the geographical focus of the present service evaluation), the latest figures of people who provide unpaid care¹ was 34,260, or 11.2% of Shropshire’s population (Shropshire Council, 2011). Within Telford and Wrekin, the number of people who provide unpaid was 17,944, or 10.8% of the population of Telford and Wrekin (Telford & Wrekin Council, 2011). What is interesting to note is that over a quarter of the unpaid carers in Telford and Wrekin provide 50 or more hours of unpaid care per week ($n = 4,978$; 28% of total number of carers). Carers UK (2014) highlight that the incidence of carers reporting ill-health themselves rises when carers provide more than 50 hours of care per week. A key issue to highlight is that these are unpaid carers who are ‘known’/or disclose the fact that they are a ‘carer’. One might expect that there are many more unpaid carers who are simply not aware of their status as an unpaid carer. Indeed, the number of people living with a limiting long-term illness² in Shropshire in 2011 was 56,826 or 18.6% of Shropshire’s population (Shropshire Council, 2011). Within Telford and Wrekin, the number of people living with a long-term illness was 30,995 or 18.6% of the population of Telford and Wrekin (Telford & Wrekin Council, 2011). In the business plan for 2016/17, NHS England (2016) has recognised the importance of ensuring that carers are supported alongside services being person-centred and co-produced with citizens and communities. NHS England (2016) suggests that the clinical paradigm of, ‘what is the matter?’ can be supplemented with the question, ‘what matters to you?’; citing the importance of, “ensuring all voices are heard, especially those who have found it harder to make their opinions felt and suffered greater health inequalities as a result” (p. 49).

However, many carers (and professionals alike) will read the above statement and say, ‘when will this [really] happen?’ Findings from an earlier qualitative service evaluation (2015-2016) by the report authors³ found that carers may lack a ‘voice’ in the care of their loved-ones, exemplified in the quote below:

¹ An unpaid carer looks after or gives help or support to family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age (Shropshire Council, 2011).

² Covering any long-term illness, health problem or disability which limits daily activities or work (Shropshire Council, 2011).

³ Report to NHS England (2016): Development of a multi-agency, multi-disciplinary action-learning programme based on ‘story telling’ learning from patients, carers and staff.

“[Carer] offered ward staff information about her mother’s care needs but felt she was not being heard ... very agitated and frustrated ... not involved in her mother’s care ... repeating [information].” (Narrative. 3).

The importance of ensuring carers are supported is embedded within the Care Act (2014), which focuses on the importance of, “preventing or delaying the development by adults [and carers] in [the local authority] of needs for care and support” (p. 2). Additionally, to “identify carers in the authority’s area with needs for support which are not being met (by the authority or otherwise)” (p. 3). The Care Act (2014) goes on to detail further information on promoting integration of care and support (discussed in the previous qualitative service evaluation 2015-2016 by the report authors); providing information and advice; promoting diversity and quality in service provision; ensuring sufficient and effective co-operation between services; and assessing needs, care, and planning for adults, and carers themselves.

The Care Act (2014) also details regarding the rights of a child carer’s needs for support. This is also emphasised in the Children and Families Act (2014), which explains that, “a local authority in England must take reasonable steps to identify the extent to which there are young carers within their area who have needs for support” (p. 73). Crucially, both pieces of legislation make a case for carers, to be given the same “recognition, respect and parity of esteem with those they support ... [that they may be] truly acknowledged and valued as expert partners in care” (Russell, 2016, as cited in HM Government, 2016).

2.1 The carer’s voice

Carers need to be **listened to and heard** when dealing with healthcare professionals and respected for the information they can provide in support of the person they care for. The prospect of not being listened to or actively involved in their loved one’s care would undoubtedly impose a significant level of stress on a carer, who might typically be struggling with their situation:

“[Carer] described herself as being overwhelmed by the situation and appreciates an outside view.” (Narrative. 4).

When a carer is listened to and adequately supported this has the potential to alleviate stress and promote well-being:

“Straight away, I felt understood and supported and could ask silly questions and felt less alone ... advice on practical things ... sharing my experience with other carers ... concerns and relief of bottled-up emotions which are hard to share with family members as guilt and helplessness gets in the way.” (Narrative. 4).

2.2 Recognising carers

The National Carers’ Strategy (HM Government, 2008) highlighted the importance of supporting the needs of carers and providing them with the recognition and status they deserve; that carers will be, “universally recognised and valued as being fundamental to strong families and stable communities” (p. 9). However, the issue of

carer identity may pose further questions and warrant investigation. In our former service evaluation, we found that some carers would not readily identify, or believe themselves to be carers. Molyneaux et al. (2011) highlight that the term 'carer' might imply that those whom are cared-for might be a burden to the carer, thus devaluing the individual who is cared-for. Our previous findings also indicated that the transition to being a carer for many new carers was often sudden and negatively impacted the relationship between the 'carer' and their loved one; as such transforming the carer into "something [they] never wanted to be" (Taylor, 2015, p. 26). Despite this, the term 'carer' has been argued by Clements (2013) to become a protected status to support non-discrimination legislation. There is also further evidence that having a 'recognised' identity might also influence the carer's perception of their dignity, with Nordonfelt and Edgar (2005) suggesting the *dignity of identity* represents a person's integrity and identity as a human being.

Issues of identity aside, the importance of *recognising* carers and valuing the care they provide for their loved ones has been pivotal, not only to the National Carers' Strategy, but also in NHS England's (2014a) Commitment to Carers. Raising the profile of carers and what carers do is central to this strategy (NHS England, 2014a), and could be achieved through continuation and drive of the Carers' Network; sharing experiences, best practice and evidence. A key part of the success of these informal networks would be in ensuring that best practice and evidence is shared across sectors and geographical boundaries to influence care and support. To address this, strong partnerships need to be created and maintained with carers, in addition to voluntary organisations and local communities to help support carers; evidenced in the *Five Year Forward View* plan (NHS England, 2014b). Currently NHS England (2017) have, in partnership with local councils, proposed *Sustainability and Transformation Plans* (STPs) to drive improvements in health and social care. In Shropshire, one of the ambitions of the STP is for organisations to work collaboratively to deliver person-centred care and support and reduce the need for treatment in the local population (STP, Shropshire and Telford & Wrekin, 2017). The essence of this ambition is to focus on creating a "Multi-Speciality Community Provider as a vehicle for joint working", to focus on "removing organisational boundaries" and provide community support for carers and those they care for (STP, Shropshire and Telford & Wrekin, 2017, p. 18).

The *Commissioning for Carers Principles* (NHS England, 2014) illustrates 10 areas to record progress in supporting adult and young carers. It is important to note that these principles orientate around thinking of (and recognising) when a person becomes a carer⁴; supporting what works for them; measuring what matters to them; and prioritising their health and well-being. Recognising and valuing the voice of carers of all ages is one of the key principles that has driven this service evaluation.

2.3 Aim

Hearing the carers' voice to improve the health and well-being of carers.

⁴ The issue of when a person becomes a carer is open to interpretation, whether this be when someone becomes unwell, or perhaps progression of older age.

2.4 Objectives

- To obtain stories from carers across Shropshire, and Telford and Wrekin as a joint venture, who care for patients within the identified working group strands⁵ by either direct contact or offering a secure email address.
- To collate carers' stories via a central database for analysis in contributing to the production of evidence to support proposed national/local change.
- To work within relevant groups to review the analysis and consider proposed recommendations.
- Working groups to feedback outcomes of recommendations to carers within their category.
- Working groups to support the content of a conference to deliver the outcomes.
- To commit to carers that actions identified from recommendations will be taken forward as a co-production with carers, service users, commissioners and providers (in line with STPs).

⁵ Dementia; parent carers; young carers under 25 years; and forensic carers.

3 Methodology

3.1 Design

A qualitative methodology was utilised for the collection and analysis of data. A Carers' Voice Networking Group was facilitated by NHS England and it was decided that the following four areas would be used as a focus for carers' stories:

- Dementia, including young people with early-onset dementia.
- Parent carers.
- Young carers under 25 years.
- Forensic carers.

3.1.1.1 Collection of stories

It was important to take into account, that when capturing the carers story, there may be emotions that are expressed by the individual at the time. The Carers' Voice Network considered that those who would be best placed for understanding how a carer may feel, would be someone who was very familiar with that particular health issue.

Through the contacts available to our health organisations, service users and carers were approached and volunteers identified. These included:

- George Rook, a service user for dementia.
- Sarah Thomas, a carer and Participation Co-ordinator (Shropshire Parent and Carer Council).
- Val Cross, Health and Wellbeing Officer (Shropshire) and Jill Tiernan, Carers Commissioning Officer (Telford & Wrekin) joined together and worked in partnership, holding Forums for Young Carers as it was considered a better way of capturing the issues faced by Young Carers.
- Sue Stewart, a Forensic Carer.

3.2 Qualitative data (stories)

A total of 21 stories were submitted by key stakeholders within the Carers' Voice Network. Collectively, these stories totalled 27,497 words (mean: 1309 words; range: 442 – 3512 words), and spanned the different areas of focus as outlined above. A total of 6 stories were submitted in dementia care; 11 stories by parent carers; 3 stories from forums conducted with young carers and young people; and 1 forensic carer story.

3.3 Ethical considerations

An official letter was received from NHS England, dated 20th October 2015, indicating that this was part of a service evaluation/development project, whereby anonymised stories and narrative would be utilised as secondary data sources/evidence.

All carers submitting stories provided written informed consent, that was affixed to their story and kept on file by NHS England. All carer stories were submitted (by carers) to a secure NHS email address that was managed by NHS England. These

carer stories were then read by either the Assurance Programme Manager, NHS England (HP), or colleague, and redacted if required before being emailed to the Research Associate (AB) for review, qualitative analysis, and reporting. Details of informed consent were separated from each carer story prior to being submitted to AB for review, qualitative analysis, and reporting.

To ensure quality assurance, qualitative reliability, and anonymity⁶ of carers, initial drafts of this report were reviewed by HP; Mark Donovan (Patient Experience and Engagement Lead, Shropshire Community Health NHS Trust); and WM before dissemination to the Carers' Voice Network for review. Subsequent versions of this report reflect the feedback provided by the Carers' Voice Network during a consultation period.

3.4 Co-production

A former qualitative service evaluation⁷, conducted between November 2015 to July 2016 within the same locality (Shropshire) and by the same research team, formed the empirical basis of the Carers' Voice Network project. The former project explored how co-production between carers and health and social care professionals might inform collaborative decision-making and joint planning for carers, using stories/narratives as an evidence base. The present, Carers' Voice Network project, was formed out of the need to discuss and implement recommendations arising out of the former project, and to establish working groups to ensure co-production between carers/service users and professionals.

Each working group was chaired by carers/service users and facilitated by professionals who provided advice and guidance relating to organisational boundaries and policies. The purpose of each working group was to establish regular contact to review the recommendations of the former report and discuss the optimal method(s) in obtaining a significant response from carers whilst respecting patient confidentiality.

It is worth highlighting the notion of co-production, such that it involves the creation of equal partnerships between people who use health and care services, carers and communities, to influence the design of services (Coalition for Collaborative Care (CfCC, 2016)). It is often the case that individuals living with a particular condition are usually best on advising how care and support can make a positive difference to them and their family (CfCC, 2016). Co-production has the potential to influence social norms and cultural changes in health and social care, as evidenced in Figure 1. However, the process to genuine co-production is often quite involved, as highlighted in Figure 2. In our first report, we highlighted that the Social Care

⁶ Due to the number of carer stories submitted, and specific geographical focus, all references to a carer's (and those they care-for) personal details (such as gender, age, occupation, locality, etc.), have been removed to maximise anonymity. Furthermore, specific details regarding professionals (such as occupational designation, service, and locality) have been removed.

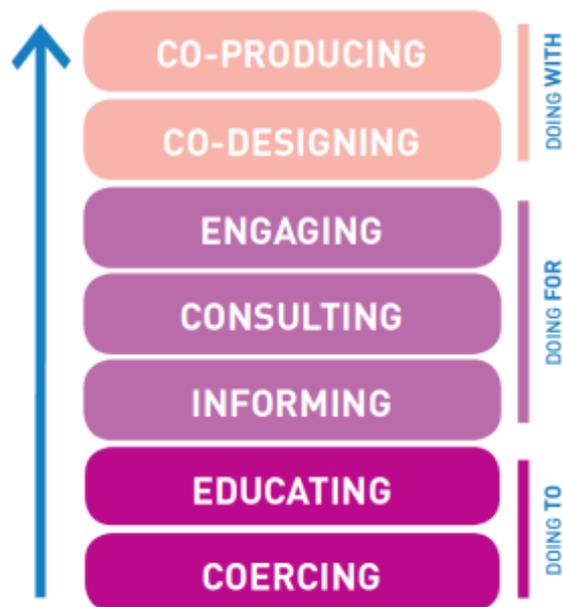
⁷ Report to NHS England (2016): Development of a multi-agency, multi-disciplinary action-learning programme based on 'story telling' learning from patients, carers and staff.

Institute for Excellence (SCIE, 2015, p. 6) consider co-production involving, “people who use services taking over some of the work done by practitioners”, compared with co-creation which refers to, “people who use services working with professionals to design, create and deliver services”. Either way, the most important issues at stake here are in ensuring that carers and those they care-for are *involved* and *have a voice* in the design and delivery of services. The extent to which this is the case will depend on the service in question, but further details can be found in Appendix 1.

Figure 1: *Values and behaviours* (adapted from CfCC, 2016)



Figure 2: *Ladder of participation* (New Economics Foundation, as cited in Social Innovation Exchange, 2014)



Source: new economics foundation

In respect of Figure 2 above, it is worth highlighting that, for this particular project, we have strived to only focus on the ‘*doing with*’ aspects of co-production where we engaged with participants in the co-design of the project and co-producing recommendations.

3.5 Data analysis

The 21 anonymous stories that were submitted by carers were managed using NVivo⁸. All carer stories were read multiple times and 'coded' to highlight pertinent themes arising from the context of each story. Each one of these themes was then mapped against other themes arising from other stories, and developed into broader (superordinate) themes that represented numerous other themes. This analysis broadly follows the principles of *inductive thematic analysis* (Braun & Clarke, 2006), where patterns and themes are identified, analysed, and report on that are strongly evidenced by the data itself (Patton, 1990). Inductive thematic analysis can be summarised in three phases (Figure 3) and in more detail in six phases (Figure 4).

Figure 3: *Three-phase inductive thematic analysis summary*

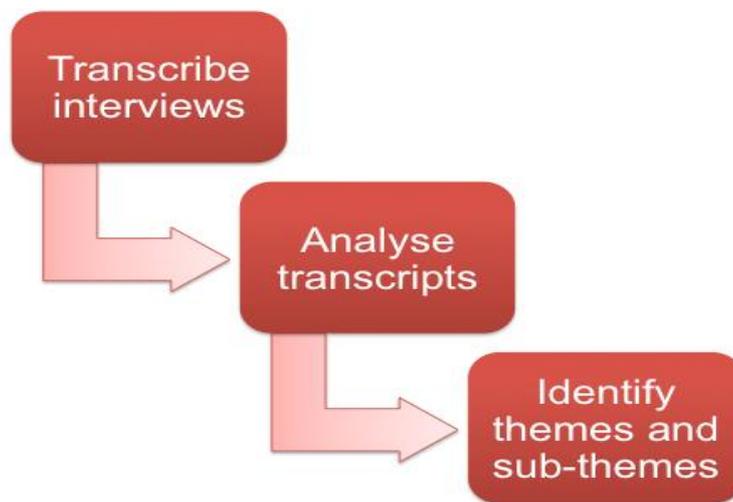
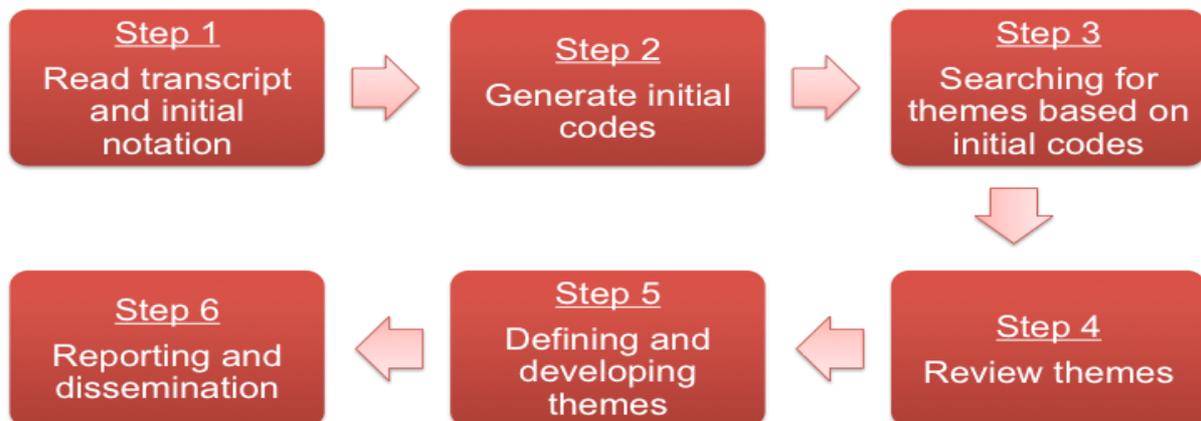


Figure 4: *Six-phase inductive thematic analysis*



⁸ NVivo is software that supports qualitative research, aiding the organisation and analysis of data. NVivo is effective in helping the analyst determine connections across the dataset (carer stories), and support findings with evidence.

4 Findings

4.1 Themes unique to each working group

The focus taken for each of the carers' stories brings with it unique issues that can only really be interpreted within the context of the story. The following are themes that were apparent for each one of the working group areas:

- Dementia, including young people with early-onset dementia.
- Parent carers.
- Young carers under 25 years.
- Forensic carers.

4.2 Overall list of themes per working group

Group	Themes	Subthemes
Dementia	Signs and symptoms	Memory loss
	Diagnosis and referral	Care from general practitioner (GP) Memory Service
	Carer support	Assessment and advice Paid care Respite care Support networks
	Progression of condition	Psychological Physical
	Carer stress	Demands on carer's time Funding challenges Occupational challenges
Parent Carers	Communication	Being greeted, included, involved and empowered Compassion Information sharing
	Transition between services	Co-ordination Resources
	Assessment and treatment	Assessment skills Form of treatment
	Advanced planning	
Young Carers	Accessing support	
	Awareness of young carers Young carer identity Young carers support	Academic support Practical caring support
Forensic Carers	Listen to forensic carers	
	Better training for mental health staff around autism	
	Easily available help, support, and information regarding the CJS*	
	Carers to be asked on how well their concerns were addressed	
* Criminal Justice System		

4.2.1 Dementia

4.2.1.1 Themes

A total of 5 themes were formulated to represent issues arising from carers' stories of dementia. These themes and subthemes are illustrated in Table 2.

Table 2: *Themes and subthemes in dementia stories*

Themes	Subthemes
Signs and symptoms	Memory loss
Diagnosis and referral	Care from general practitioner (GP) Memory Service
Carer support	Assessment and advice Paid care Respite care Support networks
Progression of condition	Psychological Physical
Carer stress	Demands on carer's time Funding challenges Occupational challenges

4.2.1.2 Diagnosis and referral

Care from GP

As expected, the GP was one of the first key professionals to assess a patient for the possibility of dementia and their carer's needs. In the case of a younger adult in story 2 (eventually diagnosed) with early-onset dementia, there appeared to be some missed opportunities where the GP had consulted with the patient regarding their alcohol consumption, resulting in a referral to the "alcohol advisory service ... and counselling". This service considered that the patient's condition ("fixation to the television, taking no interest in making friends, eating ... and with worsening memory") was not linked with their alcohol consumption and referred them back to the GP for further assessment, including the possibility of assessing for depression. Even despite "a course of anti-depressants, this patient's health did not improve and [they] started to become incontinent on occasions". This patient's carer ended up:

"demanding a brain scan as [their] concern was beginning to grow, mainly because of what appeared to be rapid deterioration in memory, ability, incontinence, etc." (Story 2).

This patient's carer made their demands based on their strong family history of neurological conditions, specifically with two family members having frontal lobe dementia commencing in their 50s. Eventually the elusiveness of early-onset dementia was laid bare and a subsequent brain scan revealed pathology in the frontal lobe, resulting in a referral to the Memory Service. Some carers highlighted that there has been significant improvements in awareness and knowledge of dementia:

"[Parent] was diagnosed in 2005 and [other parent] diagnosed in 2014, during that time I have noticed that dementia care, awareness and

knowledge has improved dramatically. There are so many more services for people with dementia now which is great.” (Story 9).

However, in the case of story 2 (early-onset dementia), the carer considered that GPs need to have more training to recognise this condition:

“Even GPs have admitted that they would not recognise FLD [frontal lobe dementia] in younger people, without having prior experience.” (Story 2).

It would seem that the importance here pertains to that of a training issue and potentially making referrals to specialists where there is any cause for concern. In story 2, the carer highlights that missed opportunities in earlier diagnosis might have been avoided through more focus being placed on the psychological rather than physical needs of the patient:

“In most cases of assessment, emphasis is given to the physical ability of the patient ... a dementia patient who is physically fit, but cannot get up and walk, because [their] brain does not tell [them] to do so, is not given any recognition of physical disability. Until assessment of a young dementia sufferer moves from the physical ability to the mental ability, frontal lobe sufferers will never receive the full support ... they deserve and have a right to expect.” (Story 2).

Memory service

The Memory Service was considered by carers to be an invaluable resource of help and support. This was through the whole process of dementia care, from diagnosis to the provision of support and management of the condition:

“The Memory Service [have helped] as right from the start they gave me lots of reading material which I’ve been able to refer to throughout the various stages of my [spouse’s] condition. They have also prescribed medication which slowed the progression ... and 6 monthly reviews.” (Story 10).

What appears important here in the context of the support provided by the memory service is that carers *are* actually supported and provided advice that is specific to their needs, so they can help those they care for.

4.2.1.3 Carer support

Assessment and advice

Receiving early assessment and specific advice was essential for carers and those they cared-for with dementia. In hindsight of their parent receiving dementia care, a carer in story 3 suggests that receiving advice and information regarding the system would have been particularly useful from the outset:

“Decent advice early on, [with] one person to stop, sit down and talk through how things SHOULD happen and a timescale so you know it’s going to end/be sorted one day. [Part of this would include] producing a crib sheet of jargon for carers and families; a step-by-step guide

[regarding] Carer's Assessment and financial assessment; [and] what might be needed when an elderly patient returns home [from hospital]." (Story 3).

Practical help and advice is clearly essential, but so too is that professionals listen to carers' needs and signpost carers to services that can offer help and support:

"I constantly [asked for help] from all kinds of sources ... I needed someone to listen, to explain how the system should work, to unravel the endless jargon everyone talks ... most of all TO BE BELIEVED. I have mostly been treated like a drama queen ... the word 'sorry' has only been said by ONE individual." (Story 3).

This was not just unique to story 3, with a carer stating in story 7 that social services really needed to help more:

"[What would have helped?] A key person who would really listen, from social services..." (Story 3).

Even though assessment is crucial to ensuring carers are supported adequately, this does need to be person-centred and timely for their situation. One carer highlighted that they received a Carer's Assessment, but that this might not necessarily have been the most appropriate form of assessment at the time:

"I have had a Carer's Assessment but nothing came of it as there were no issues that could be resolved." (Story 9).

In another story where a Carer's Assessment was conducted, there were multiple challenges and the assessment ended up being a very protracted and stressful process for the carer:

"[Person undertaking the Carer's Assessment] couldn't write English very well ... [they were] put in a position which was way over [their] head ... said [they] couldn't write on the form ... it was just terrible ... I was actually writing how to spell words and what words meant ... when I got the report two weeks later [they had] got dates and names mixed up, everything was spelled wrong ... happened four times. In the end, I had written and spelled everything on there. This took four months." (Story 7).

Delays in undertaking Carer's Assessments were also evident in another story, where the assessment took a year:

"I asked for a Carer's Assessment (and financial assessment) in [late] 2015 and it was finally agreed in [late] 2016 – YES a year later. The process has been slow, time consuming and tortuous and I have never felt supported until very recently, and then only minimally." (Story 3).

Paid care

When a programme of care is agreed for the cared-for and the carer, there were often challenges in ensuring that paid care was provided when it was required. In

the case of story 7, the family carer had to cover gaps in the provision of care by paid staff:

“[Parent] was having to go through the night without care, unless I was there.” (Story 7).

Whilst there was evidence in the stories that paid carers provided a much-needed lifeline for family carers, it was sometimes the case that paid carers attended somewhat unprepared for their duties:

“One day I was there, the [paid] carer didn’t know anything about [my parent], or about [their] sight, [their] confusion, anything like that, so it was difficult.” (Story 7).

This indicates that there appear to be problems of communication between paid carers or the agency they are employed by. This is perhaps highlighted through the inconsistency in how paid carers provide care:

“I went from one carer to three carers plus me everyday. It was a recommended home care service, but like all care services it could be anybody who turned up.” (Story 7).

Although these issues appear strongly in story 7, one might expect that these challenges are perhaps more widespread across the social care economy.

Respite care

In addition to paid care at home, temporary respite care was required to enable carers additional support during the day. This was reported to be in the form of the cared-for attending day care centres:

“A lifeline to me ... [spouse] went to a day centre which we had to pay for ourselves. Started going once a week, then twice and finally three times [per week]. This meant I had 6 hours of ‘me time’ although I was always clock watching and wondering if [they] were okay there.” (Story 10).

The above excerpt is interesting in that, although day care support is required to afford the carer time to themselves to maintain their own health and well-being, the carer would often struggle to ‘switch off’ from their caring role and would be concerning themselves with the care and welfare of those they cared-for. Temporary support in the form of day care was highly welcomed and appeared to make a tangible difference to the health and well-being of the cared-for:

“[Their] emotional abilities have improved since attending the day centre and [they] now smile, occasionally laugh. [They] always have to be reminded, however, to hug [their] children or to show any physical emotion.” (Story 2).

Support networks

In addition to the day care support, carers could draw upon the care and support of other networks. Some that were mentioned included Age UK, the Alzheimer’s Society, and the Dementia Action Alliance. There were sometimes specialised

groups, such as a 'Men's Group' for men with dementia, not to mention the carer's support from their family and friends, and religious groups.

4.2.1.4 Progression of condition

The extent to which carers required support depended on the progression of the dementia that the cared-for presented with. In the initial stages of memory loss, potentially before a diagnosis of dementia was made, the carer would perhaps find themselves supporting their loved ones with everyday activities, such as cooking meals, and helping with finances etc.

"[The cared-for] was no longer cooking meals for [their child] and [their] child had to have [their] evening meal with [their] grandparents ... as time went on [the cared-for] [parent] took a bigger role in the care of [their child and grandchild]." (Story 2).

Psychological

The deterioration of the condition was typically reported to be in phases, with the first phase including the carer trying to help manage their loved one's memory loss whilst also maintaining their own activities of daily living. Over time, however, the condition progresses to a point where it becomes impossible for the carer to leave their loved ones, and difficult decisions regarding their future care and support have to be made:

"In the beginning, I was able to continue working full-time ... left Post-it™ notes with reminders for my [spouse] ... a few years later ... needed to reduce my working hours ... [spouse] was no longer safe to be left too long ... had to stop meeting up with friends for a meal ... [eventually] no longer possible to leave my [spouse] alone at all ... started doing everything for [them] ... [they] resisted my help ... often verbally aggressive ... extremely hard for me and upsetting ... I felt very isolated ... had to make the heart-breaking decision to put my [spouse] into a care home ... both mentally and physically worn out ... found giving up work extremely difficult." (Story 10).

It is clear that the challenges of the progression of dementia and eventual deterioration took its toll on this carer. Not being able to continue with their job, and becoming gradually more withdrawn from their circle of friends was extremely challenging. For the carer, just seeing their loved one be robbed of their identity and lose their memory of their family is also extremely difficult:

"In the end, [parent] couldn't make a cup of tea, didn't know how to cook. I would take [them] out in the car but [they] couldn't coordinate to get in and out of the car. [They] would sit in the car and say, 'where am I?' [They] always knew me, but... it was extremely, extremely difficult ... [they are] deteriorating but it's very slow." (Story 7).

"As the end drew nearer [my parent] became more reluctant to become involved in anything. [They] lost interest in the television and seemed to want to sleep for most of the time." (Story 1).

"It is really sad that the person you have been married to for [many] years has become a stranger to you due to Alzheimer's." (Story 10).

The identity of the carer is also worth highlighting as this was pertinent in story 1, where the carer experienced a transition in how they perceived themselves in relation to their parent they were caring for.

“In the last 18 months of [my parent’s] life, [their] condition had deteriorated considerably and the ‘carer’ role began to kick in. [They] quickly became the ‘patient’ rather than my [parent].” (Story 1).

Physical

If the psychological deterioration was not challenging enough, people with dementia will often experience physical problems that will impact on the care that they require. Physical deterioration is typically progressive and is illustrated in story 1:

“We bought a bath life, which lasted for about 1 year, but then that became too much and by the time [my parent] turned [years], [they] were having bed baths by myself ... I realised I was struggling to physically move [my parent] to [their] commode in only 18 inches from [their] bed and finally applied for ‘carers’ to visit [them] and help me look after [them].” (Story 1).

This physical deterioration will often have a psychological element which might impact on the perceptions of both the cared-for and the carer. The cared-for stated that they clearly wanted their plight to end, to alleviate the pressure for their family carer:

“[My parent] often used to say to me, ‘I wish I could kick the bucket’; a famous saying for ‘I want to die’. [They] had no purpose in life and felt [they] had become a burden.” (Story 1).

In the case of story 2, the deterioration in speech was very challenging, and eventually problems with swallowing became problematic:

“[Their] speech is deteriorating quite quickly and [they] now usually confine [their] speech to, ‘yes’, ‘no’, and other such-like words ... family believe that this was not considered when [their] needs were assessed ... [their] ability to swallow and eat [their] meals has deteriorated to the extent that [their parent] now blends [their] evening meals ... the danger of choking still remains a real possibility.” (Story 2).

4.2.1.5 Carer stress

Demands on carer’s time

From the outset of signs and symptoms of dementia, through to diagnosis, and subsequent progression of the condition, the demands on a carer’s time rarely ever abate. In one story, the carer for their spouse with dementia became so consumed by the situation that they were not able to have a life of their own outside of caring:

“During the latter stages of my [spouse’s] illness, I found that I became withdrawn into myself, and if friends wanted to visit, I would make excuses so that they would not. I found it too much effort to make conversation as I thought that they would find me boring as I hadn’t

been anywhere or done anything that wasn't carer related. I'm still finding this difficult now." (Story 10).

Aside from the friendships that carers' hold with others outside of their family network, the relationships that carers have with their loved one's can be tested to the extreme in the case of providing on-going care without additional support:

"All the 'chores' have left me feeling as though there is always something I have to do for [my parent] – it's like looking after a child who doesn't live with you – and this has wrecked any [parent-child] relationship." (Story 3).

The demands on a carer's time might ultimately lead to the difficult decision in placing their loved one into full-time care and support, but that it remains difficult for the carer to leave their loved one:

"Unfortunately, a few weeks ago I had to make the heart-breaking decision to put my [spouse] into a care home. I was mentally and physically worn out. The first week [they] were there was the worst in my life and I don't think I'll ever get over the guilt I feel for putting [them] there, even though [they] are settled, happy and content." (Story 10).

"Where [they] are now [their care home] say the family is part of the care team. I still find it very difficult to leave [them]." (Story 7).

Although the decision to place their loved one into a care home is immensely difficult for the carer, the situation the carer is faced with often leaves them with no choice but to select this option. The demands on the carer's time leaves them feeling stressed and exhausted:

"Two weeks before [my parent's] death, [they] became very agitated and [were] trying to get out of bed ... tried to reassure and quieten [them] with very little success ... I was unable to leave [their] room at all as [they] were so agitated ... one occasion I had to leave the room to take a call from social services, who I previously contacted for help and [my parent] left [their] bed and fell to the floor ... the next day I pleaded with social services for help as I was utterly exhausted." (Story 1).

Funding challenges

Some carers reported that a major source of their stress were the challenges they encountered in obtaining funding for their loved one to have respite care or care at home. Two carers report that the system is effectively broken:

"The current system is going to create a generation of adult/middle-aged children who are worn out, suffer financially and physically/mentally because there is no coherent support system ... lot of good people and some good organisations, but it's not working properly, coherently, sequentially or dare I say with CARE. Too often it's all about money and cost ... I was desperate for a night sitter for [parent] and the agency that could provide one DOUBLED the standard rate and said, 'take it or leave it'. I left it." (Story 3).

“The GP saw all this but [they] couldn’t do anything about social service because it’s government policy. It was hell, absolute hell ... it’s so uncaring ... no compassion ... you come up against social workers and you know they want to care but they can’t do anything ... health services, social services need to connect up ... it’s causing pain, it’s ruining lives.” (Story 7).

It appeared the case that carers were effectively left to beg for care and support before this was afforded to them:

“I begged. I sat there in tears ... I was advised by the head of the private care home service I used that it would have to reach crisis point before they would do anything ... the only way anyone would do something was if I said I could no longer take care of my [parent]. I had to say it was beyond me, and once that was recorded ... they would help.” (Story 7).

It also appears that case that crises were not acknowledged by the support services, when carers raised concerns about their loved ones:

“The week the new care regime was due to kick in [my parent] became sick with two infections and as I write this has not eaten solid food for more than three weeks. Even when I contacted social services, they did not recognise this as a crisis and asked for evidence before they would help (which 10 days later was not forthcoming!)” (Story 3).

One of the main issues here regarding funding appears, not only in the acknowledgement of the carer and the cared-for being in crisis, but also the delays that are encountered when trying to obtain care and support:

“[Cared-for] attends an excellent private day care centre, three-days-a-week, paid for by [them], though the [Council] have confirmed that they will fund one day, but we are still waiting for the process to kick in 6 weeks after it was approved!!” (Story 2).

One of the complexities in the system regarding funding pertains to the threshold that is in place, whereby up to a certain point the carer and cared-for will be eligible for additional financial support, but over that threshold, they are expected to meet their own care needs. This was a fundamental source of stress and heartache for many carers:

“[Parent] was a self-funder. [They] had too much money in the bank. Until that got below £23,500, social services would not get involved ... because of self-funding the door was completely closed ... slammed in your face. If you’re self-funding families have got to do it themselves ... this is what the system is... we’ll help you after you reach the threshold.” (Story 7).

Even when funding is provided, it should still be able to meet the person-centred needs of the carer, which in some cases is not happening:

“While Health is funding [my parent] there does not need to be any consideration of my needs as a carer ... refused funding for night

sitters (agreed with social services before) and I have been asked to either look after [parent] on my own from 2-10pm a few days a week to let the live-in get some sleep (then apparently stay up all night) or take over some waking nights 'because in the community we need the family to help'." (Story 3).

The impact of the above excerpt is the knock-on effect it can have on a carer's health and well-being in addition to them holding down a job. The difficulty carers experience trying to balance their caring responsibilities and work is clear:

"I wasn't doing my job as well as I could. I was cutting corners. I was staying up late doing [work] preparation... as a [professional], you know... it was getting very difficult." (Story 7).

This difficulty in working and balancing caring responsibilities was especially difficult if carers were self-employed, where they would subsequently have a significant loss in their annual income through loss of working hours:

"My last calculation ... was that I have lost at least £17,000 in income because I have not been able to stay at my desk ... I can't take on contracts as I can never guarantee I will be at my desk long enough to do the job." (Story 3).

Aside from the loss of income, there is also a 'human' element here for a carer not being able to work whilst caring for a loved one. Many carers will really miss having a 'life outside of caring', and being able to relate to other people in helping to 'offload' the demands on their time as carers:

"I [worked] ... for 27 years. I had a fairly busy job as a [senior professional], and I enjoyed my job ... I gave up my job two years ago to look after [my parent]. I missed it. I still miss it. I miss [my job], [the people I worked with], my office, colleagues... I thought I had something to give... but [my parent] [they had] given up a lot for me." (Story 7).

4.2.2 Parent carers

4.2.2.1 Themes

A total of 4 themes were formulated to represent issues arising from parent carers' stories. These themes and subthemes are illustrated in Table 3.

Table 3: *Themes and subthemes in parent carers stories*

Themes	Subthemes
Communication	Being greeted, included, involved and empowered Compassion Information sharing
Transition between services	Co-ordination Resources
Assessment and treatment	Assessment skills Form of treatment
Advanced planning	

4.2.2.2 Communication

Being greeted, included, involved and empowered

For many parent carers, simply being included, involved and empowered in the care of their children was essential. The way in which they were included was also important. All of these aspects are the result of the communicative processes between professionals, parent carers and those they care for. There were examples of good and poor communication across the parent carer stories. Those stories where communication was poor included the parent carer not being listened to or involved in their child's care:

"[The service] don't take your experience [seriously], they just see you as 'oh the parent'. Well, actually I am my children's expert; I live with them 24/7 and know what creates a problem ... I don't want you to try and make me feel stupid because I'm not'." (Story 12f).

"I am not addressed ... I am once more a mere bystander. I listen as my [child] readily agrees to take the medication and return as an outpatient. The medication is passed to [them] and an appointment date given. I am full of foreboding. I am [their parent], I know [them] well, and I know [they] have no intention of taking the medication. And so it proves. The appointment will be a DNA [my child took their own life]." (Story 11 – negative section).

In the excerpts above, one gets a sense of just how important it is to ensure that parent carers are included in the care and support of their children, especially in the case where the cared-for is especially vulnerable, as in story 11. As in story 12f (above), other parent carers reiterate the fact that they are the experts in their children's care and support and that they also have a need to be listened to and receive support that is specific to their needs:

“I started going to the [professional] conferences ... it kind of empowered me to say this is what I need because most of the children have this, so we need to rule things out rather than waiting for things to go wrong ... fighting up against all the professionals ... had to really up my game ... say in meetings, ‘excuse me, it’s my child that’s got some learning difficulties, not me, so you don’t need to talk to me in that [way].” (Story 12d).

It is absolutely essential that all professionals are aware of the importance of involving the support of parent carers:

“We cannot stress enough that, from our perspective and previous experience, it is absolutely vital that ALL hospital staff understand the role of the carer and work with them to develop the trust, which is required to support the more vulnerable people in society.” (Story 4).

Fortunately, there were also many examples of good communication between professionals, parent carers, and the cared-for. Some examples worth highlighting include the seemingly unremarkable facets of communication that can make a significant difference to the way in which parent carers feel they are being greeted, included and involved in the care of those they cared-for:

“We were greeted and informed that a mental health assessment would take place; we were also advised that there could be a long wait ... greeted not only by the ward staff but more importantly by the social worker who had been involved in the mental health assessment process.” (Story 11 – positive section).

The aspect of including parent carers in the care of their children extends to allowing parent carers to express their concerns in full, resulting in solution-focused, proactive care and support:

“[The professional] allowed us to explain our fears in terms of our previous experience, including the fact that my [spouse] was our [child’s] nearest relative and that the ‘power’ which lay alongside this role was of concern to me. In our presence, [the professional] spoke on the telephone to my [spouse] and assured us that this sectioning [of my child] would be different.” (Story 11 – positive section).

Maintaining contact with key professionals is a fundamental aspect of good communication and continuity of care:

“[We] had constant touch with [the service] ... the [responsible professional] was very good, very understanding and showed empathy towards us as a family as a whole, and you could see [they] really wanted to help [child] and us.” (Story 12f).

Compassion

One of the key aspects of compassionate care was in the act of professionals demonstrating empathy and providing reassurance to parent carers:

“We were advised that there could be a long wait [in assessment of our child], and assured that our [child] was safe and would not be left alone ... comforting and welcome words.” (Story 11).

“Continuity of compassion of all clinical staff to treat patients with a learning disability with dignity, as demonstrated by nursing staff.” (Story 4).

“You need staff that have got a passion who want to be able to help these people because the knock-on effect is massive.” (Story 12f).

Unfortunately, despite the above excerpts there were stories that highlighted a lack of compassion towards the cared-for and their parent carers:

“Initial assessment with a [professional] was not a particularly positive one for me, when [they] visited us at home ... I offered [them] a chair, [they] looked uncomfortable as they had to sit down in [smart clothes], when the table and chairs were festooned with [food], which [child] had been throwing about at breakfast and I hadn't had time to clean up. At the time, I felt very judged about how I was dealing with my child, and upset that someone would come into my house and show an apparent lack of empathy; [they] were after all the one person I expected to understand the challenges I was facing.” (Story 12h).

Information sharing

One final aspect of communication was in highlighting the importance of ensuring that information is shared accurately and responsibly. One parent carer alluded to the Data Protection Act when they highlighted that information regarding their child was over-shared between professionals:

“[Professionals] should know [regarding data sharing] in [their] basic training, you know data protection.” (Story 12a).

In this particular story, the parent carer was very distressed at the fact that information was shared quite freely with other professionals:

“That was the sledgehammer in my face ... I got really angry, upset turned to anger, which turned to, ‘you aren't doing this to me’.” (Story 12a).

Although the issues of over-sharing sensitive information were only mentioned in story 12a, it has relevance for all stories where information is shared between professionals and across sectors of health and social care. Professionals need to be mindful regarding the implications of sharing information:

“[Information regarding my child] went out to everybody, which is about ten people ... ‘why do all those people need to know about my [child]?’ Don't even know who they are, what their roles are, why do they need to know it? Oversharing ... what relevance does any of that information have to all of these professionals?” (Story 12a).

4.2.2.3 Transition between services

Co-ordination

Parent carers are in a unique position amongst carers, because of the fact that their children will at some point experience a significant transition from children's to adult services. This transition is usually challenging for all involved, and important lessons can be learned. A parent carer is usually faced with a plethora of administrative challenges when services change:

“There’s been a lot more I’ve needed to do, a lot more admin and a lot more co-ordinating since we’ve gone into adult services, because there’s more people to co-ordinate.” (Story 12e).

One of the challenges that this parent carer faced in this situation was in the sheer number of additional professionals that became involved in their child's care, after they made the transition into adult services. Whereas before the paediatrician was the key professional, a plethora of other professionals become responsible for their child's care and support:

“Now we’ve obviously lost the paediatrician, who controlled all that [care], everything from a health point of view, and only referred out to specialists if there was a specific issue that they wanted more expert overview on ... now we have a respiratory [professional], a gastro [professional, we’ve got [ophthalmology, urology, neurology, and orthopaedics involved] ... you get to a point where you think is this actually beneficial to us?” (Story 12e).

Although the transition between services is typically stressful for parent carers, there were instances where the transition was relatively smooth:

“Our experiences with [the service] were overwhelmingly positive and staff were hugely supportive both working directly with [my child], but also supporting me in attending transition meetings.” (Story 12h).

One of the challenges, however, in the above excerpt was when there were problems with adult services accessing the child's notes from children's services:

“Seen a number of locums and have had to repeat our story from the start each time we visited. When I questioned why the [professional] had not read [my child's] notes, which I assumed would have been passed from [children's] to adult services, I was informed that the notes do not actually belong to the child/patient but to [the service itself], and that adult services could request them, but they did not automatically get passed over.” (Story 12h).

The above excerpt highlights the fine balance that needs to be achieved in the sharing of information between services; such that there should not be an over-sharing of information, but that information critical to the provision and coordination of care should be shared where required.

Resources

Aside from information sharing, there also appeared to be challenges in adult services being able to provide person-centred care and support to the cared-for and their parent carers. This was particularly the case in story 12e, where the care provision was particularly complex, as alluded to above. One of the challenges was in the provision of equipment by adult services, that was readily available in children's services:

"We can wait anything from two weeks – I've waited seven weeks for suction tubing. It got to the point where I filed a complaint about it, and I'm hoping that things will improve, but I just couldn't function not knowing how long it was going to take for stuff to come ... we are talking infection control here ... [adult services] don't stock [equipment] ... everything you ask for is to order and then you are just beholden to whenever it arrives; whereas in children's services they stocked most of that stuff." (Story 12e).

4.2.2.4 Assessment and treatment

Assessment skills

Some parent carers highlighted that there was a distinct lack of assessment skills that some professionals had when assessing their children's needs:

"The first thing [the professional] said to [our child] was, 'do you hear noises'. [Our child] just said to [them], 'I'm not crazy' and [they] walked out. It's just bizarre – they just seem to have no sort of skills in how to speak to children; it's just ridiculous." (Story 12g).

Another parent carer highlighted the issue that although professionals might have the skills to conduct assessments of children (with learning disabilities), the inadequacy in the staff-patient ratios render this not possible:

"I know [the hospital staff] can't look after [my child], not because they are not professionally capable but because there's only one of them and they've got eight or nine patients." (Story 12c).

Form of treatment

In terms of treatment, parent carers highlighted that there was a distinct lack of behavioural support from services, and an overreliance of medication to help manage their child's behaviour:

"I attended a [psychological] conference, which focused on whether children were over-medicated for behavioural problems, and I took these ideas back to [the service] who were prepared to listen, and make adjustments according to what was perceived to be appropriate by all concerned, including myself and [child's] school. However, I do feel that there was a definite reliance on medication by all concerned and that the move to reduce that medication was only driven by my instance at the time." (Story 12h).

"[The service] sort of dish out melatonin, but they don't seem to give that much support in terms of behavioural stuff." (Story 12g).

4.2.2.5 Advanced planning

Although the issue of advanced planning featured most strongly in stories concerning learning disabilities care and support, the theme of ensuring that advanced planning takes place to enhance coordination of care and support runs central to all parent carer stories. In the case of learning disabilities care, advanced planning helps parent carers to ensure routine for their child:

“[Child’s] routines, out of necessity, are very well established to ensure that [their] anxiety and fears are reduced as much as possible, so when given a date for surgery it was necessary to make significant changes to [their] routine.” (Story 4).

In this story, there were examples of good advanced planning and support from the various acute care professionals:

“The staff working with [our child] were fantastic and worked hard to ensure [they] had both the advanced visit and the care [they] needed whilst there ... we were most grateful that a side room was provided and on our return to the ward, staff were extremely sympathetic and supportive, which was reassuring.” (Story 4).

However, there were also problems in this story which came about through a breakdown in the advanced planning arrangements, when locum members of staff had to cover the absence of key professionals who were part of the advanced plans:

“[The professional] whom we understood to be a locum, seemed to be mindful of time [pre-surgery] and [their] irritation with the situation seemed clear. This heightened the emotional state for everyone. We felt hopeless, which is a great pity, as a more collective and empathic collaboration could have influenced the situation in a much more positive way.” (Story 4).

In another story, a lack of advanced planning for a person with learning disabilities, admitted into an acute care environment was evident:

“[They were] in a side room ... the desk’s out there and [the staff are] up the other bay ... they can’t even hear [our child – if they needed help] ... [the ward] is just a barn full of people who’ve been discharged from A&E to get them out of A&E ... [child] in there with people with all sorts of problems.” (Story 12c).

4.2.3 Young carers under 25 years

4.2.3.1 Themes

A total of 4 themes were formulated to represent issues arising from young carers' stories. These themes and subthemes are illustrated in Table 4

Table 4: *Themes and subthemes in young carers stories*

Themes	Subthemes
Accessing support Awareness of young carers Young carer identity	
Young carers support	Academic support Practical caring support

4.2.3.2 Accessing support

In the forums held for young carers (stories 6 and 13), and young people concerning young carers (story 8), accessing support was a key issue. Because young carers are usually in the unique position where they are also in the education system, having access to key teaching staff and awareness of what services there are available to support them was a crucial part of their support. One carer states that it is not always easy:

"[It is] difficult to get a teacher by yourself." (Story 6).

The importance of this cannot be understated because the type of support a young carer might require; both academic and also pastoral. When young carers were able to access specific teachers, this was usually based on whether they could place their trust in the teacher and whether the teacher was prepared to listen and understand their situation:

"Some young people had a teacher they could go to, and this tended to be one they could trust." (Story 6).

"One young person said one of their teachers was very understanding, and they felt able to tell [them] if extra time was needed because they are a young carer." (Story 6).

In one of the young carers forums (story 6), they were asked if they knew about the school nursing service, to which very few were aware of this.

4.2.3.3 Awareness of young carers

It was clear that professionals need to be far more aware of young carers and the important role they undertake in the care of a family member. When presented with a scenario where a young carer (15-year-old) cares for their parent who was due a care assessment, young carers stated that:

“None of [them] had been involved in care assessments for the person they care for, but did want to be involved, and wanted the same amount of respect that an adult carer would have. Being given support and understanding was also cited. ‘There is a lot we don’t know about, and should’.” (Story 6).

In story 8, young people were asked regarding what might promote awareness of young carers and the support they might require. They considered the usefulness in having:

“Mentoring programmes for sixth formers.” (Story 8).

One of the challenges for young carers was in being identified by others who could offer them help and support. A staff member in the young carers forum (story 6) highlighted:

“An initiative had been put in place for GPs to put on the young person’s notes that they were a young carer, but wasn’t sure to what extent this had been implemented.” (Story 8).

Indeed, findings from story 6 indicated, *“there needs to be more awareness of young carers”* and a variety of methods were considered in story 8 that might help promote awareness. Some included:

“Young carers day/week – schools encouraged to promote young carers. Target younger children in year 5 and 6, before they go to secondary school and potentially meet young carers.”

“Send letters to young people along with free school meals letters about young carers: ‘are you eligible for help and support?’”

“Schools should be made aware of who their young carers are? If young people don’t get help and support from school, they are not going to do well at school!”

“Might not know what they do is ‘caring’ – it might seem normal to them. Like to hide it. Don’t want people to know that they haven’t got a life other than caring.”

“Young carers are people with responsibilities that are not typically expected of young people. The responsibilities can vary including house work and administrating medication.”

4.2.3.4 Young carer identity

The above excerpts are clear: young carers need to be identified in a sensitive and compassionate way. Of the excerpts above, the last two are most interesting; concerning the notion of the young carer identity. It seems that the young carer might simply see what they are doing: supporting another person, as entirely normal warranting no special status. However, of concern here is the notion that young carers might like to *“hide”* (story 8) from others what they are doing, especially if they perceive that *“they haven’t got a life other than caring”* (story 8). This is also depicted in the following:

“[There] is a split between whether it is a choice to identify yourself as a young carer or if it is your responsibility to tell someone (older carers voiced it is the young carer’s responsibility more).” Story 6.

Some young carers stated that they were “fearful” of being seen as a ‘young carer’, and that “people treat you differently” for being a young carer. Clearly, these issues are bound to have an effect on whether a young person identifies themselves as a carer, and subsequently the extent to which they decide to seek and receive help and support.

4.2.3.5 *Young carers support*

Academic support

Because of their unique position, young carers require not only help and support with their caring role, but also with academia. Young carers stated that it was helpful for them if their school/college acknowledged their caring responsibilities and provided additional academic support if required. This was in a multitude of forms, namely:

“[Due to] study periods [with] one young person stating it was easier to study at college compared to school.” (Story 6).

The issue here appears to be in young carers having *flexibility* in balancing the demands on their time with caring for another person and meeting their academic needs. Consequently, at school young carers/young people considered:

“More revision time at school would be useful” (story 6), as would having, *“schools setting aside time for everyone to do homework in the school day”* (story 8).

In addition to having flexibility during the academic working day, young carers commented on their experience of school pastoral care:

“Experience of pastoral care within school for young carers was mixed – several felt [that] knowledge was lacking.” (Story 6).

This perhaps highlights that schools need to support their academic staff more to provide the support that young carers require; to be able to achieve a careful balance between meeting their responsibilities of caring and also their academic work. Aside from this, one issue that young people considered young carers might miss is the extra-curricular activities, that can enrich their learning experiences:

“Young carers miss out on experiences like school trips, skills you learn, social skills...” (Story 8).

Practical caring support

The sort of practical caring support young carers would face depended on the sort of care they needed to provide for those they were caring for. Young people considered that young carers would require:

“[A] helpline for questions and queries; emergency help; and emotional support.” (Story 8).

Young people also considered that part of the emotional support young carers would require would include:

“[Having] time off [caring] and free time with friends and others with the same experiences.” (Story 8).

Young carers alluded to the need for practical caring support needing to be centred to their specific needs, such that too much care and support would be excessive. It is not clear whether *too much* caring and support would in some way be threatening or reinforce the identity of a young carer, that some young carers were fearful of, but it was clear that some practical support was important:

“A bit of compassion [is needed] but not overboard – one young person had been to counselling and although they didn’t want to talk, [they were] pressed to [do so]. On this occasion they wanted to keep things to themselves and not bring [anything] up that made them upset. [There needs to be] understanding, but support if we need it. It takes your voice away, and can be a bit too much being asked, ‘are you okay?’ all the time.” (Story 6).

Clearly, any professional offering help and support to young carers need to be especially mindful of how their intervention might be perceived by the young carer. Other young carers highlighted more practical types of support that would be required, depending on the caring situation. These usually pertained to receiving training to meet their caring responsibilities safely, and working with medication:

“A young person watching a parent prepare medication for the cared-for person in order to learn, but the parent would rather they didn’t [observe this].” (Story 6).

“Having to research about different medications themselves because no information was provided. One young carer’s [parent] takes 26 types of medications a day, but no one had ever explained what they do or discussed it with them, as the young adult carer. Not understanding the side effects of medication, such as one young person stated their parent would twitch, and this was a side effect of their medication which the young person did not realise.” (Story 6).

Considering the above excerpt, if professionals had provided information and support for the young carer in relation to medication administration and looking out for side effects, this would have better-prepared the young carer to understand any side effects, and to alert professionals if this were any cause for concern. Professionals supporting young carers need to be mindful that young carers might require training and skills in administering medication to those they care for, and also with regards to ensuring that medications are stored safely:

“Consideration for, and space for medication to be stored safely as this added an additional risk for families with younger siblings.” (Story 6).

4.2.4 Forensic carers (story 5)

Because only one forensic carer story was received for qualitative analysis, it is not possible to compare the experience of this forensic carer, against other forensic carers. However, there are most definitely learning points that can be implemented as a result of the experiences this forensic carer reported. The recommendations that this forensic carer states have been chosen to represent the subthemes of their story. Before illustrating the themes of this story, it is worth illustrating the context first to understand the lack of support afforded to both them and their child.

4.2.4.1 Context

The stress that the forensic carer reported was multifaceted:

“[My child] began to appear stressed when [they] started working full-time ... apparent inward anger became directed at me ... mood swings and outbursts because more physical, with doors punched at regular intervals ... grabbed me one day, pushing me down on my bed ... I was very frightened, especially when [they] pressed a cushion over my face for a minute or two ... reported this assault to the police ... noted as attempted murder, but I refused to press any legal charges, believing [my child] needed medical help of some kind.” (Story 5).

It is important to note from the excerpt above, the wider context of this carer’s child’s violence; indeed the broader context of any carer story is important to acknowledge, but difficult to address fully in a report that summarises the main findings from all stories.

“My [child] was diagnosed with Asperger syndrome and psychosis [and after being sectioned and taken to hospital then] discharged back into my care, [there was] no medication, no advice to us, and no support for me ... [child] moved into a social housing flat and gradually refused to accept any contact from me or the support worker. I used to sit in my car gazing at [their] flat and wondering how [they were]?” (Story 5: Forensic carers).

This story exemplifies the subsequent stress a carer can face when there is little advice and support offered to them when the person they care for is transferred between health and social care services. One of the main action points this forensic carer raised was that, *“authorities [need] to better commission specific forensic services (and not liaison forensic services)”*. The commissioning of specialised services would need to account for the unique situation forensic carers find themselves in.

4.2.4.2 Listen to forensic carers

As illustrated above, this forensic carer faced a heart-breaking situation: being assaulted by their child with severe mental health problems and having to report this to the police, but then refusing to press legal charges, believing that their child needed medical help of some kind:

"I had visited a doctor to document my bruising where my [child] had gripped my arms, and also the police. Both had referred me back to the other, so I knew I had to try a different approach."

It seems that there needs to be specialised services in place to be able to assist forensic carers and have the listening skills to be able to address the complex situations they face. It was only through this carer contacting...

"...a member of the police domestic violence team ... and eventually 3 doctors [attended home] diagnosing my [child] with Asperger syndrome and psychosis ... sectioning [them] and admitting to hospital."

However, when this carer's child was discharged from hospital there was:

"No medication, no advice to us, and no support for me [as their carer]."

4.2.4.3 Better training for mental health staff around autism as well as common conditions and psychosis

"[Being] put on a police domestic violence list and two policemen calling round every week to check on me, helped keep me safe during a time [after my child assaulted me a second time, but] my child's mental health [professional] seemed unable to understand autism, psychosis, or even mental health problems!"

One would assume and expect that a mental health professional would be able to understand the complexities of the situation a forensic carer would face. It seems that if there was not only better understanding, but better communication between the mental health professional and the forensic carer, this would have gone some way to providing better carer support.

4.2.4.4 Easily available help, support and information to deal with, and get the best outcome from, the Criminal Justice System (CJS)

"Dealing with solicitors, probation officers, barristers and courts brought its own stresses, on top of juggling work and taking my [child] to appointments ... working through the CJS ... none of the professionals involved knew anything about autism or how an autistic person's reactions [would change]."

How a forensic carer (or other carer having to liaise with the CJS) could obtain easily available help and support seems an area that health and social care needs to explore further. This carer's recommendation that, "*authorities [need] to better commission specific forensic services (and not liaison forensic services)*" could potentially go a long way in ensuring that forensic carers receive the support that is appropriate to their needs. It seems that no one professional was initially able to help this forensic carer manage the situation, having been referred by the doctor to the police, and from the police to the doctor.

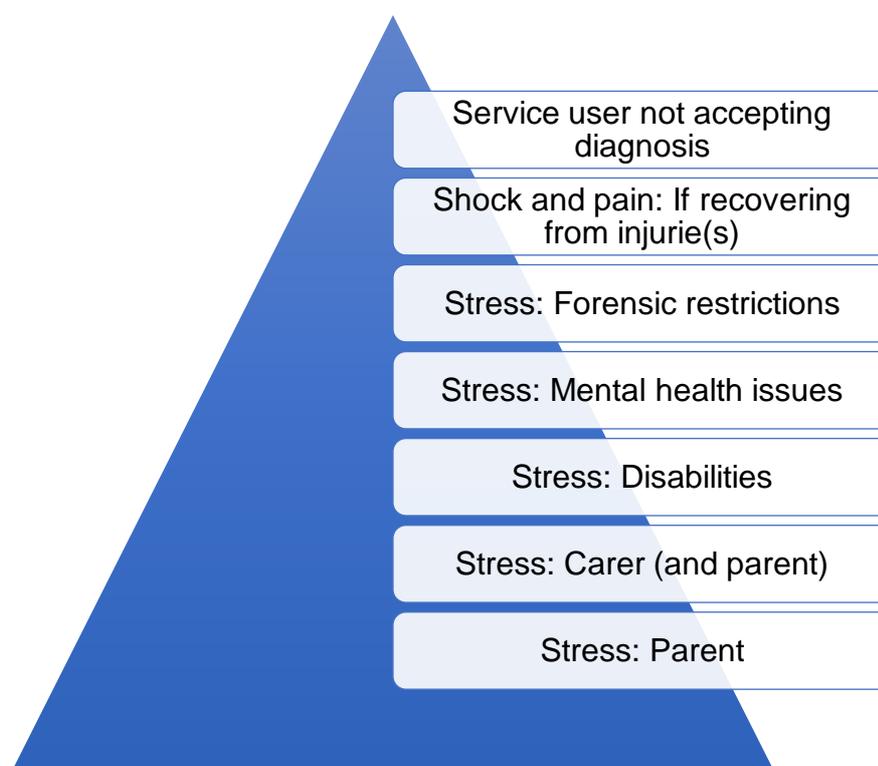
4.2.4.5 Carers to be asked on how well their concerns were addressed

One would assume this recommendation, simply, to be good professional practice expected of any professional. However, it appears the case within this forensic carer's story that numerous opportunities to ask how they were coping were missed. The issue that their child was, "*discharged back to [their] care, with no medication, no advice, and no support for [them]*" is definitely an issue that needs to be avoided.

4.2.4.6 Stresses borne by forensic carers

The forensic carer provided a variety of additional materials along with their story to help contextualise the specific challenges they faced. A key material is summarised in Figure 5 below.

Figure 5: *Stresses borne by forensic carers*



In conclusion, the forensic carer highlighted some key differences between the challenges they face in comparison to other carers, which are highlighted below:

- Forensic carers must undergo sniffer dogs and security checks, and provide assurances that they are not bringing any banned items or drugs to visits [of the person they are caring for]. Furthermore, they must be photographed for identification purposes, lock personal items away, and are unable to take photographs of their loved one on-site or be alone with them on a supervised visit.
- Forensic carers also have no real support because agencies are not set-up to understand their complex needs.
- Forensic carers also need to undergo face-to-face interviews to reassure and obtain even non-personal information of their situations. Many details remain

confidential and relate to the service user who cannot always provide permission, but many forensic carers are living incognito and do not want to be photographed or filmed showing their face, for the fear of recognition and retribution.

- Forensic carers are 'hidden in full view' as they seek to pass-off their situations in general vague terms to others they meet and mix with; such that it is a constant strain.

5 Further Considerations and Summary

The aim of this service evaluation was to hear the carers' voice and improve their health and well-being, by obtaining stories from carers across Shropshire, and Telford and Wrekin as a joint venture. Of the 21 stories that were submitted by carers in the areas of dementia care, parent carers, young carers and forensic carers, it is clear that professionals were able to offer a good level of support to carers and those they cared-for. However, there is also much more progress to be made in understanding the complexities specific to each of these working areas (especially young carers and forensic carers) and the sort of care and support carers require to provide effective and responsive care to their loved ones.

Referring to the issue of challenging the clinical paradigm of, 'what is the matter?' to, 'what matters to you?' (NHS England, 2016), our findings have demonstrated that the carer's voice can be immensely powerful in contextualising the challenges they face, and proposing new ways of working. Our first service evaluation report, which focused on developing a multi-agency, multi-disciplinary action-learning programme that was based on story-telling, highlighted that there were challenges in terms of integrating carer support services, and that much more consistency was required between services to enhance carer support. Our findings from this service evaluation (developing the Carers' Voice Network) supports these challenges and indicates that carers are subject to a significant level of stress and heartache when the services they depend on do not adequately support them, either due to a lack of integration, or reactive rather than proactive care.

In our first report, we found that for integration of services to be successful there needed to be much better consistency between services, and that communication processes between professionals within and between services needed to be monitored and improved where necessary. Our findings herein support this notion. It was clear in early-onset dementia care, for example, that referral to specialised services is absolutely essential to ensure adequate care and support for the patient and their family carers. This was not always the case and led to carers having to effectively *demand* specialised care and support, which could subsequently increase their stress levels and add to their frustration with the system if their needs were not met. This was not just the case with dementia care, but also with parent carers, who were considered to be *experts* in the care of their children, and would typically attend professional conferences to receive specialised information and develop knowledge of how to better care-for and support their child. A key finding here was that parent carers felt that there was an overt focus on the physiological treatment of their child's condition, rather than focusing on the psychological/behavioural interventions that would have likely benefited their child.

Receiving prompt assessment and specific advice from professionals was essential across all stories. In the case of dementia care, it was vital for carers to have a prompt referral to specialised services, such as the Memory Service, who were able to offer specific information to the carer and their loved ones. The way in which information was provided or communicated was also evident across all stories, and especially so for parent carers. Parent carers highlighted that being greeted and included in their child's assessment and treatment was a significant source of support and helped them feel valued and empowered. It was also essential for

professionals to demonstrate compassion towards their situation and ensure that information was shared sensitively.

One of the challenges carers reported was ensuring that those they cared-for received the right assessment and support in the way services were co-ordinated and funded. For carers' stories in dementia care, it was clear that the lack of social care funding available to them, especially if they were assessed as being over the threshold of £23,500, was a significant source of stress and frustration. There were stories where the carer was left to *beg* for help and support from professionals and forced to admit that they were *unable to cope* with providing care and support for their loved one to have help provided. It seems that this should not have to happen and that services should be more person-centred and focus more on the needs of carers and the those they care-for.

For parent carers, one of the main challenges was in maintaining consistency of care for those they cared-for when there were significant transitions in services. For example, the transition between children's and adult services was reported to be a highly stressful time, where the carer and those they cared-for were left without person-centred support. When those they cared-for accessed children's services, it appeared that there was specialised support readily available and that equipment, for example, was also available to meet care needs. The transition to adult services brought about changes of professionals who seemingly did not communicate effectively or readily with children's services, and this resulted in care being fragmented and inconsistent. To compound matters further, this fragmented and inconsistent care was especially problematic for those that were cared-for; who, due to their condition (often learning disabilities, autism, etc.) required joined-up and consistent care and support.

Being able to access care and support, and for professionals to adequately identify when a person is a carer, was also a key theme across stories. The narratives submitted pertaining to young carers under 25 years highlighted both of these issues. Young carers stated clearly that it can be challenging to obtain the support they require, partly because of the challenges of informing others of what a young carer does, and also because young carers themselves are sometimes reluctant to acknowledge their caring role to others who might be perceived to judge them unfairly or inaccurately. Professionals, whether they be academic (in the case of young carers specifically) or health and social care, have a collective responsibility to ensure that they are aware of when a person might become a carer, and to offer person-centred care and support to meet their needs and the needs of those they care-for. For young carers, it was especially the case that there was a, "*split between whether it is a choice to identify yourself as a young carer or if it is your responsibility to tell someone*" (story 6). Some carers (especially young carers) might feel uneasy disclosing to others (professionals and family alike) that they are a carer of another person. This can have negative consequences, potentially not only the person they are caring-for, but also their own health and well-being. This is further compounded by the sheer demands carers experience on their time, and often the need for them to achieve a delicate balance between meeting the needs of those they care-for and sustaining a job, household, and sense of health and well-being.

The case of the forensic carer story is highly unique in respect of needing to access *specialised* care and support. The sheer magnitude of the challenges forensic carers face, because of the fact they must negotiate not only the health and social care system, but also that of the Criminal Justice System (CJS), warrants the need for highly-specialised intervention by dedicated and experienced professionals in forensic care, and not liaison forensic services. The challenges forensic carers face run parallel to other carers in respect of needing to access easily-available help and support, and crucially to be listened to when concerns are raised. However, forensic carers require professionals to clearly understand the considerable stress they incur through the challenges of being a parent to their child with either a profound learning disability or serious mental health condition. These challenges are then exacerbated when there are incidences of physical violence towards the forensic carer, which are typically due to the failure of the system to adequately support forensic carers from an early stage where they might highlight their plight. Unfortunately, when physical violence is displayed towards them, forensic carers are then having to negotiate working with the CJS, which further adds to stress of the forensic restrictions imposed on those they care for, resulting in psychological distress for the forensic carer, and dealing with injuries incurred through physical violence.

Collectively the stories highlight a multitude of findings across many themes, some of which are common to each story, such as carer stress, and others which are unique to the context of the story, as illustrated above. What appears of much importance in these findings, refers back to our recommendations of our first qualitative report, specifically that:

- Carers are highly resilient individuals and would go to great lengths to ensure that those they care-for receive the best possible care and support. However, carers themselves are not infallible and require professionals and services to be responsible, proactive, compassionate and caring, to help carers feel cared-for themselves, supported, and avoid stress and burnout.
- Carers need to be included, involved, and empowered in the care and support of those they cared-for, and be able to influence decision-making. This is especially the case for critical times in care and support, such as when funding decisions are made and during transitions of care between services.
- Carers need to be supported in identifying as carers (if appropriate to their needs), which might open-up possibilities of extra care and support. Additionally, the identification of the carer role and subsequent support might contribute to enhancing a carer's sense of identity and psychosocial support, which supports their health, well-being, and quality of life.

5.1 Limitations

Although the focus of this qualitative service evaluation has been very much about the depth of investigation for each unique carer story, caution should be applied if trying to generalise the findings of these stories across the broader health and social care economy. Due to the complexity of each carer story, and the multitude of unique qualitative *codes* ascribed to pertinent sections of transcript, it cannot be possible in a report of this kind to report on absolutely every idiosyncrasy. Consequently, although every effort has been made to capture the *essence* of each story and link this with other similar stories, and with all stories across the dataset,

finer details might have been omitted which need to be interpreted in the context of each story specifically.

The pragmatic issue of focusing on four working groups, on dementia care, parent carers, young carers and forensic carers, means that our findings might not be transferable to other specialised groups of carers that we have not been able to capture. It is also the case that the disparity between the *number* of stories submitted in each working group might be problematic when interpreting the findings across the broader health and social care economy. Specifically, the only story focusing on forensic carers, whilst illustrating issues that many forensic carers will face, is also highly personal to the forensic carer in question and findings need to be interpreted with this in mind (refer to section 4.2.4.6 – Figure 5). This highlights that much more work and research is required that focuses on forensic carers specifically and the unique challenges they incur.

Despite these limitations, we believe that our analyses and findings are robust and capture the essence of the complexities carers reported in their stories.

5.2 Recommendations

The following recommendations have been considered in relation to not only the findings analysed and presented herein, but also after careful consultation with the Carers' Voice Network and key stakeholders. These recommendations have been categorised according to the categories:

- Awareness of carers.
- Ensuring carer support:
 - Communication and ways of working with carers and those they care for.
 - Improved listening and observation to better support carers and those they care-for.
- Integration of services.
- Professional practice and development.

Awareness of carers

- Professionals need to be far more aware of (unpaid) carers and the role they undertake in maintaining the health and well-being of those they care for.
- Although it is not always easy for a professional to be aware of when a person under their care becomes a carer, a professional needs to be aware of the person's broader circumstances that might provide clues as to their role. For example, a carer might present with stress and exhaustion during a routine GP consultation, which should make the GP stop and think about what might be causing these signs and symptoms.
- Professionals need to receive training that is relevant and person-centred to adequately assess whether a person is a carer and to initiate support or referral to specialised professionals.
- Sufficient opportunities should be generated for carers to raise concerns that should be noted and addressed. This might happen during the stage where a carer has just been identified, or it might be during the on-going provision of carer and support for the carer and those they care for.

- Generating awareness of carers depends on making sure that there is clear and accessible information in prominent locations, such as GP surgeries and healthcare centres, libraries, community cafés etc., regarding what unpaid carers do. For example, it might be the case that a carer is visiting their GP, and whilst waiting for their consultation they see a poster in the practice that highlights what a carer does and where they can find help and support.
- There needs to be improvement in the public perception about what caring really means. This is particularly the case for young carers, who are often in a challenging situation in trying to reconcile their carer identity with that of being a young person.
- Adequate resource needs to be identified for meeting with forensic carers to gain further information and insights from their unique situations.

Carer support

Communication and ways of working with carers and those they care for

- One of the key findings from our work concerns the level of stress carers are under. This stress is often persistent, 24 hours a day and 7 days a week, and tends to consume carers' health and well-being. Professionals need to be more aware of this and offer psychological support for carers where it is required.
- Professionals need to treat carers as equal partners, and experts by experience, in the care and support of those they care for.
- We know that when carers are included and involved in the discussions around care and support of those they care-for in partnership with professionals, this leads to better outcomes for all concerned. Through inclusion of the carer, the stress and anxieties experienced by the carer can be relieved significantly. It is the responsibility of all professionals to ensure that carers are empowered and become an integral part of the care and support being discussed, whilst ensuring that they are offered and receive care and support themselves.
- Professionals should provide carers with clear information, particularly regarding the technical elements of the carer and support of those they care-for. For example, young carers should be informed regarding medicines management and should be afforded opportunities to raise concerns.
- Professionals need to be aware that the technical information they have is powerful, and if it is not used sensitively when working with carers, a power imbalance might be generated.
- Professionals should not forget the importance of ensuring that communication is embedded in principles of compassionate and dignified care.

Improved listening and observation to better support carers and those they care for

- In the case of young carers, it is important for staff working with young people, for example, school teachers, school nurses, etc., to be aware of how young carers may feel when interacting with professionals.
- Education professionals need to have awareness of when a young person would require reasonable adjustments to be made to their learning needs and education timetable, to enable them to meet their caring responsibilities.
- Professionals should actively and purposefully listen to carers, using sensitive questioning and engagement to make the carer feel valued and supported.

- Professionals need to be aware of both the national and local contexts of carer support.

Integration of services

- Services need to be far more proactive in reaching out to and supporting carers.
- Carers should be involved in the commissioning of services where indicated, thus supporting the carers' voice and ensuring that future planning is implemented appropriately. This recommendation reaffirms the need to ensure co-production between professionals, service users and carers is a founding principle of integrating services.
- There especially needs to be better integration between children's and adult services, to ensure consistency in the care and support offered to parent carers (for example), and those they care-for.

Professional practice and development

- It is important for professionals to recognise the benefits of listening to and sharing carers' stories and best practice.
- Sharing evidence across organisations and geographical areas.
- Ensuring the development of services is the result of co-produced work.
- As many carers first contact with a professional will be their GP, it is important for the GP to be aware regarding Carer's Assessment, and be able to initiate a referral to other key professionals who can offer these if required.
- Professionals should have the opportunity to participate in continuing professional development modules (or during professional training) to develop their knowledge of the emotional impact on carers for unpaid caring. Out of this, training should focus on the sort of practical advice and support carers might need to maintain their health and well-being.
- Through integration of services, provide a central point of contact for carers, to act as advocates, sign-posting to appropriate support services within a timely manner prior to any immediate need that materialises as the healthcare needs of the person cared-for progresses through their health and social care journey.

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7 Appendix 1

7.1 Co-production matrix

The Challenge of Production (2010) as cited in Social Innovation Exchange (2014)

		Responsible for design of service		
		Professionals as sole service planner	Professionals and users/communities as co-planners	No professional input into service planning
Responsible for delivery of service	Professionals as sole service deliverers	Traditional professional service provision	Professional service provision but users/communities involved in planning and design	Professionals as sole service deliverers
	Professionals and users/communities as co-deliverers	Users co-deliver professionally designed services	Full co-production	User/community deliver services with little professional input
	Users/communities as sole deliverers	User/community deliver professionally planned services	User/community deliver co-planned or co-designed services	Self-organised community provision

Source: The Challenge of Co-Production, 2010