

**Carers Chapter  
Cumbria Joint Strategic Needs  
Assessment (JSNA)**

*June 2016*

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## 1 Introduction

The Health and Wellbeing Board requested an assessment of carers in Cumbria, in order to consider current needs and current provision, and future needs and demand.

Throughout this chapter when we refer to a 'carer' we refer to unpaid carers, unless otherwise stated. As set out in the Care Act 2014, an adult carer is someone who helps another person, usually a relative or friend, in their day-to-day life (Source: Care Act 2014, Factsheet 8). A young carer is a child or young person under the age of 18 who takes on a level of practical and emotional caring responsibilities that would generally be expected of an adult (Source: Carers Organisations: <https://www.carers.org/what-young-carer>) Further details of the definition and description of an adult carer can be found in section [4.1](#); young carers can be found in section [5.5](#).

## 2 Key issues and gaps

- Cumbria's population is 'super-ageing' and is ageing faster than the rest of England; numbers of people aged 65+ years are projected to increase while numbers of the working age population (16-64 years) are projected to fall.
- Numbers of people with long-term health conditions and dementia are projected to increase; people with cancer are living for longer, creating a greater demand and need for carers in the future – it is important to ensure that the right level of support is available to meet the increasing need.
- 1 in 5 people in Cumbria have a limiting long-term illness or disability while almost 1 in 3 carers in have a long-term health problem or disability themselves.
- Areas with high levels of deprivation have poorer health, however, it is likely that the provision of care is under reported in these areas.
- The number of carers is thought to be significantly underestimated; despite existing services and support networks already in place many carers remain hidden. Male carers are less likely to be identified as they may not be accessing help or support.
- All health and social care organisations have a key role in helping to identify carers' and ensuring help and support services are accessible.
- There is a gap in the Adult Social Care reporting systems within Cumbria County Council; limited information about carers is known as information and service provision is often recorded against the person being cared for rather than the carer.
- Historically, there has been low numbers of individual Carers Assessments and high numbers of Joint Assessments within Cumbria County Council; Joint Assessments do not always pick up the needs of the carer and therefore individual Carer Assessments should be carried out.

- More than half of Cumbria's population are living in a rural area therefore services need to be delivered in a way which ensures help and support is accessible, for example digital solutions where possible and community support
- There is no Children & Young People with caring responsibilities lead within Cumbria County Council, therefore there is a risk that referrals for appropriate support and intervention from the information provided by Carers Support Cumbria is not being acted upon.
- Numbers of referrals from Adult Social Care practitioners are reducing; and there are concerns from organisations that assessments are not always offered to the carer. In addition to this, there is no referral system set up with housing organisations. There are concerns from organisations that assessments are not always offered to the carer by the social care worker.
- Quality of life is important to carers. The highest level of need amongst carers is around being able to participate in activities outside of caring that they value and enjoy, and having control over their daily lives. Respite care, even if only for a few hours to provide a break, can help to facilitate this and is considered important by carers.
- There are barriers to services in terms of information and procedures – it is felt they are over complicated. Carers have concerns about the number of agencies and organisations involved, and the feeling of being passed around between different organisations.
- There are gaps in relation to support services provided to parent carers – greater communication between professionals and parents is needed; and a more joined up approach. Evidence gathered suggests that there is a gap in the support provided for 16-18 year olds and in particular poor quality of transition into adult services. Some parent carers feel that there is a lack of support from schools, and teachers do not always understand how to deal with situations; some also feel that there is a lack of crisis support and bereavement support for families.
- Further clarification is required in terms of parent carer assessments – the role of Carers Support Cumbria needs to be defined.

### **3 Recommendations for consideration by commissioners**

This chapter identifies many factors which will affect not only the health and wellbeing outcomes of carers in Cumbria, but the future demand and need.

It is recommended that commissioners fully investigate the evidence base and consider all factors identified within this chapter together when developing services.

## 4 What is the population overview?

### 4.1 Who is a carer?

The term of “carer” can be applied to anyone who provides unpaid care to help another person in their day-to-day life (Source: Care Act 2014, Factsheet 8). The person requiring care could be a friend or family member and is someone who is unable to cope without some level of support. Care may be required for reasons that could include illness, disability, a mental health problem or an addiction. A young carer is a child or young person under the age of 18 who takes on a level of practical and emotional caring responsibilities that would generally be expected of an adult. (Source: Carers Organisations: <https://www.carers.org/what-young-carer>). It is worth noting that the definition of a carer does not apply to parents or guardians whom are carrying out general parental responsibilities, however, it does apply if the child they are responsible for has one of the care reasons mentioned above. Further details about young carers can be found in Section 5.4.

Carers come from a wide variety of backgrounds, cultures and age groups. Support provided by carers can cover practical tasks such as cooking, housework and shopping, physical care, personal care, and administering medication (Source: What is a Carer? Carers Trust, 2012). Time spent caring for a friend, relative or partner can range from a few hours each week to care around the clock. Carers may provide care in their own home, or may have to travel long distances (Source: Facts about carers, Carers UK, 2014).

**Figure 1: Provision of unpaid care, county and district**

	Provides unpaid care		Provides 1 to 19 hours unpaid care a week		Provides 20 to 49 hours unpaid care a week		Provides 50 or more hours unpaid care a week	
	All ages	% of total population	All ages	% of all carers	All ages	% of all carers	All ages	% of all carers
Cumbria	56,495	11.3	35,927	63.6	7,265	12.9	13,303	23.5
Allerdale	10,774	11.2	6,632	61.6	1,436	13.3	2,706	25.1
Barrow-in-Furness	8,245	11.9	4,573	55.5	1,308	15.9	2,364	28.7
Carlisle	11,305	10.5	7,233	64.0	1,418	12.5	2,654	23.5
Copeland	7,981	11.3	4,695	58.8	1,179	14.8	2,107	26.4
Eden	5,962	11.3	4,208	70.6	620	10.4	1,134	19.0
South Lakeland	12,228	11.8	8,586	70.2	1,304	10.7	2,338	19.1
England	5,430,016	10.2	3,452,636	63.6	721,143	13.3	1,256,237	23.1

(Source: Census 2011)

There are approximately 5.4 million unpaid carers in England, accounting for 10.2% of the total population. One in three carers are aged 50-64years, while more than half of all carers are female and more than half are aged 50+. There are more than 100,000 carers aged 0-15 years and more than 300,000 aged 16-24 years. Many carers across England are working as well as caring for someone with 2 out of 3 carers (aged 16+) in employment; while 1 in 5 carers are retired. Many carers themselves have their own health issues with almost one third of carers reporting that their own activities are limited due to a long-term health problem or disability. Most carers provide between at least 1-19 hours of unpaid care

per week; while almost one in four provide 50 or more hours. Despite these reported numbers it is recognised that many carers will not be identified and will not be known, with that in mind it is likely that numbers of carers are much greater than those reported.

Communities are a key asset in Cumbria with more than 56,000 residents across the county providing unpaid care to either family members, friends, neighbours or others because of either a long-term physical or mental ill-health / disability or problems relating to old age. It is important to note that this number is drawn from the 2011 Census and reflects adult carers only; the estimated number of young carers is around 7,700 (Source: Carers Support Cumbria, 2014) giving an estimated total of 63,700. There are greater proportions of carers in Cumbria compared to the rest of England (11.3% compared to 10.2%). The greatest proportion of people providing care in Cumbria are living in the district of Barrow-in-Furness (11.9%), likely reflecting the needs of the population - high proportions of residents with a limiting long-term illness or disability; and high levels of health related benefit claimants. 60% of carers in Cumbria are aged 50+, in South Lakeland this increases to 70% reflecting the older age profile of the district (Provision of unpaid care, Source: Census, 2011).

More than half of carers (around 58%) in Cumbria are female, reflecting the national picture. And 1 in 3 carers in Cumbria are aged between 50-64 years. The general age profile of carers in the county compared to the rest of England is older with greater proportions of those aged 50+ and fewer proportions of younger carers, reflecting the older age profile of Cumbria.

Most carers in Cumbria (around 64%) provide on average 1 to 19 hours of care per week; yet 1 in 4 carers (around 23.5%) provide 50 or more hours. Numbers of those providing unpaid care are increasing, particularly in the districts of Carlisle and Eden, which may have implications on services provided by local authorities and partners in terms of support needed by both the carer and the person(s) they are caring for. Cumbria's population is ageing and at a faster rate than England, and people are living for longer both of which may have a significant impact on the numbers of people providing care in the future.

It is important to note that carers have health issues also, with 28% of carers in Cumbria reporting that their own activities are limited due to long-term health problem or disability. Direct support from Adult Social Care is provided to carers ranging from physical support to mental health; throughout 2014-15, more than 3,500 carers received support (where evidence is available).

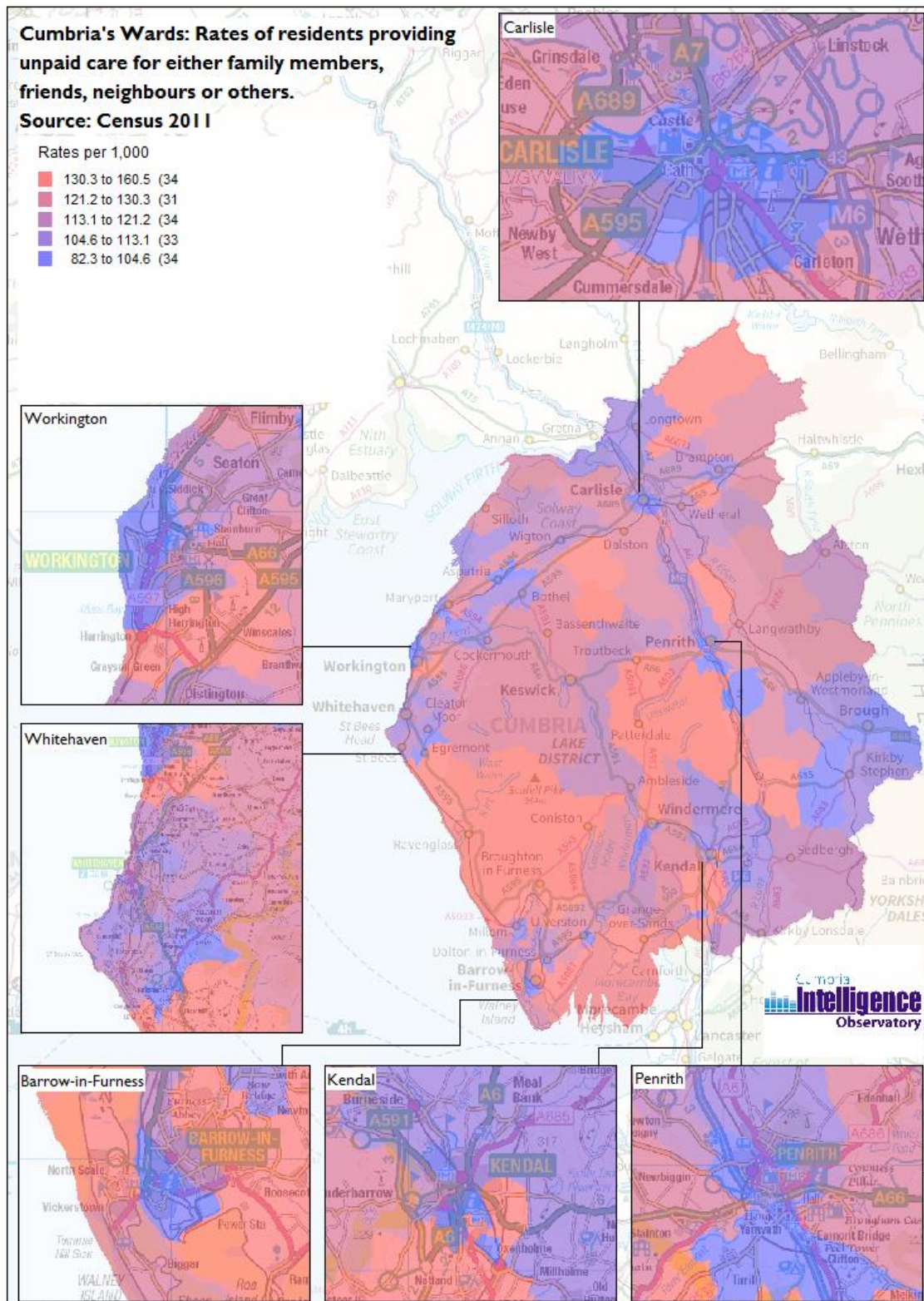
Areas where there are high levels of unpaid carers tend to be areas where there are greater numbers of older residents, as shown in Figure 2 below – the map presents rates of residents (by ward) who provide unpaid care to either family members, friends, neighbours or others, drawn from the 2011 census; higher rates are shown in pink/red, lower rates are shown in blue.

It is important to note that areas with high levels of unpaid care provision have relatively low levels of deprivation, despite deprivation being significantly linked to poor health and wellbeing. Although areas with high levels of deprivation are areas with poorer health, in relation to the provision of care then there is a greater correlation with demographics and older residents rather than deprivation.

The wards across Cumbria with the greatest rates of unpaid care are: South Lakeland: Low Furness, Ulverston West, Grange South, Arnside & Beetham, Levens and Broughton; Barrow-in-Furness: Hawcoat; Copeland: Bootle; Carlisle: Lyne; and in Eden: Orton with Tebay.



Figure 2: Rates of residents in Cumbria providing unpaid care, by ward



## 4.2 Policy context



Government policy aims to support carers to be able to care effectively for friends and relatives, whilst at the same time ensuring their own needs are met (Source: Carers strategy: Second National Action Plan 2014-2016, Department of Health, 2015). Carers are protected under the Equality Act 2010 from direct discrimination or harassment that may arise as a result of their caring responsibilities (Source: Equality Act 2010, Chapter 15).

Through the Care Act 2014 carers are, for the first time, recognised in law in the same way as those they care for. Local authorities have an obligation to assess the support needs of carers in their area where the carer appears to have such needs. Prior to the Care Act 2014, carers had to be providing a substantial amount of care on a regular basis to qualify for an assessment. The Act relates mainly to adult carers, those aged over 18 years who are caring for another adult (Source: Care Act 2014 Factsheet 8: Carers, Department of Health).

Young carers, those aged under 18 years, are assessed and supported under children's law. The Children and Families Act 2014 gives young carers (and parent carers) similar rights to assessment as adult carers have under the Care Act 2014. The Act states that local authorities in England must assess the support needs of young carers in their area as soon as they know they might need help, or if a young carer requests a needs assessment. Prior to the Children and Families Act 2014, needs assessments were carried out only when requested by a young carer (Source: Young person's guide to the Children and Families Act 2014, Department for Education).

In the context of national policy and legislative reforms, an Adult Carers' Strategy for Cumbria is currently in development in order to support carers and ensure they are recognised and valued (Source: Adult Carers Strategy for Cumbria, 2015, CCC).

Consultation is currently taking place (18<sup>th</sup> March – 31<sup>st</sup> July 2016) on a new national Carers Strategy, from the Department of Health; details about the consultation can be found here: <https://consultations.dh.gov.uk/carers/how-can-we-improve-support-for-carers>

## **4.3 Cumbria's population**

### **4.3.1 Total population**

The current population of Cumbria is 497,900; in England & Wales it is estimated to be 57.4 million (Source: Mid-2014 Population Estimates, Office for National Statistics). The number of people on Cumbria's GP register is higher than the resident population; in October 2015, there were 521,742 people on Cumbria's GP register.

Compared to England and Wales, Cumbria has an older age profile, with lower proportions of residents aged 0-44 years, and higher proportions of residents aged 45+ years. The age profile of Cumbria's districts varies considerably: Barrow-in-Furness, Carlisle and Copeland have the greatest proportions of residents aged 0-44 years, while the districts of Allerdale, Eden and South Lakeland have the greatest proportions of residents aged 45+ years. South Lakeland in particular has a high proportion of older residents aged 65+ years - out of 348 local authority districts in England & Wales, South Lakeland has the 12<sup>th</sup> highest proportion

of residents aged 65+ (Source: Mid-2014 Population Estimates, Office for National Statistics).

Further details of Cumbria's population can be found in the Population chapter of the Joint Strategic Needs Assessment, here:

<http://www.cumbriaobservatory.org.uk/health/JSNA/2015/population.asp>

#### **4.3.2 Black and Minority Ethnic population**

In the 2011 census 17,734 Cumbrian residents reported that they were from Black and Minority Ethnic (BME) groups (3.5%); this is much lower than the average for England & Wales (19.5%). Across Cumbria's districts, the proportion of residents from BME groups ranged from 2.4% in Allerdale to 5% in Carlisle. In Cumbria, 475 people who are providing unpaid care are from BME groups, accounting for just 0.8% of all carers compared to 10.9% in England. The greatest proportion of carers from BME groups are in the district of Carlisle (1.2%). More than half (51.8%) of BME groups are of Asian ethnicity (Source: Census, 2011). Although levels of BME groups in Cumbria are relatively low they have been increasing and it is therefore important that service provision reflects this.

Carers can be of any age and come from any cultural background. Whilst carers from BME communities face similar difficulties to all other carers in carrying out their caring roles, for example social isolation, stress, and financial pressures, many BME carers face particular difficulties in accessing and using support services. People from BME communities do not make up a uniform group; they have diverse support needs. Many BME carers are simply not aware of the services that exist to support them, whilst others have language and cultural barriers to accessing services and support (Source: Improving Support for Black and Minority Ethnic (BME) Carers, 2010. The Institute for Research and Innovation in Social Services).

Evidence from Carers UK suggests that black and minority ethnic carers experience a lack of advice and information, and find it hard to access culturally appropriate services. As a result, they are likely to miss out on receiving practical and financial support with caring (Source: Facts about carers, 2014. Carers UK).

Young carers are more than one and a half times more likely to be from BME communities, and twice as likely not to speak English as their first language (The Children's Society. Hidden from view 2013).

Further details of BME Groups in Cumbria can be found in the Population chapter of the Joint Strategic Needs Assessment, here:

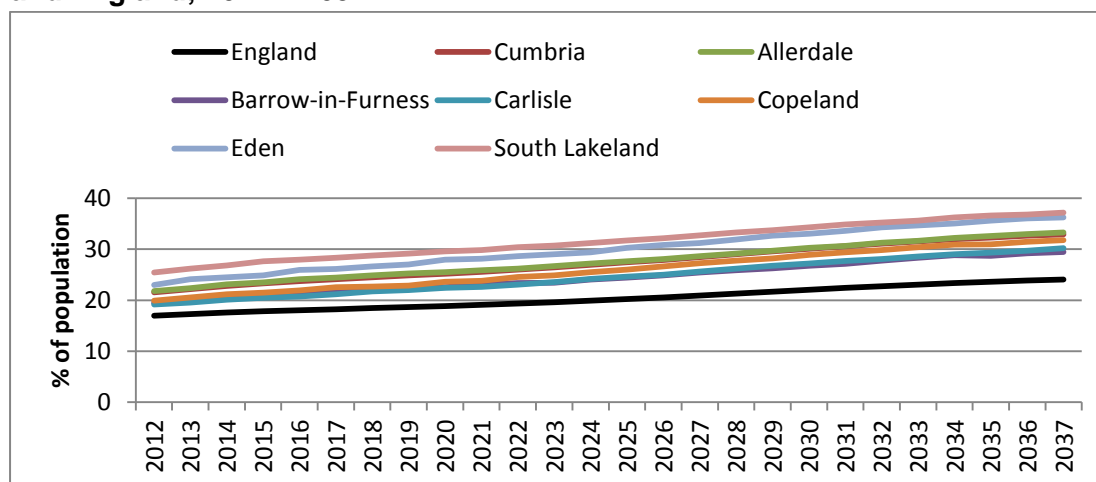
<http://www.cumbriaobservatory.org.uk/health/JSNA/2015/population.asp>

#### **4.3.3 Population projections and future demand**

Current projections show that the number of residents aged over 65 in Cumbria and England will increase each year to 2037. By 2017 numbers of residents aged over 65 will increase by

12,300 persons (+11.4%) across Cumbria (England +11.6%), but that the proportion of residents aged over 65 will increase to 24.1% across Cumbria: the 6th greatest proportion of all counties (England 18.2%). All Cumbrian districts will have greater proportions of residents aged over 65 than the national average. In rural areas this disparity will be even greater.

**Figure 3: projection of proportion of residents aged over 65 years by county, district and England; 2012 – 2037**



Source: 2012 based Sub-National Population Projections, Office for National Statistics

These projections highlight some key factors for Cumbria. Older people are more likely to require care and support therefore if numbers are to increase so will demand. People are living for longer and so are those with long-term conditions and complex needs.

Demand on care isn't just from older people; younger people with disabilities and high levels of need are more likely to live into adulthood and old age.

Numbers of Cumbria's working age population (15-64 years) are projected to fall year on year over the next 20 years; by 2037, numbers will decrease by 52,400 (-16.6%), the greatest decrease of all counties across England. Numbers of 15-64 year olds will decrease across all Cumbrian districts, all within the 20 greatest decreases of all authorities nationally. (Source: 2012-Based Subnational Population Projections, Office for National Statistics, Ref: 042)

#### 4.3.4 Population with health problems and disabilities

The question "Are your day-to-day activities limited because of a health problem or disability which has lasted, or expected to last, at least 12 months?" was posed in the 2011 Census. Of Cumbria's 499,858 residents on Census Day 2011:

- 48,523 reported that their day-to-day activities were limited a lot (9.7%)
- 53,198 reported that their day-to-day activities that were limited a little (10.6%)
- 101,721 day-to-day activities limited total (20.3%)
- 398,137 reported that their day to-day-activities were not limited (79.7%)

When compared to England, Cumbria has a slightly higher proportion of residents whose day to day activities are limited (20.3% compared to 17.6%). Of the six districts, Barrow-in-

Furness had the greatest proportion of residents whose day-to-day activities are limited (24.6%), while Eden had the smallest proportion (18.0%). In Cumbria, there are more females than males who have a long-term health problem or disability, 53.4% compared to 46.6%.

**Figure 4: Long-term health problem or disability (day-to-day activities limited); Cumbria, Districts v England**

	Day-to-day activities limited a lot	Day-to-day activities limited a little	Day-to-day activities not limited	% Day-to-day activities limited
Cumbria	48,523	53,198	398,137	20.3
Allerdale	9,718	10,309	76,395	20.8
Barrow-in-Furness	8,961	8,062	52,064	24.6
Carlisle	9,919	10,704	86,901	19.2
Copeland	7,537	7,524	55,542	21.3
Eden	4,098	5,370	43,096	18.0
South Lakeland	8,290	11,229	84,139	18.8
England	4,405,394	4,947,192	43,659,870	17.6

(Source: Census, 2011).

As people get older health often deteriorates. In Cumbria, 36.5% of residents aged 50+ years have a long-term health problem or disability, in line with the national average; this increases to 46.2% in Barrow-in-Furness and 39.4% in Copeland. Just over half (51.8%) of Cumbria's residents aged 65+ years have a long-term health problem, just under the England average (48.1%); in South Lakeland this increases to 59.0%. An area (lower super output area) within the Harbour ward in Copeland has the greatest proportion of residents who have a health problem or disability at 38.1%; in Allerdale it is an area within the Moss Bay ward (27.3%); in Barrow-in-Furness it is an area within the Hindpool ward (36.7%); in Carlisle it is in an area within the Morton ward (33.3%); Penrith Pategill in Eden (26.5%); and Grange in South Lakeland (30.7%).

It is important to note that areas with high levels of unpaid care provision have relatively low levels of deprivation, despite deprivation being significantly linked to poor health and wellbeing. It is considered likely that people living in deprived areas with poor health do require support and care but that the provision of care is under reported in these areas.

In response to the 2011 Census Day question "How is your health in general?" the response from Cumbria's 499,858 residents on Census Day 2011 was as follows:

- 225,018 had very good health (45.0%)
- 172,789 had good health (34.6%)
- 71,966 had fair health (14.4%)
- 23,604 had bad health (4.7%)
- 6,481 had very bad health (1.3%)

When compared to England, Cumbria has a slightly lower proportion of residents with bad or very bad health (6.0% compared to 5.5%). Across the districts, Barrow-in-Furness had the greatest proportion of residents with bad or very bad health (8.4%), whilst Eden and South Lakeland had the smallest proportions (both 4.5%). Within the districts, Central ward in

Barrow-in-Furness has the greatest proportion of residents with bad or very bad health at 12.5%; Moss Bay ward in Allerdale (10.6%); Upperby ward in Carlisle (9.1%); Harbour ward in Copeland (10.2%); Penrith Pategill in Eden (9.7%); and Ulverston Town in South Lakeland (7.2%).

**Figure 5: Long-term health problem or disability (good/bad health); Cumbria, Districts v England**

	Very good health	Good health	Fair health	Bad health	Very bad health	% bad/very bad health
Cumbria	225,018	172,789	71,966	23,604	6,481	6.0%
Allerdale	42,887	33,297	14,210	4,762	1,266	6.3%
Barrow-in-Furness	29,538	22,865	10,898	4,542	1,244	8.4%
Carlisle	48,593	37,494	15,030	4,964	1,443	6.0%
Copeland	31,329	23,938	10,516	3,760	1,060	6.8%
Eden	24,210	18,810	7,195	1,875	474	4.5%
South Lakeland	48,461	36,385	14,117	3,701	994	4.5%
England	25,005,712	18,141,457	6,954,092	2,250,446	660,749	5.5%

(Source: Census, 2011).

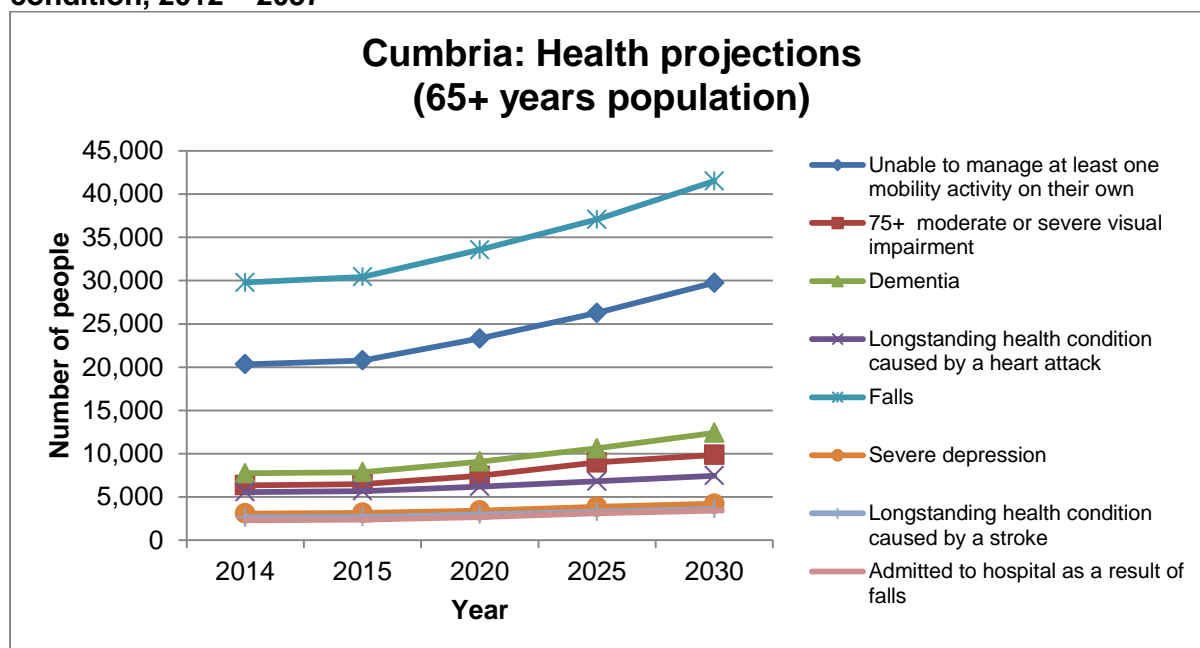
#### 4.3.5 Long-term health conditions and projections

Limiting long-term health conditions have a significant impact on demand on health and social care as well potential demand on the need and level of support from carers. If numbers of long-term health conditions increase then so may the need for care and support. There are different conditions requiring different levels of care.

Currently in Cumbria there are more than 20,000 people aged 65+ years 'unable to manage at least one mobility activity on their own'. By 2020, this number is estimated to increase by 14.7% (+3,000); and by 2030, it is predicted to increase by a staggering 46.4% (+9,500). Numbers are predicted to increase in all of the districts across Cumbria. Numbers are greater in South Lakeland, however, they are set to increase at a greater rate in Copeland and Eden (+17% by 2020; and +56% by 2030).

Other health conditions including visual impairment, dementia, longstanding health conditions caused by heart attacks and strokes, falls, and depression are all predicted to increase for residents aged 65+ in Cumbria.

**Figure 6: Projected numbers of residents (aged 65+ years) in Cumbria with a health condition, 2012 – 2037**



(Source: POPPI, 2015)

#### 4.3.6 Life expectancy and Disability Free Life Expectancy

Life expectancy for both males and females in Cumbria is below the England averages; despite this, people in Cumbria are living longer. There is a significant correlation between areas with high levels of deprivation and areas with a lower life expectancy - the more deprived an area is the lower the life expectancy. Disability free life expectancy (DFLE) for both males and females in Cumbria is also below the England average; DFLE is a measure of the average number of years that an individual can expect to live free from a limiting persistent illness or disability in their lifetime. There is significant variation in DFLE in areas across Cumbria; there is a 18.8 years difference between a male living in the most and least deprived areas, from 51.7 years in parts of Barrow-in-Furness (significantly lower than England) to 70.5 years in parts of Eden (significantly higher than England). Variation in female DFLE across Cumbria between the most and least deprived MSOAs is slightly lower than males at 18.3 years, from 52.7 years in parts of Barrow-in-Furness (significantly lower than England) to 71.0 years in parts of South Lakeland (significantly higher than England). If an individual has low levels of DFLE they are likely to need support and care.

#### 4.3.7 Older people health projections

In Cumbria, numbers of the total population aged 65+ years with depression (mental health); moderate or severe learning disability; or mobility issue (activities include: going out of doors and walking down the road; getting up and down stairs; getting around the house on the level; getting to the toilet; getting in and out of bed) are projected to increase year on year up to 2030, reflecting the increasing older population.

**Figure 7: Cumbria: Projected number of people aged 65+ predicted to have a mobility issue (physical disability), learning disability, or depressions (mental health disorder), 2014-2030.**

	2014	2015	2020	2025	2030	Numerical change
Mobility (physical disability)	20,322	20,765	23,307	26,267	29,746	9,424
Learning Disability	322	328	349	370	402	80
Depression (mental health)	9,708	9,905	10,718	11,647	12,787	3,079

(Source: PANSI, 2015)

By 2020, numbers of people aged 65+ with a moderate or severe learning disability will increase by 8%; by 2030, this will increase by 25%.

By 2020, numbers of people aged 65+ with a mobility issue (physical disability) will increase by 15%; and by 2030 this will increase by a staggering 46%.

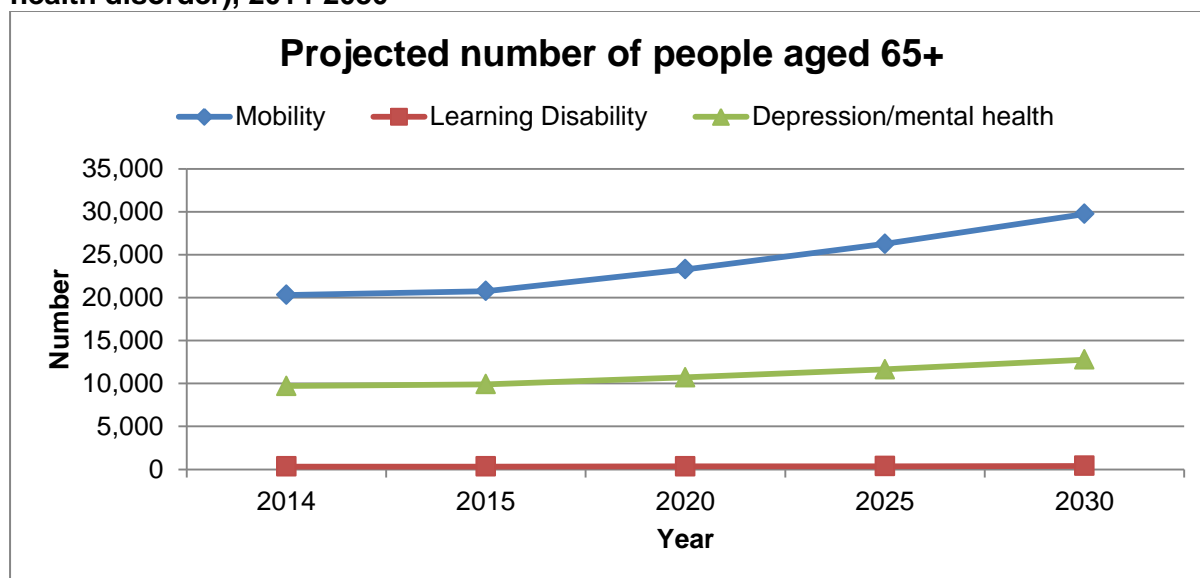
By 2020, numbers of people aged 65+ with depression (mental health disorder) will increase by 10%; by 2030, this will increase by 32%.

**Figure 8: Cumbria: Projected proportional change of people aged 65+ predicted to have a mobility issue (physical disability), learning disability, or depressions (mental health disorder), 2014-2030**

	2014	2015	2020	2025	2030
Mobility (physical disability)		2%	15%	29%	46%
Learning Disability		2%	8%	15%	25%
Depression (mental health)		2%	10%	20%	32%

(Source: PANSI, 2015)

**Figure 9: Cumbria: Projected proportional change of people aged 65+ predicted to have a mobility issue (physical disability), learning disability, or depressions (mental health disorder), 2014-2030**



(Source: POPPI, 2015)



### 4.3.8 Younger adult health projections

In contrast to the projected increase in the number of 65+ years with a common mental disorder, moderate physical disability, or learning disability, numbers of the total population aged 18-64 years are projected to decline year on year up to 2030. This does not necessarily reflect a decline in prevalence but is likely to reflect a decline in the projected working age population (those aged 16-64 years).

**Figure 10: Cumbria: Projected number of people aged 18-64 predicted to have a learning disability, mental health disorder or physical disability, 2014-2030.**

	2014	2015	2020	2025	2030	Numerical change
Learning Disability	7,045	6,997	6,782	6,543	6,297	-748
Physical Disability	24,538	24,428	24,224	23,468	22,151	-2,387
Mental Health	46,957	46,635	45,196	43,538	41,713	-5,244

(Source: PANSI, 2015)

By 2020, numbers of people aged 18-64 years with a learning disability are projected to fall by -4%; by 2030 they are projected to fall by -11%.

By 2020, numbers of people aged 18-64 years with a physical disability are projected to fall by -1%; by 2030, they are projected to fall by -10%

By 2020, numbers of people aged 18-64 years with a common mental health disorder are projected to fall by 4%; by 2030, numbers are projected to fall by 11%.

**Figure 11: Cumbria: Projected proportional change of people aged 18-64 predicted to have a learning disability, mental health disorder or physical disability, 2014-2030.**

	2014	2015	2020	2025	2030
Learning Disability		-1	-4	-7	-11
Physical Disability		0	-1	-4	-10
Mental Health		-1	-4	-7	-11

(Source: PANSI, 2015)

### 4.3.9 Mental Health

There are approximately 1,200 mental health service users receiving support from Adult Social Care, accounting for around 10% of all service users; there are approximately 270 carers receiving support relating to service users with a primary mental health issue (Source: Adult Social Care, Long-term Support, SALT, Q3). It is recognised that numbers of people with mental health issues is underestimated therefore the relatively low proportion of mental health service users may not accurately reflect the health profile of Cumbria's residents or numbers of those providing care or support.

**Mental Capacity and Deprivation of Liberty:** The Deprivation of Liberty Safeguards (DoLS) aim to protect people who lack mental capacity, but who need to be deprived of liberty so they can be given care and treatment in a hospital or care home. If a person's right to liberty needs to be infringed in other settings, an authorisation must be obtained from the Court of Protection (source: Law Commission, May 2016).

Throughout 2014-15, 480 DoLS applications were received across Cumbria, 220 of those were granted, accounting for around half (45.8%), compared to 38% nationally; on behalf of 195 individuals (please note that multiple applications can be made on behalf of an individual) (Source: Health & Social Care Information Centre - Deprivation of Liberty Safeguards (DoLS), final data for the reporting period 1 April 2014 to 31 March 2015). There has been a significant increase in the number of applications both locally and nationally; compared to the previous year (2013-14) applications in Cumbria increased by +395, from 85 (+465%); in England, applications increased tenfold, +958% from around 13,000 applications in 2013-14 to 137,550 in 2014-15. The significant increase in numbers of applications follows the March 2014 Supreme Court judgment gave new guidance on the use of the Deprivation of Liberty Safeguards.

In 2014-15, there were a total of 4,855 people registered with a mental health condition (schizophrenia, bipolar affective disorder and other psychoses) on GP Registers across Cumbria CCG, a prevalence rate of 0.94%; this is above the England average of 0.88%. (Source: Mental Health prevalence, Quality Outcomes Framework, 2014-15)

In 2014-15, there were a total of 33,932 people aged 18+ across Cumbria's CCG registered with depression on GP Registers, a prevalence rate of 8%; this is above the overall prevalence rate in England of 7.33%. (Source: Depression prevalence, Quality Outcomes Framework, 2014-15).

Levels of deprivation are a key determinant of mental health disorders. People living in more deprived areas are likely to have higher levels of mental health conditions and higher needs for services (Source: Common Mental Health Disorders, PHE).

In the 2015 Indices of Deprivation, in terms of overall deprivation Cumbria ranks 86th nationally out of 152 upper tier local authorities (with 1 being the most deprived); this places the county within the 57th percentile nationally (suggesting that 57% of upper tier local authorities are more deprived than Cumbria).

In terms of overall deprivation Barrow-in-Furness is the most deprived district in the county and ranks 29th most deprived nationally (out of 326 local authorities in England); falling within the 10% most deprived of districts nationally. Furthermore, Barrow-in-Furness is the 5th most deprived district in England in terms of health deprivation & disability. Copeland is the second most deprived district in the county, it falls within the 30% most deprived nationally in terms of overall deprivation, and falls within the 10% most deprived nationally in terms of health deprivation & disability.

There are pockets of severe deprivation with a total of 29 lower super output areas (LSOAs) in Cumbria falling within the 10% most deprived nationally. These LSOAs fall within the wards of Ellenborough, Ewanrigg, Moss Bay, and St. Michael's in Allerdale; Central, Barrow Island, Hindpool, Newbarns, Ormsgill, and Risedale in Barrow-in-Furness; Belle Vue, Botcherby, Morton and Upperby in Carlisle; and Sandwith, Harbour, Mirehouse, Frizington, Cleator Moor South, and Cleator Moor North in Copeland.

#### **4.3.10 Dementia**

Dementia is caused by a number of diseases that affect the brain, the most common disease being Alzheimer's. Dementia has major health, social and economic impacts on individuals, families and the whole community.

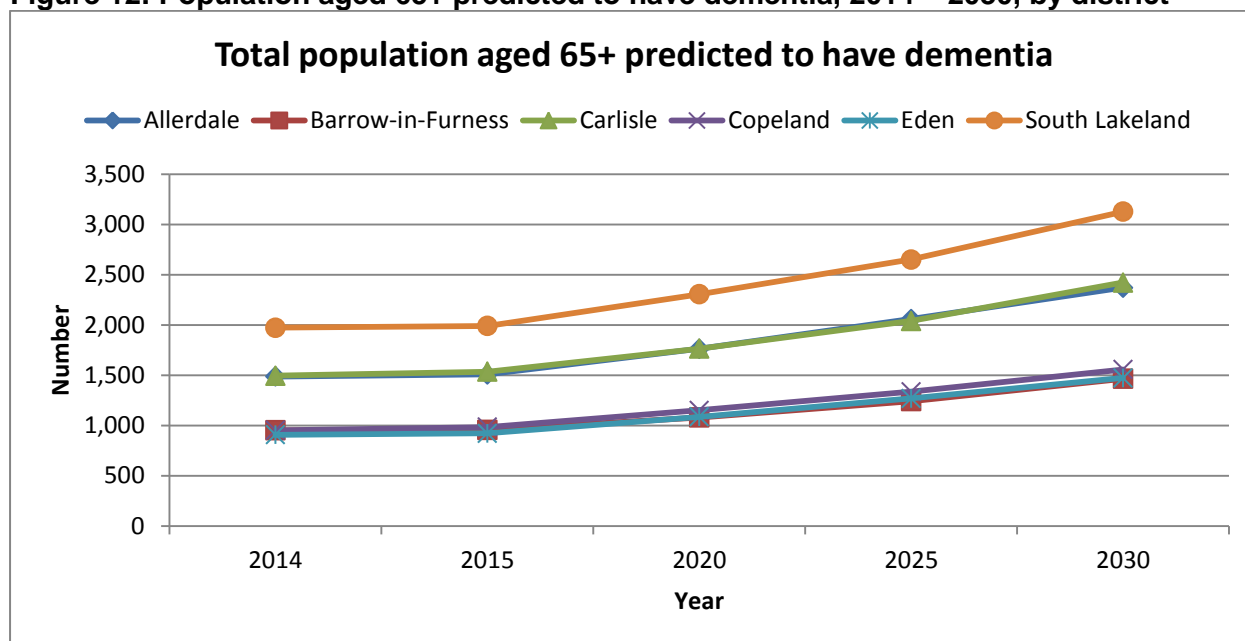
Dementia is characterised by progressive deterioration of mental faculties ending in severe incapacity. A person may live with dementia for several years, initially with mild dementia and progressing to severe. The condition has a major impact on the general health and wellbeing of the person and family and presents great challenges for both informal and formal carers.

Dementia can affect individuals in different ways and at different rates. Personal circumstances can affect the individual, along with the people and support they may have; and their environment. Dementia is most prevalent in older people aged 65+ however it is not an older person's disease and can affect younger people.

People are often happier if they can live independently and remain in their own homes for longer. Carers enable individuals to do this. As well as carers there are 'dementia friends' which is an initiative set up to help communities across England become dementia friendly – helping people understand dementia; providing support to those with dementia and helping people to live independently for longer.

There are an estimated 7,721 people living with dementia in Cumbria (source: POPPI, 2015, Ref: 043) however, it is recognised that numbers are underestimated. The number of people with dementia is expected to rise substantially as our population ages. Over the next 5 years, numbers of people with dementia are predicted to increase by 17.7%; by 2030 numbers are projected to increase significantly by 60.7%, from 7,721 to 12,410. This will have a huge impact on the provision of carers and adult social care services. Numbers of people with dementia are greater in the district of South Lakeland, reflecting the older population; although projected numbers will be greater in South Lakeland, in Copeland, by 2030 they are predicted to increase by +63.7%, compared to 53.8% in Barrow-in-Furness.

**Figure 12: Population aged 65+ predicted to have dementia, 2014 – 2030, by district**



(Source: POPPI, 2015)

#### 4.3.11 Cancer

Nationally, cancer cases are increasing. 280,000 people were diagnosed with cancer in England in 2013/14 and this is expected to reach more than 300,000 by 2020, and more than 360,000 by 2030. One in two people will develop cancer at some point in their lives. With survival rates increasing, more and more people are living with cancer (Source: Independent Cancer Taskforce: “Achieving World Class Cancer Outcomes – A Strategy for England, 2015 – 2020”).

Cancer prevalence rates and new cancer case rates in Cumbria are above England averages. In 2014/15, there were 14,863 cancer patients in Cumbria, a prevalence rate of 2.9% (of the total population), this is above the England prevalence rate of 2.3% (Source: QOF). In 2012/13, there were 3,360 new cancer cases in Cumbria equating to a rate of 643 per 100,000, this is above the England rate of 508 (Source: Public Health Outcomes Framework).

As more and more people are living with cancer the need for help and support from a carer will increase. However, it is important to note that it is not just those who are being cared for who are at risk, it is those who are caring, too.

#### 4.3.12 Population profile of Cumbria’s carers

There are approximately 8,600 carers in contact with Adult Social Care, and around one in three of those are in receipt of support. Most carers are aged between 18-64years (54%), yet 1 in 3 are aged between 65-84 years (36%), and around 1 in 10 are aged 85+ years. Most carers known to Adult Social Care are female, 2 out of 3 (67%). In Allerdale there are 1,395 carers in receipt of support; in Carlisle there are 1,989; in Copeland there are 1,022; in Eden there are 1,175; and in Furness there are 1,579 (please note that numbers may not

sum due to missing postcodes/unmatched addresses). (Source: Service users and Carers registered with Adult Social Care, Adult Social Care).

#### **4.4 The value of carers' support**

In the Carers strategy: Second National Action Plan 2014-2016 (Source: Department of Health) it states that the country cannot do without the contribution of carers. In financial terms the contribution made by unpaid carers in the UK is estimated to be in the region of £132.0 billion per year (2015) and plays a central role in the health economy. This represents an increase of +7.0% (+£8.7 billion) compared to 2011, and is almost double (+93.0%) the estimated figure of £68.4 billion in 2001 (Source: Valuing Carers 2015 – the rising value of carers' support. Yeandle, S. & Buckner, L). It is estimated that 1.2 million carers spend over 50 hours each week caring for others, equating to a full time workforce larger than the entire National Health Service (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013).

Cumbria's estimated 57,789 carers provide unpaid care valued at £1.1 billion, an increase of 4.9% (+£52 million) compared to 2011, and a significant increase of +86.6% (+£513 million) compared to 2001 (Source: Valuing Carers 2015 – the rising value of carers' support. Yeandle, S. & Buckner, L).

Measuring the financial contribution is only one way of valuing carers. Providing unpaid care is more than a contribution to the economy. An important aspect of caring is the expression of love and respect for another person; carers enhance the quality of life of those they care for, and help the person they care for to remain independent (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013). However, these are not qualities that can be easily quantified, and it is therefore difficult to measure the complete value of the contribution made by unpaid carers.

The increase in unpaid care is likely to reflect the growing numbers of people aged 85 and over and those living with a limiting long-term illness requiring support, as well as carers potentially increasing support in the context of a reduction in homecare support provided by local authorities in some areas of the country (Source: Valuing Carers 2015 – the rising value of carers' support. Yeandle, S. & Buckner, L).

### **5 Who is at risk, and why?**

More than 56,000 adult (18+ years) residents across Cumbria provide unpaid care to either family members, friends, neighbours or others because of either a long-term physical or mental ill-health / disability or problems relating to old age; with a further estimated 7,700 young carers in the county. There are greater proportions of adult carers in Cumbria compared to the rest of England (Provision of unpaid care , Source: Census, 2011).

Cumbria County Council's Directorate of Health and Care Services provide care and support for adults aged 18 years and older. Services include support for adults and older people with physical or mental health needs; learning disabilities; sensory impairment; substance misuse issues; as well as providing support for those who care for others. There is a range of

support available to people including support in the community, support at home or accommodation based support.

## **5.1 Risk of becoming a carer**

The risk of becoming a carer in Cumbria is an increasing one. With the projected changes in demographics such as the increasing number of older people; and the projected health and wellbeing needs of Cumbria's population such as increasing numbers of people with long-term health conditions/disabilities, and increasing numbers of people with dementia. Furthermore, people with cancer are living longer and may therefore require the help and support of a carer. The projected demand of future carers is an increasing one.

Known carers are most likely to be female, aged between 50-64 years. Carers are most likely to live in areas where there are high proportions of older people and people with long-term health problems or disabilities.

As more and more people are living with cancer the need for help and support from a carer will increase. However, it is important to note that it is not just those who are being cared for who are at risk, it is those who are caring, too.

## **5.2 Health risks of being a carer**

The projected changes in demographics alongside the projected health and wellbeing needs of Cumbria's population are all health risks to not just the cared for but for those who are providing care, too.

Caring for another person can have an adverse effect on a carer's physical and mental wellbeing. Research carried out by Carers UK in 2015 highlighted that 82% of the carers surveyed reported that caring has had a negative impact on their health; 76% are concerned about the impact of caring on their health over the next year and 41% have experienced an injury or their physical health has suffered as a result of caring (Source: State of Caring, Carers UK, 2015).

Carers often neglect their own health, putting their own needs second to the person or people they are caring for. Contributory factors include being unable to attend hospital appointments, or regularly missing routine health appointments such as check-ups with a doctor or dentist. Caring responsibilities may make it difficult to find time to exercise. Reduced income and lack of time to cook mean that many carers struggle to maintain a balanced diet. Alcohol consumption may increase in response to emotional and psychological pressures. The demands of caring may be such that carers do not notice their deteriorating health (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013). Almost 1 in 3 carers in Cumbria (28%) have a long-term health problem or disability themselves, who may or may not be receiving the help or support they need because of their caring role and duties. In Barrow-in-Furness this increases to 33.5% compared to 25.6% in Eden (Source: Census, 2011).

It is estimated that two in five carers experience psychological distress or depression, with the highest levels of distress experienced by those caring for people with behavioural

problems. Just under half (44%) of carers experience verbal or emotional abuse from the person they care for, whilst 28% endure physical aggression or violence (Source: The Commissioning for Carers guide. Royal College of General Practitioners, 2013).

Many carers spend more than 50 hours per week caring for another person. One third (33%) of people providing in excess of 50 hours per week report feeling depressed and suffer from disturbed sleep patterns (Source: The Commissioning for Carers guide. Royal College of General Practitioners, 2013). Over half of carers surveyed by Carers UK (55%) reported that they had suffered from depression as a result of their caring role and 74% struggled to get enough sleep (Source: State of Caring, Carers UK, 2015).

Carers providing more than 20 hours care per week also double their risk of psychological distress over a two year period compared to non-carers. Providing higher levels of care is also associated with a 23% higher risk of stroke, whilst older carers (those aged 65+ years) under pressure have a 63% higher likelihood of death in a 4 year period.

Pressures of caring very often restrict a carer's social activities, and carers may feel isolated and disconnected from their family and social networks. Relationships with other family members may deteriorate. All this is a cause for concern as links between social interaction and physical and mental wellbeing are strong; carers are at higher risk of mental and physical illness, including depression, than people with no caring responsibilities. Carers often suffer from worry and anxiety, and lowered self-esteem. Emotional impacts for young carers have been identified as worry, depression and self-harm (Source: The Commissioning for Carers guide. Royal College of General Practitioners, 2013).

Training opportunities can be found on the CSAC web site

There are many physical risks for carers in relation to moving and handling, wheelchair and equipment usage and maintenance, with a growing need for training (source: Age UK, West Cumbria).

### **5.3 Disability and health**

Daily pressures and restrictions can often lead carers to neglect their own health (Source: Adult Carers Strategy for Cumbria, 2016, CCC). This can result in a detrimental effect on a carer's own mental and emotional wellbeing. Carers UK report that 92% of carers consider that caring has had a negative impact on their mental health, including stress and depression (Source: Facts about carers, Carers UK, 2014). In the 2009-10 Survey of Carers in Households (Source: HSCIC), it is reported that over half (52%) of respondents said their health had been affected as a result of care they provide. The reported effects included tiredness (34%); stress (29%); disturbed sleep (25%); and being short tempered or irritable (22%) and carers are less likely to describe their general health as good. Carers can also at times be subjected to aggressive and violent behaviour from those they care for; coping with this is understandably difficult and has been shown as another cause of stress for carers (Source: Dementia in the Family, the impact on carers Alzheimer's Research UK, 2015).



Responses to Carers UK's *State of Caring 2013* survey indicate that 8% of carers were receiving Disability Living Allowance as a result of their own disability or ill health. National figures indicate that over 40,000 carers in receipt of Carer's Allowance also receive Disability Living Allowance. Evidence shows that carers with their own disabilities are significantly more likely to give up work to care for others (61% of working age disabled carers compared to 52% of non-disabled working age carers). Many of these disabled carers are caring for partners and are therefore substantially likely to be on lower incomes or to have no-one in the household in paid work; 75% of carers receiving Disability Living Allowance are thought to be in this situation, compared to 55% of all working age carers (Source: Facts about carers, Carers UK, 2014).

GPs are able to play a part in identifying who is a carer, and helping carers to access services. GPs have an opportunity to identify carers as it is known through the annual Department of Health survey of carers that two thirds (66%) of cared for people have some kind of regular contact with a health or social care professional (Survey of Carers in Households – England, 2009-10, HSCIC).

Providing appropriate support to carers can significantly improve their health and wellbeing. It can be difficult sometimes for GPs to recognise carers; becoming a carer can, for some people, be a gradual process with the responsibility of being a carer increasing slowly as the condition of the person they care for gradually worsens. Many people in this situation do not see themselves as carers, and are therefore difficult to identify (Source: How GPs can better identify and support carers, Marie Curie, 2015).

However, many older carers have reported having mixed experiences when looking for support from their GP or other health professionals. Those who had had positive experiences considered it important that they did not have to explain their situation each time they visited their GP. Carers also considered it beneficial if GPs adopted an understanding attitude and were able to be flexible around appointments (Source: "You don't stop the worrying": The difficulties of caring in later life. Independent Age, 2015).

## **5.4 Financial risks of being a carer**

There is a direct correlation between the amount of hours spent caring and the likelihood that a carer will find themselves in financial difficulties. Carers can find it extremely difficult and stressful to juggle the demands of employment alongside caring responsibilities. There can be a direct impact on career prospects; rather than advancing up the career ladder, carers may feel there is no alternative but to opt for lower paid, flexible or less demanding work, or reduce their hours. Around 20% of carers give up paid employment entirely to deliver care and on average, carers tend to retire 8 years earlier than people with no caring responsibilities. In 87% of households with working age carers looking after partners, no member of the household is in paid employment (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013).

Giving up paid employment or reducing hours can have a devastating impact on a carer's finances. The Royal College of General Practitioners reports that 55% of carers are in debt as a direct result of their caring responsibilities, 74% struggle to pay essential utility bills,

52% cut back on food and 65% live in fuel poverty. Less than 50% of carers claim the benefits for which they are eligible (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013). In the Carers UK 2015 State of Caring survey 26% of carers resort to borrowing from family and friends, and 38% use savings to get by. In addition to this, many carers can face increased expenditure relating to the additional costs of caring and disability, such as higher utility bills, higher transport costs, higher shopping bills, and the cost of home adaptations (Source: State of Caring, Carers UK, 2015)

Financial prospects for young carers can also be bleak. The average annual income for families with a young carer is £5,000 less than for families who do not have a young carer (Source: Hidden from View, The Children's Society, 2013). Caring can also have a negative impact on schooling and educational achievement, and furthermore young carers can find it difficult to leave home to pursue further education and training opportunities. These factors combined can affect longer term job prospects and earning potential (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013).

Lack of income can enforce a carer's sense of social isolation and loneliness. The need to cut back and save money can prevent carers from meeting up with family and friends (Source: State of Caring 2015, Carers UK).

## 5.5 Young carers

A young carer is a child or young person under the age of 18 who takes on a level of practical and emotional caring responsibilities that would generally be expected of an adult, in order to look after a parent, sibling or family member who has an illness, disability, mental health problem, learning difficulty, drug or alcohol problem, or for some other reason (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013). One in 12 young people are caring for more than 15 hours per week, with responsibilities that can include housework, healthcare, personal care, and translating for non-English speaking family members (Source: Hidden from view, The Children's Society, 2013).

The full extent of the number of young carers may not be known. Although figures are available from the 2011 census, the forms will most likely have been completed by parents or guardians rather than the children or young people themselves. In addition, not all young carers may be known to health, social care or education services as families may fear that their children could be taken into care (Source: Hidden from View, The Children's Society, 2013). In Cumbria there is an estimated number of 7,717 young carers (Source: Carers Support Cumbria, 2014).

Research shows that young carers often fare less well than their peers in relation to educational achievement. Educational difficulties experienced by just over one in five (22%) of young carers include repeated absence or lateness, failure to submit homework or coursework, tiredness, lack of concentration and poor quality work (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013). Young carers are more likely than the national average to be 'not in education, employment or training' (NEET) between the ages of 16 and 19 (Source: Hidden from View, The Children's

Society, 2013). Under attainment and restricted educational options as a result of caring responsibilities can have a lifelong impact on future employment and earning opportunities (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013)..

Young carers are often mature beyond their years. However, the pressures experienced by young carers can result in emotional and mental health problems. Young carers may be subject to bullying and are more likely to experience poverty. They can also suffer from isolation, find it difficult to play and socialise with other young people and lack of opportunity to build and maintain new personal relationships. Difficulties establishing relationships can be carried into later life (Source: The Commissioning for Carers Guide, Royal College of General Practitioners, 2013).

Access to sporting and leisure activities is often problematic for young carers, due to lack of spare time, or not having an adult to support them. This can have an adverse impact on the health of young carers. Results following a question relating to general health in the 2011 Census show the relationship between the hours of unpaid care provided and deteriorating health. Five times as many young people who provide more than 50 hours care per week are reported to have 'not good' health compared to young people who provide no unpaid care. The term 'not good' health relates to those who answered 'fair, bad or very bad' to the general health question in the 2011 Census (Source: Providing unpaid care may have an adverse affect on young carers' general health, Office for National Statistics, 2013). Figure 13 below shows the relationship between unpaid care provision and poor health.

**Figure 13: % of unpaid carers with 'not good' general health**

Hours of unpaid care per week	% of young unpaid carers (age 5-17) with 'not good' general health	
	North West region	England
None	3.0%	3.0%
1 – 19 hours	5.0%	5.6%
20 – 49 hours	9.5%	10.1%
50+ hours	14.9%	15.6%

(Source: Providing unpaid care may have an adverse affect on young carers' general health, Office for National Statistics, 2013)

As at March 2015, the number of young carers known to Cumbria County Council was 1,060. This amounts to 1.4% of the county's 5-18 year olds. Eden district had the highest rate of known young carers (2.4). Young carers in Cumbria are more likely to live in areas belonging to the most deprived socio-economic categories. Analysis using the ACORN socio-economic profiling tool, developed by the company CACI, suggests that 68% of known young carers in Cumbria live in postcodes classified as belonging to the two most deprived socio-economic categories; this is much higher than the proportion of Cumbria's total population living in postcodes assigned to these socio-economic categories (42%) (© 1979 – 2015 CACI Limited. This data shall be used solely for academic, personal and/ or non-commercial purposes). The number of young carers in the county could be higher. Many young carers may remain hidden due to the fear of being identified, not realising they are a young carer or through professionals not acknowledging their role and therefore failing to identify and support them (Source: CACI, 2015).

Between July – December 2015, Carers Support Cumbria had supported 1,090 young carers, by locality this was as follows: Carlisle (169); Eden (218); Furness (225); South Lakeland (223); and West Cumbria (255).

### 5.5.1 Parental Drug & Alcohol Misuse

It is important to consider children in households where parents are misusing drugs and alcohol. Not only are those children at risk of neglect and abuse but they may be responsible for carrying out a caring role for those who are misusing as well as themselves. In 2011/12, Public Health England reported that 92 parents in Cumbria were attending treatment for substance misuse; this equates to a rate of 110.4 per 100,000 children aged 0-15, which was the same as the national average. In addition to this, throughout 2014/15 there were 3,118 service users in Cumbria in contact with Unity (the provider of drug and alcohol services in the county). 1 in 5 of those service users (21%, 654) had children living with them; 33.4% (1,040) had children who lived with family/partner/other; while 45.7% (1,424) were not a parent.

For further information about groups at risk of misusing drugs and alcohol, please see the Healthy Living and Lifestyles Chapter of Cumbria's JSNA.

## 5.6 Older carers (65+ years)

Data from the 2011 Census shows that there are almost 1.3 million carers in England and Wales over the age of 65, and that the number in this age group is growing. It is estimated that over half of all people are likely to end up caring for partners, family members or friends in later life (Source: "You don't stop the worrying": The difficulties of caring in later life, Independent Age, 2015). Older carers may find themselves juggling a combination of caring roles, not only supporting children, grandchildren or partners but their older parents as well (Source: Older Carers, 2014, Carers Week).

Caring has a wide ranging effect on the physical, emotional, social and economic wellbeing of older people. Providing long term care is associated with a decline in quality of life. Feelings of isolation are common amongst older carers, with less free time to keep up with family and friends combined with the natural declining of social networks associated with the ageing process. There are financial constraints too; reduced retirement income and potentially increased costs of caring, whilst carers in receipt of a state pension do not receive a Carers allowance (Source: "You don't stop the worrying": The difficulties of caring in later life, Independent Age, 2015).

Older carers may have their own health problems and disabilities related to ageing, and find it difficult to care for someone with the unpredictable behaviour associated with dementia or mental health issues. The physical demands of caring can be difficult and can lead to injuries. Older carers may also fail to maintain their own health and may delay or cancel their own medical appointments as a direct result of the strains of caring (Source: "You don't stop the worrying": The difficulties of caring in later life, Independent Age, 2015).

Stress, anxiety and worrying about the future is a familiar problem, along with worrying about the future and what will happen to loved ones when and if they are no longer able to provide care. Many older carers also experience bereavement when the person being looked after dies, or moves into care (Source: "You don't stop the worrying": The difficulties of caring in later life, Independent Age, 2015).

## 5.7 Parent carers

In Cumbria, there are around 104,000 children aged 0-19 years (Source: Mid-2014 Population Estimates, Office for National Statistics). The HM Government Office for Disabilities suggest that 1 in 20 children will be disabled (Source: Family Resources survey 2009/10, Office for Disability Issues), if we apply this estimate to children in Cumbria there will be an estimated 5,200 children with a disability requiring care.

There are 576 Parent Carers registered and receiving support from Cumbria Carers Support; of those 396 are caring for children under the age of 18 years, while 180 are caring for children and young people between the ages of 18-25 years.

The Cumbria Parent Carer Forum is a group made up of parents, carers, grandparents and foster carers in Cumbria who have children with disabilities and/or additional needs who are particularly keen that their views are heard, understood and acted upon. Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families. Parent Carer Forums have been established in most local areas and local authorities are actively encouraged to work with them.

## 6 What is the level of need and gaps?

### 6.1 Carers in Cumbria

The South of the county, both Barrow-in-Furness and South Lakeland, has the greatest proportion of carers. More than half of carers (around 58%) in Cumbria are female, reflecting the national picture. And 1 in 3 carers in Cumbria are aged between 50-64 years. The general age profile of carers in the county compared to the rest of England is older with greater proportions of those aged 50+ and fewer proportions of younger carers, reflecting the older age profile of Cumbria (Source: Provision of unpaid care, Census, 2011).

The greatest proportion of people providing care in the county are living in Barrow-in-Furness, perhaps reflecting the needs of the population. 60% of those carers are aged 50+, however, in South Lakeland this increases to 70% reflecting the older age profile of the district.

Most carers in Cumbria (around 64%) provide on average 1 to 19 hours of care per week; yet 1 in 4 carers (around 23.5%) provide 50 or more hours. Numbers of those providing unpaid care are increasing, particularly in the districts of Carlisle and Eden, which may have implications on services provided by local authorities and partners in terms of support needed by both the carer and the person(s) they are caring for. Cumbria's population is

ageing and at a faster rate than England, and people are living for longer both of which may have a significant impact on the numbers of people providing care in the future.

There are more than 12,500 people in receipt of Adult Social Care services across Cumbria, around 75% of those are aged 65 years and over. The greatest number of service users are aged 65+ and are resident in the north of the county around the district of Carlisle, however, the greatest proportion of social care services users are in the south of the county. 76% of service users are using the service because of a physical disability; this increases to 87% in the south. There are approximately 8,600 carers in contact with Adult Social Care, and around one in three of those are in receipt of support. Most carers are aged between 18-64 years (54%), yet 1 in 3 are aged between 65-84 years (36%), and around 1 in 10 are aged 85+ years (Source: Service users and Carers registered with Adult Social Care, CCC).

It is felt that carers' put the needs of the person they are caring for first and therefore don't feel there is always a requirement for them to be assessed, they don't feel like they have any needs or requirements themselves.

Despite this, there will be some carers who are being 'missed' from the health and social care system, those who's voices and needs aren't being heard or picked up on. It is those who we need to try to engage with by joint working. Identifying carers and those who are perhaps in need of help and support isn't just the role and responsibility of adult social care; all health and care providers have a role to play including GPs, health visitors and nurses; social workers and occupational therapists. For example, a nurse visiting the cared may pick up a need of support for the carer and may then make a referral to a GP or carers organisation. It is this health and social care system that should be strengthened.

Carers' don't necessarily require a formal assessment and therefore do not always approach ASC for help or support as they may already receive this through carers' organisations and other support networks.

Support can often be indirectly given to carers for example when the person they care for attends a day care service which then gives the carer a break/respite.

In some cases carers don't wish to show that they may not be coping and may therefore not reach out for help and support, sometimes there is a stigma with regards to admitting to needing help.

Carers' organisations are pro-active in terms of reaching out to carers, being visible in the community is a great help. Information, help and support is readily available.

## **6.2 Carers and those they support**

With a growing elderly population, it is estimated that the need for carers will increase by +40% by 2037. Carers are not a static population as the needs of the person being cared for change over time; they may for instance recover, be admitted into residential care, or pass on. As the needs of the cared for change, it is estimated that up to 3 in 5 people nationally will find themselves in the position of caring for someone else at some point in their lives. The majority of carers are of working age, with the peak age for caring between 50-64 years, often leaving carers juggling their work and caring responsibilities (Source: Facts about carers, Carers UK, 2014).



In Cumbria, it is estimated that 60% of all persons receiving social care services (in the region of 19,000) have one or more carer. Of the carers known to Cumbria County Council's Adult Social Care teams, 45% are aged 65 years and over and 55% are aged between 18 and 64. Of the carers aged 65 and over, 86% are caring for someone aged 65 and over (Source: Adult Carers Strategy for Cumbria 2015, CCC).

The 2009-10 Survey of Carers in Households, carried out by the Department of Health, shows that around 2 in 5 carers (37%) are the only support for their main cared for person. It is estimated that around 1.7 million adults in England fulfil a sole carer role. The survey also showed that the majority of carers (82%) look after one person only, 14% look after 2 people and 3% are responsible for looking after 3 or more people. Half (50%) of carers were looking after someone aged 75+; 8% were looking after someone under 16. The cared for person is most likely to be a close family member, parent, spouse or partner. Only 9% of carers reported looking after a neighbour or friend. Almost 3 in 10 (27%) have been caring for their main cared for person for at least 10 years and this figures includes almost 1 in 10 (8%) who have been caring for more than 20 years (Source: Survey of Carers in Households – England, 2009-10. Health & Social Care Information Centre).

More than 20 hours of care per week is provided by nearly half of all carers (48%). Carers providing more than 20 hours of care per week are more likely to be aged 65 and over (30% compared to 20%). The majority (61%) anticipated that the amount of time spent caring will increase over the next 5 years, with only 8% feeling that the amount of time would decrease.

Carers reported carrying out a range of tasks. The most frequent types of help reported were: practical help, such as meal preparation, shopping and laundry (82%); keeping an eye on the person they cared for (76%); keeping the cared for person company (68%); and taking the cared for person out and about (62%).

### **6.3 Gender and ethnicity**

Women are often providing care at an earlier stage than their male counterparts. Whilst women have a one in two chance of being called upon to care by the time they are 59 years old; men have the same chance by the time they reach 75 years. Women often have additional responsibilities in that they are more likely to be "sandwich carers" combining the role of caring for the elderly with responsibilities for dependent children. It is likely that factors such as these, and perhaps a social expectation that women are better carers, are behind the reasons that women are more likely to give up paid work in order to care (Source: Facts about carers; Carers UK, 2014). In Cumbria, the number of female carers known to the Adult Social Care teams (67%) is double that of male carers (Source: Carers Strategy, Cumbria County Council). This is a higher proportion than found in the Department of Health survey where 60% of carers were found to be women. The survey also found that 61% of carers were looking after women compared to 39% looking after men perhaps reflecting women's longer lifespan.

The 2009-10 Department of Health survey of Carers in Households indicates that 92% of carers are white, and 8% from black and minority ethnic backgrounds. The proportion is



likely to be lower in Cumbria where only 3.5% of residents are of black and minority ethnic origin. Further details about ethnicity can be found in Section 4.3.3.

## 6.4 Carers Assessment

The 2014 Care Act gives local authorities a responsibility to assess a carer's needs for support, where the carer appears to have such needs. This replaces the existing law, which says that the carer must be providing "a substantial amount of care on a regular basis" in order to qualify for an assessment. This will mean more carers are able to have an assessment, comparable to the right of the people they care for. The local authority will assess whether the carer has needs and what those needs may be. This assessment will consider the impact of caring on the carer. It will also consider the things that a carer wants to achieve in their own day-to-day life. It must also consider other important issues, such as whether the carer is able or willing to carry on caring, whether they work or want to work, and whether they want to study or do more socially. If both the carer and the person they care for agree, a combined assessment of both their needs can be undertaken (Source: Care Act 2014 Factsheet 8: Carers, Department of Health).

Carers require a range of support and services in order for them to carry out their caring responsibilities. In the national Survey of Carers in Households – England, 2009-10 (source: HSCIC) only a small proportion of carers (6%) had actually been offered a carer's assessment, and only 4% had actually been assessed. Of those who were assessed, two thirds (67%) were found to be eligible for some kind of support such as mobility aids, services or an assessment for the person they cared for, or information about benefits. A consultation on the national carers strategy found that carers find the assessment process bureaucratic and slow, and are frequently disappointed about the lack of services that follow (Source: Adult Carers' Strategy, CCC).

As reported in the 2011 Census, we know that there were around 56,000 unpaid adult carers in Cumbria. Throughout 2014/15, around 7,530 carers were assessed for care and support; 4,230 assessments were joint assessments with the cared for. From the information available, 17% of carers were in receipt of direct support. It is likely that the proportion of carers receiving direct support is higher, however, because most assessments are joint the true figure is not known. Processes within Cumbria County Council do not always allow us to assess carers needs. During the period July – December 2015, 1,021 carers assessments had been recorded through Carers Support Cumbria; up until that point not all assessments were recorded on systems therefore this numbers may be higher. The rate of carers assessments were lowest in the districts of Carlisle (15.3 per 10,000 population) and Allerdale (17.7), compared to 31.5 in Eden and 30.8 in Furness.

It is recognised that within Cumbria's Adult Social Care, carers predominantly continue to be assessed and reviewed jointly (for both the cared for and carer) rather than individual assessments and thus not always identifying the needs and health and wellbeing of the carers. Around 73% of carers are supported jointly. In order to identify need and then provide suitable support, consideration should be given to improving the assessment process.

Because of the way information is recorded (i.e. joint work is recorded against the cared for/service user rather than the carer) it makes it difficult to profile the carers and evidence the support provided directly to the carer. Based on the information have available we know that more than half (54%) of carers in touch with health and social care are aged 18-64years; 36% are aged 65-84 years, while 10% are aged 85+.

In order to ascertain a complete picture of our carers in Cumbria we need to consider the way in which we process assessments, gather and record information and data; essentially so that we understand our carers and communities, and so that we are able to meet the needs of those who need support. Unfortunately we are unable to identify support needs for carers as information about needs are recorded against the person they care for.

Historically, we know that significant numbers of carers who have been offered an individual assessment by practitioners have declined, around 75% (more than 2 out of 3 people) compared to just 9% in England. In order to improve the take-up it is important we consider why this is and try to improve the way in which we are offering the service and consider other ways of doing it.

Under the 2014 Care Act, assessments consider the impact of caring on the carer and how to secure carers' general health and wellbeing, using available resources and support in the community. In order to achieve this it is vital that carers assessments are carried out and information is recorded accurately.

The Carers Assessment aims to identify areas where greater support can be given to you as carer, including help from an occupational therapist or social worker involvement; respite; or emotional and physical support.

An assessment should be regularly reviewed taking into account changes in personal circumstances. From July - December 2015, around 400 assessment reviews were carried out by Cumbria Carers organisation, with greater numbers in Carlisle and Furness; Eden had the lowest number of reviews.

It is recognised that the ability to evidence direct support to carers is difficult because of the way that information is recorded. From the evidence we do have we know that levels of direct support to carers in Furness are significantly low; and levels in Allerdale and Copeland are also relatively low. Attention on improving the service should be focussed in these areas. The districts with the greatest proportions of carers receiving direct support are Eden and South Lakeland. If numbers of individual carers assessments improve then so will the evidence of direct support to carers.

Following an assessment a carer may receive a care plan. A care plan helps to identify needs and then sets out how needs will be met. Throughout 2015 (January – December), a total of 2,028 support plans were completed by Carers Support Cumbria. The number of care plans was greatest in Furness, low numbers were recorded in Eden and South Lakeland.

#### **6.4.1 Direct Payments**

Direct payments or personal budgets are provided by Cumbria County's Council's health and social care following an assessment; they are given to both the cared for and the carer. If

the council decides that support and a budget is needed then a direct payment can be made allowing the individual(s) to arrange their own care and support instead of the council. If an individual is unable to manage their own finances another person can do this on their behalf. It is difficult to accurately measure the number of carers in receipt of direct payments in Cumbria because of the assessment process and the way in which information is recorded i.e. Cumbria continues to record services for the cared for rather than the carer. Likely due to this fact, Cumbria is well below average for carers direct payments at just 23.6% of those known to health and social care compared to 66.7% in England (source: ASCOF, 2014/15, Ref: 048). Changes to process and practice should see these numbers increase and improve, with a particular focus on individual carers assessments. There are approximately 1,100 people in receipt of direct payments in Cumbria; looking more locally, rates are relatively low in Copeland, Carlisle and Eden; rates are greater in Allerdale and South Lakeland.

## 6.5 Income and employment

The demands of caring are such that carers often feel forced to give up work in order to care (Source: Adult Carers Strategy for Cumbria 2015, CCC). This is often the case where carers have heavy commitments. The 2009-10 survey by the Department of Health states that carers providing more than 20 hours of care per week are less likely to be in full time employment than those providing less care (17% compared to 35%). A quarter of carers (26%) feel that caring responsibilities have affected their ability to either take up or stay in employment; this attitude is prevalent amongst carers aged 35-54. The survey by the Department of Health identified that 46% of the respondents were in paid employment. Of the carers of working age but not in employment, 27% would be interested in taking up paid employment, 16% would be interested in the near future and 10% would be interested when caring responsibilities were reduced (Source: Survey of Carers in Households – England, 2009-10. Health & Social Care Information Centre).

However, in order to take up paid employment, many carers would like flexibility in working hours (68%) and the ability to work from home (34%). Many carers are simply unaware of the right to request flexible working from an employer (19%). Around a quarter (27%) of carers in full time employment are aware of the right, falling slightly to 24% for those in part-time employment (Source: Survey of Carers in Households – England, 2009-10. Health & Social Care Information Centre).

Losing an income can have a dramatic effect on household income. Almost a third (30%) have seen a drop of £20,000 or more a year in their household income as a result of caring and half of working age carers live in a household where no-one is in paid employment (Facts about carers: Carers UK, 2014). Although carers may be entitled to a Carer's Allowance, many believe the value of the allowance is inadequate, the rules around overlapping benefits are unfair and the earnings limit a discouragement to work (Source: Carers Strategy, 2016, Cumbria County Council). Many carers may not understand what financial support is available to them. Carers UK believe that up to 42% of carers have missed out on financial support as a result of not getting the right information and advice. There is also an estimated cost of £5.3 billion a year to the economy in lost earnings and tax revenue and additional benefit payments (Facts about carers: Carers UK, 2014).

## 6.6 Paid care workers

In order to provide context, for this chapter we are considering paid care workers. We understand that Cumbria Care is not the only provider and employer of care in the county, however, we have access to their information which can help to provide a picture of care workers in Cumbria.

It is nationally recognised that levels of pay for those in the care sector are below average levels for all workers. For those in paid employment working as 'care workers, home carers and senior care workers' the current rate of pay is around £8.18 per hour, compared to the national earnings average of £11.80 (Source: Annual Survey of Hours and Earnings 2015 - Median Gross Hourly Earnings, Great Britain).

It is worth noting that many people receiving care are paying for their support privately. Details of registered agencies are available from Care Sector Alliance Cumbria.

## 6.7 Cumbria Care

There are currently more than 2,100 employees within Cumbria Care. Compared to the profile of those who provide unpaid care across the county, there are greater proportions of female paid care workers within Cumbria Care, accounting for 92% of its workforce (compared to 58% of female unpaid carers). The majority of paid care workers are aged between 50-59 years, accounting for 35% of staff – similar to the demographic of unpaid carers with 1 in 3 aged between 50-64 years. Most Cumbria Care workers are employed part-time, with just 10% employed full-time; while 1 in 3 employees are employed as care/support workers. There are different areas and different types of provision within Cumbria Care, these include: day care services; home care/domiciliary services; residential care; physical or learning disability, mental health (DMH) residential care; and DMH supported living (younger adults with learning difficulties, physical or mental health issues).

Care workers in Cumbria have contracted hours however they also often work additional hours for which they are paid, in addition to this they may also receive additional payments for working bank holidays and night working. There are different types of care workers within Cumbria Care and therefore different rates of pay; at the least Cumbria County Council has committed to pay the Living Wage Foundation minimum wage to carer workers which is £8.25 per hour. In terms of staff retention within Cumbria Care, more than half (58%) of staff have 10 or more years service; for staff working in day services this figure increases to 73%. Many care staff have more than one post, some have both a day services post and a residential post, one may be permanent while the other may be relief; to add to this, posts may also be in different locations.

In addition to the information above, the Health and Social Care Information Centre (HSCIC) publish information about social services staff by local authority. There are 3,270 social services staff within Cumbria County Council; 2,035 (62.4%) of social services staff provide direct care; while almost all of those providing direct care (2,025) are care workers (Source: Personal Social Services: Staff of Social Services Departments, England as at September 2015, HSCIC).

### 6.7.1 Carers Allowance

Carers in receipt of carers allowance: financial support (up to approximately £60 per week) is available from government to individuals who spend at least 35 hours a week caring for someone with substantial caring needs through the carers allowance benefit. Individuals do not have to be related to or live with the person they care for.

In Cumbria, around 5,200 people are in receipt of a carers allowance; across the districts, the greatest rates of claimants are in the districts of Barrow-in-Furness (confirming the greater proportions of unpaid carers) and Copeland, where rates are above national levels. Most carers' in receipt of the allowance are female (70%) and are of working age (98%), reflecting the national picture; there are some pension age people who claim however numbers are low. (Source: DWP, May 2015).

In addition to carers allowance, individuals may also be entitled to Carer's Credit if they provide at least 20 hours per week of care. Carer's Credit is a National Insurance credit that helps with gaps in national insurance records which later has a direct impact on an individual's state pension.

### 6.8 Quality of life

In the Survey of Carers in Households – England, 2009-10 (Source: HSCIC) 80% of carers described their quality of life as good. This dropped to 75% for carers looking after someone in the same household, and to 72% for those providing more than 20 hours care per week. However, whilst reporting of a good quality of life was relatively high, 42% of carers considered that caring had affected their personal relationships, social life or leisure time. The greatest reason for this affect was that 69% of carers simply had less time for leisure activities; a further 32% were too tired to go out, 23% reported that they were unable to go on holiday and 20% reported that the affect on their own health from caring affected their relationships and social life.

Caring for someone with dementia causes particular problems for carers. Relationships can often alter from an adult relationship to become more a parent / child relationship. Carers often find that as amount of required care increases, their relationship with their siblings can become strained. There is evidence to suggest that around 57% of carers looking after someone with dementia lose touch with their family or friends as a result of their caring responsibilities. This lack of ability to socialise can lead to increased isolation and emotional distress. According to Carers UK, the reduced ability to socialise has led to 4 out of 5 carers reporting feeling lonely or isolated as a result of their caring responsibilities (Source: Dementia in the Family, the impact on carers. Alzheimer's Research UK, 2015).

Caring for someone approaching the end of their life presents carers with significant challenges. The needs of the person being cared for can become complex and demanding, and carers typically coordinate care and visits from professionals around the clock. At this stage, carers are at higher risk of mental health issues, and are more likely to put off visiting their GP with their own physical health issues. Following such intensive caring, it can be very difficult for the carer to come to terms with the feelings of loss, grief and bereavement

once the cared for person has died (Source: How GPs can better identify and support carers. Marie Curie, 2015).

Within the Adult Social Care Outcomes Framework (ASCOF), a quality of life score is reported which gives an overarching view of the quality of life of carers in local authorities. It is a composite measure which combines responses to six questions in the national Carers Survey relating to the following six domains: occupation, control, personal care, safety, social participation and encouragement and support. In 2014-15, Cumbria had a score of 8.2 (out of 12) which was above the average score for England of 7.9. (Source: ASCOF, HSCIC).

## 6.9 Rurality and access to services

Rurality can have a negative impact on a carer's daily life. Cumbria is a rural county, and Cumbria's carers living in remote and rural areas may have less access to support than their counterparts in urban areas of the county (Source: Adult Carers' Strategy for Cumbria, 2016. CCC).

It may be more difficult to access services such as short respite breaks, carer training, health services and employment. Access to services from rural areas may be made more difficult from a transport perspective; many carers in rural areas have to travel long distances to access services, and the frequency, availability and cost of public transport may present barriers. This can make it difficult to keep hospital and GP appointments, and access employment and training opportunities for carers.

Rurality may have further negative impact on older carers, some of whom already consider that available services and support on offer from statutory services are limited and not sufficiently geared to their needs. Perceived problems include services that are of poor quality, inappropriate to needs, lacking in flexibility or consistency.

Around 54% of Cumbria's population are living in a rural area, significantly higher than the rest of England at just 18%. In the districts of Allerdale and Eden this increases to 72% and 71% respectively. There are significant geographical barriers to services for many rural areas which many carers will face. Further information about geographical barriers to services can be found in the Indices of Deprivation, 2015, on the Cumbria Intelligence Observatory website: <http://www.cumbriaobservatory.org.uk/antipoverty/ID.asp> .

Cumbria's rurality means that many residents face barriers in accessing key services whether by public transport, walking and cycling, or by car. Access times to key local services are higher than the national average. Further information about connectivity and travel times can be found on the Cumbria Intelligence Observatory website: <http://www.cumbriaobservatory.org.uk/economy/Transport.asp> .

Consideration should be given to those living in rural areas and the way in which services are delivered; where possible, emphasis should be given to digital solutions; and the use of community services.

## 6.10 Support for carers



There are many provisions of support for Carers' through various bodies including Cumbria County Council, Cumbria Carers Organisation, and many other organisations. Support includes:

### **6.10.1 Respite care**

Quality of life issues, and lack of time for keeping up with family, friends and hobbies suggests that carers need regular breaks from their caring responsibilities in order to sustain their role as carers. The 2009-10 Survey of Carers in Households – England reported that 66% of carers would need someone else to care for their main cared for person if they wanted to take a break for a day or two. Whilst 84% had someone that they could rely on if required to look after their main cared for person, 16% (or 11% of all carers) had no one at all to rely on. The survey found that 42% of the carers who would need someone else to look after their cared for person in order to have a break of at least 2 days had not taken a break since they started caring (Source: HSCIC). Just over a quarter of carers (27%) would need someone else to look after their cared for person if they needed a break of just a couple of hours.

However, the take up of respite care services appears low. The “2009-10 Survey of Carers in Households – England” indicates that only 3% of cared for people had used a sitting or befriending service in the previous 12 months. The reasons for low uptake are not fully understood. However, the 2015 “Dementia in the Family, the impact on carers” (Source: Alzheimer’s Research UK) reports that although carers are aware that respite care is potentially available to provide a break, a sense of duty and responsibility prevented carers accessing the support, as carers did not consider that it would be right or practical to leave their loved one with someone else. The 2015 “You don’t stop the worrying: The difficulties of caring in later life” reported that some carers had refused respite services due to poor quality services being offered (Source: Independent Age).

Nationally, many carers face further barriers to some level of respite. In the “2009-10 Survey of Carers in Households – England” 37% of carers reported that their main cared for person went to any outside places or activities that they were offered. The reason for this is unclear, but transport may be an issue. A relatively low proportion (13%) of cared for people appeared to regularly make use of community or voluntary transport. Around a fifth (19%) of carers stated that the person they looked after regularly went to a social club or similar, 10% attended school or college, 8% attended a day centre, and 5% went to work. (Source: HSCIC). In Cumbria, it is understood that there are barriers to respite care, too. Feedback from both Carers Organisations and Cumbria County Council suggests that applications for respite care are often turned down and therefore prevent future requests.

### **6.10.2 Carers Contingency Plans (Cumbria Carers Emergency Card)**

The Carers Contingency Plan is more widely known as the Cumbria Carers Emergency Card. The scheme is designed to give reassurance to the carer using pre-agreed arrangements in the form of an Emergency Plan covering a 72-hour (3day) period. The Emergency Plan comes into action if something like an accident or sudden illness meant that the carer was unable to look after the person they care for. The Carers Contingency Plan is



discussed as part of the Carer's Assessment and Supported Self-Assessment under Planning for Emergencies.

### 6.10.3 Information and advice

Information is not available for Cumbria, however, nationally we know that consultation on the national strategy identified that carers require better and well timed information on a range of topics such as including the illness or condition of the person they are caring for, appropriate caring, accessing benefits and other support, and financial and employment issues (Source: Adult Carers Strategy, 2016. CCC).

Other factors limit the support that can be provided to all carers. Research by Alzheimer's Research UK (Source: Dementia in the Family, the impact on carers, 2015) suggests that many male carers are reluctant to describe themselves as carers or to ask for help to support them in their caring role (as identified in Section 2 – Key issues and gaps: known carers are most likely to be female and male carers are less likely to be identified). Another problem is reaching out to carers that are not known. Many young carers do not have contact with support agencies and are hidden from view (Source: Hidden from View, The Children's Society, 2013). Cumbria's Adult Social Care teams are also unable to identify all carers in Cumbria, as not all are referred (Source: Adult Carers Strategy for Cumbria, 2016, CCC).

The satisfaction with services of carers of people using Adult Social Care is directly linked to a positive experience of care and support. Analysis of user surveys suggests that reported satisfaction with services is a good predictor of the overall experience of services and quality. 42.0% of carers in Cumbria are satisfied with social services (as reported in the 2014-15 Adult Social Care Outcomes Framework), above the England average of 41.2%. 67.7% of carers reported that they have been included or consulted in discussion about the person they care for, below the England average of 72.3%.

### 6.10.4 Reablement

By providing support at home, reablement is a service aimed at helping people regain independence, rebuild skills and confidence following a hospital admission or similar episode; reablement may also help to prevent future hospital or care home admissions. It is a free short term service provided for up to six weeks. Reablement helps people to live independently by providing support with daily tasks and encouraging individuals to do things for themselves. Reablement can help carers to continue to care by helping to reduce the burden or by enabling a person to be cared for at home who may otherwise need to go into residential care. Reablement can also relieve pressure on the carer and slow the speed at which they decline and ultimately need care themselves (source: Carers Strategy, Ref: 014). Because of the way in which reablement is recorded it is difficult to identify the service which is directly linked to a carer, however, what we do know is that around 2,500 reablement plans are started throughout a year equating to 1 in 5 service users. The proportion of reablement plans is lowest in Carlisle at 15% (of all service users) compared to 25% in Allerdale. For those aged 65+, the rate in Cumbria increases to 1 in 4 service users, in

Carlisle this increases to 1 in 5. If more plans took place more support could be provided to both the carer and cared for.

### 6.10.5 Former carers

Carers can receive support up to a year after the date they become a former carer, in most cases this support finishes within the 12 month period. The main emphasis is to ensure the appropriate support is there to maintain the health and wellbeing of the former carer either through peer support, one to one support or by sign-posting to more appropriate services. Carers Support Cumbria retain a former carers register.

## 7 Geographical differences in need

Information about carers is not readily available by GP practice boundaries or the North and South health boundaries (Cumbria Clinical Commissioning Group), however, where possible consideration should be given to these areas when commissioning services in the future.

The following section will be broken down by standard local authority statistical geographical boundaries, however, it is important to note that Cumbria's Adult Social Care localities and Carers Support Cumbria localities are not coterminous; ASC and Carers Support Cumbria localities are based on operational boundaries. Further details can be found in Appendix 1 - Maps.

### 7.1 Allerdale

10,774 people living in Allerdale provide unpaid care, 11.3% of the total population (above the England average of 10.2%). The majority of those (61.6%) provide between 1 to 19 hours of unpaid care per week; while 25.1% provide 50 or more hours per week.

There are approximately 1,395 carers in the locality of Allerdale who are known to Adult Social Care and who are in receipt of support. There are 920 adult carers registered with West Cumbria Carers who live in Allerdale.

72% of residents living in Allerdale are living in rural areas, this is above the county average (54%) and significantly greater than the England average (18%). Access to support and services may be a significant issue in parts of the district therefore the need to ensure that these are accessible is fundamental.

There are greater proportions of residents aged 65+ years in Allerdale (22.9%) compared to England (17.6%). Numbers of people aged 65+ years are projected to increase, year on year, until 2037.

The proportion of carers with evidence of direct support from Adult Social Care is low in Allerdale compared to the county average (13% in the district compared to 16% in Cumbria).

40% of all service users in Allerdale are not reviewed or reassessed in a 12 month period (including joint assessments with carers), proportions of those not reviewed or reassessed is increasing.

Numbers of Carers Assessments are low in Allerdale, at a rate of 17.7 per 10,000, compared to 31.5 in Eden.

The number of young adult carers who have received support from Carers Organisations are low in Allerdale compared to other areas.

1 in 5 residents in Allerdale have a limiting long-term illness, greater proportions than England (20% compared to 17%).

By 2030, the number of residents aged 65+ years 'unable to manage at least one activity on their own' is predicted to increase by 46% (+1,820).

Numbers of residents with dementia are predicted to increase; by 2030, 2,371 residents aged 65+ years are predicted to have dementia (+60%).

There are areas of the district where disability free life expectancy for a male is significantly low, just 57.1 years compared to 64.1 years in England; for some females it is as young as 58.2 years compared to 65 years in England.

## 7.2 Barrow-in-Furness

8,245 people living in Barrow-in-Furness provide unpaid care, 11.9% of the total population (above the England average of 10.2%). More than half of those (55.5%) provide between 1 to 19 hours of unpaid care per week; while almost one third (28.7%) provide 50 or more hours per week.

There are approximately 1,579 carers in the locality of Furness who are known to Adult Social Care and who are in receipt of support. There are 971 adult carers registered with Furness Carers who live in Barrow-in-Furness.

The proportion of carers with evidence of direct support from Adult Social Care is low in Furness compared to the county average (around 8% in the district compared to 16% in Cumbria).

Almost half (around 48%) of all service users in Furness are not reviewed or reassessed in the last 12 months (including joint assessments with carers).

There are greater proportions of residents aged 65+ years in the district (20.7%) compared to England (17.6%). Numbers of people aged 65+ years are projected to increase, year on year, until 2037.

Almost 1 in 4 residents in the district (24%) have a limiting long-term illness, above the England average (17%).

By 2030, the number of residents aged 65+ years 'unable to manage at least one activity on their own' is predicted to increase by 40% (+992).

Numbers of residents with dementia are predicted to increase; by 2030, 1,464 residents aged 65+ years are predicted to have dementia (+54%).

There are areas of the district where disability free life expectancy for a male is significantly low, just 51.7 years compared to 64.1 years in England; for some females it is as young as 52.7 years compared to 65 years in England.

Rates of residents in receipt of a carers allowance in Barrow-in-Furness are greater than England average (2.2 compared to 1.5, per working age population).

### 7.3 Carlisle

11,305 people living in Carlisle provide unpaid care, 10.5% of the total population (above the England average of 10.2%). The majority of those (64.0%) provide between 1 to 19 hours of unpaid care per week; while almost 1 in 4 (23.5%) provide 50 or more hours per week.

There are approximately 1,989 carers in Carlisle who are known to Adult Social Care and who are in receipt of support. There are 1,696 adult carers registered with Carlisle Carers.

Around 44% of all service users in Carlisle are not reviewed or reassessed in a 12 month period (including joint assessments with carers), this is above the county average of 42%; and has been continually increasing.

Numbers of Carers Assessments are low in Carlisle, at a rate of 15.3 per 10,000.

The rate of reablement plans for Adult Social Care service users are low in the district at 44.0 per 10,000 compared to 64.0 in the county.

There are greater proportions of residents aged 65+ years in the district (20.1%) compared to England (17.6%). Numbers of people aged 65+years are projected to increase, year on year, until 2037.

Almost 1 in 5 residents in Carlisle have a limiting long-term illness, greater proportions than England (19% compared to 17%).

By 2030, the number of residents aged 65+ years 'unable to manage at least one activity on their own' is predicted to increase by 49% (+1,919).

Numbers of residents with dementia are predicted to increase; by 2030, 2,422 residents aged 65+ years are predicted to have dementia (+62%).

There are areas of the district where disability free life expectancy for a male is significantly low, just 56.9 years compared to 64.1years in England; for some females it is as young as 58.3 years compared to 65 years in England.

### 7.4 Copeland

7,981 people living in Copeland provide unpaid care, 11.3% of the total population (above the England average of 10.2%). More than half of those (58.8%) provide between 1 to 19 hours of unpaid care per week; while 1 in 4 (26.4%) provide 50 or more hours per week.

There are approximately 1,022 carers in the locality of Copeland who are known to Adult Social Care and who are in receipt of support. There are 818 adult carers registered with West Cumbria Carers who live in Copeland.

There are greater proportions of residents aged 65+ years in the district (21.0%) compared to England (17.6%). Numbers of people aged 65+years are projected to increase, year on year, until 2037.

65% of residents living in Copeland are living in rural areas, this is above the county average (54%) and significantly greater than the England average (18%). Access to support and services may be a significant issue in parts of the district therefore the need to ensure that these are accessible is fundamental. Copeland has the longest average travel time to key services than any other district in the county.

The proportion of carers with evidence of direct support from Adult Social Care is low in Copeland compared to the county average (around 13% in the district compared to 16% in Cumbria)

45% of all service users in Copeland are not reviewed or reassessed in a 12 month period (including joint assessments with carers), this is above the county average; levels have been continually increasing.

Numbers of Carers Assessments are low in Copeland, at a rate of 18.6 per 10,000.

1 in 5 residents in Copeland have a limiting long-term illness, above the England average (21% compared to 17%).

By 2030, the number of residents aged 65+ years 'unable to manage at least one activity on their own' is predicted to increase by 56% (+1,238).

Numbers of residents with dementia are predicted to increase; by 2030, 1,557 residents aged 65+ years are predicted to have dementia (+64%).

There are areas of the district where disability free life expectancy for a male is significantly low, just 56.9 years compared to 64.1 years in England; for some females it is as young as 58.8 years compared to 65 years in England.

Rates of residents in receipt of a carers allowance in Copeland are greater than England average (2.2 compared to 1.5, per working age population).

## 7.5 Eden

5,962 people living in Eden provide unpaid care, 11.3% of the total population (above the England average of 10.2%). The majority of those (70.6%) provide between 1 to 19 hours of unpaid care per week; while 1 in 5 (19.0%) provide 50 or more hours per week.

There are approximately 1,175 carers in the locality of Eden who are known to Adult Social Care and who are in receipt of support. There are 745 adult carers registered with Eden Carers.

71% of residents living in Eden are living in rural areas, this is above the county average (54%) and significantly greater than the England average (18%). Access to support and services may be a significant issue in parts of the district therefore the need to ensure that these are accessible is fundamental.

There are greater proportions of residents aged 65+ years in the district (24.5%) compared to England (17.6%). Numbers of people aged 65+ years are projected to increase, year on year, until 2037.

38% of all service users in Eden are not reviewed or reassessed in a 12 month period (including joint assessments with carers); levels have been continually increasing.

Eden has the lowest number of assessment reviews than all areas across the county. Numbers of care plans are low in Eden (possibly reflecting lower numbers of registered carers).

The rate of reablement plans for Adult Social Care service users are low in the district at 51.3 per 10,000 compared to 64.0 in the county.

80% of residents with a limiting long-term illness are aged 50+ years, greater proportions than England (73%).

By 2030, the number of residents aged 65+ years 'unable to manage at least one activity on their own' is predicted to increase by 56% (+1,294).

Numbers of residents with dementia are predicted to increase; by 2030, 1,472 residents aged 65+ years are predicted to have dementia (+62%).

There are areas of the district where disability free life expectancy for a male is significantly lower than the England average, 62.8 years compared to 64.1 years in England.

## 7.6 South Lakeland

12,228 people living in South Lakeland provide unpaid care, 11.8% of the total population (above the England average of 10.2%). The majority of those (70.2%) provide between 1 to 19 hours of unpaid care per week; while 1 in 5 (19.0%) provide 50 or more hours per week.

There are approximately 1,331 carers in the locality of South Lakeland who are known to Adult Social Care and who are in receipt of support. There are 1,170 adult carers registered with South Lakeland Carers who live in South Lakeland; and an additional 242 adult carers who are registered with Furness Carers but who live in South Lakeland.

61% of residents living in South Lakeland are living in rural areas, this is above the county average (54%) and significantly greater than the England average (18%). Access to support and services may be a significant issue in parts of the district therefore the need to ensure that these are accessible is fundamental.

South Lakeland has high proportions of residents aged 65+ years, 26.9% compared to 17.6% in England. Numbers of people aged 65+ years are projected to increase, year on year, until 2037.

High numbers of older people, in particular those aged 65+ living alone, therefore greater demands on social care and carers. Greater numbers of people with dementia in South Lakeland = greater demand on care and support.

35% of all service users in South Lakeland are not reviewed or reassessed in a 12 month period (including joint assessments with carers); levels have been continually increasing.

Compared to other areas, South Lakeland has relatively low numbers of assessment reviews. Numbers of care plans are low in the district.

81% of residents with a limiting long-term illness are aged 50+ years, greater proportions than England (73%).

By 2030, the number of residents aged 65+ years 'unable to manage at least one activity on their own' is predicted to increase by 44% (+2,232).



Numbers of residents with dementia are predicted to increase; by 2030, 3,127 residents aged 65+ years are predicted to have dementia (+59%).

There are areas of the district where disability free life expectancy for a male is significantly lower than the England average, 61.9 years compared to 64.1 years in England; for females it is 63.6 years compared to 65 years in England.

## **8 Housing**

It is a priority within Cumbria to help older people and people with disabilities to live independent lives by remaining in their own homes for as long as possible, in order to do this suitable housing is needed. Not only does this help the individual but it can help to support those who are providing care. In order to support carers, a number of organisations including local authorities and housing organisations/providers have a key role to play, and it is vital that good working relationships are maintained.

As people get older, their housing needs often change. Some people need support to be able to continue living in their own home, which may mean their homes need to be adapted. Younger people with disabilities may also require adaptations in their home. Some people may be unable to care for themselves or be cared for at home and the only option for them is residential care or nursing care homes.

### **8.1.1 Assistive Technology**

There are a number of support systems in place across the county including assistive technology services such as Telecare which provides sensors, detectors and a call button in an individual's home which are connected to carers (via a telephone line) which can raise an alarm if help is needed. The system can help individuals if they have had a fall; and can even help with dementia through location devices when an individual may stray from their home. The service is available 24 hours per day. Assistive technology not only supports the individual but it can also help to reduce the burden on carers.

### **8.1.2 Daily Living Equipment**

There is a wide range of daily living equipment available for the home, such as grab rails; bath lifts; ramps for wheelchairs; stair lifts etc. Equipment can be made available through Adult Social Care following completion of an assessment form; or the NHS, and may be free of charge. Organisations such as Age UK can also provide advice and support, or an individual may go to a retailer direct. Carers organisations are also proactive in terms of providing information about what is available and signposting people appropriately. There is an Independent Living Centre based in Workington with hubs in Millom, Egremont, Whitehaven, Maryport, Cockermouth and Wigton; these provide advice as well as 'try before you buy' schemes.

### **8.1.3 Adaptions**

Adaptions may be made to a home which can be arranged through Adult Social Care or the NHS, if the work is minor it may be provided by the landlord or council. If major work is



needed in the home then grants may be available to help pay for the work through, again through Adult Social Care. Individuals may be asked to make a contribution towards the cost depending on their current and financial situation. Grants for adaptations to the home are available through the Disabled Facilities Grants scheme.

#### 8.1.4 Extra Care Housing

The County Council has a commitment to support older and vulnerable people by investing in Extra Care housing (ECH). ECH will help to reduce the need for individuals to be placed in residential or nursing care. Compared to other local authority areas, Cumbria has a low level of supply of Extra Care housing (ECH).

Existing ECH schemes across Cumbria include: Allerdale: Greta Gardens, Keswick and Fairview Court in Wigton; Carlisle: Burnside Court, Heysham Gardens, Lister Court and Sycamore House in Carlisle; Copeland: Duddon Mews in Millom, and Monkway Court in Whitehaven; Eden: Lonsdale Court and Woodlands in Penrith, Rampkin House in Appleby, and Mill Gardens in Kirkby Stephens; Furness: Station View in Barrow-in-Furness; South Lakeland: Birthwaite in Windermere, Jenkins Crag Court and Lound Place in Kendal, and Rowan Court in Ambleside. Both Lister Court and Sycamore House in Carlisle are primarily for younger adults with a disability. (Source: Cumbria County Council, Extra Care Housing Factsheet, March 2015, Ref: 050)

#### 8.1.5 One (single) person households

People living on their own may be at risk of not receiving the help and support that they need at home from a partner or family member. It is helpful to consider one person households in order to identify those who are most vulnerable and whom may need support from a carer. 32% of households in Cumbria are one person households, this is above the England average of 30%. There are greater proportions of one person households in the districts of Barrow-in-Furness (35%) and Carlisle (34%). Almost half (45%) of all one person households in Cumbria are residents aged 65+, above the England average of 41%. The greatest proportion of 65+ one person households are in the districts of South Lakeland (50%) and Eden (48%); the lowest proportions are in Carlisle (41%) and Barrow-in-Furness (42%).

Within the districts, the greatest proportion of one person households are in the ward of Barrow Island (54%); Christchurch ward in Allerdale (44%); Castle ward in Carlisle (48%); Harbour ward in Copeland (48%); Penrith Pategill in Eden (41%); and Kendal Fell in South Lakeland (46%). Almost 3 in 4 households in the ward of Hawcoat in Barrow-in-Furness are 65+ one person households; in Allerdale, the greatest proportion are in the ward of Derwent Valley (58%); Stanwix Urban in Carlisle (58%); Haverigg in Copeland (63%); Dacre in Eden (61%); and Grange South in South Lakeland (70%). (Source: Census, 2011, Ref: 012). It is possibly that these areas have greater numbers of carers whether they are known to Adult Social Care or not.

#### 8.1.6 Residential and nursing care

As people get older and as health deteriorates, the need for care and support increases. Often an individual may remain at home with the help and support from a carer; however, others may be placed in a residential nursing or care home. In areas where there are low

proportions of older people in residential nursing care there may be a greater need for carers. In Cumbria, there are around 2,500 people in Cumbria who are in residential and nursing care, 86.4% of those are aged 65+ years; while almost half (49.7%) are aged 85+ years. The greatest proportion of residents aged 65+ who are in residential/nursing care are resident in the districts of Allerdale (20.1%) and Carlisle (20.1%). There are fewer proportions of older people in residential/nursing care in Eden (9.5%).

New admissions to residential and nursing care are increasing and rates are above national levels. Around 93% of new admissions are people aged 65+; while almost half (48.1%) of those are aged 85+. Rates of new admissions are greater in Allerdale and Furness, they are lowest in Carlisle (Source: Accommodation – Residential/Nursing Care, Adult Social Care, CCC, September 2015).

### 8.1.7 Projected numbers of people living in care homes

Numbers of people living in care homes are projected to increase in Cumbria; yet if we are to enable older people to remain in their homes then the need and demand for carers will also increase to match this. Over the next 5 years numbers of those aged 65+ living in a care home with or without nursing are predicted to increase by 18%, from just over 3,600 in 2014 to over 4,300 in 2020. By 2030, numbers are projected to significantly increase by 65% to over 6,000 residents. (See Figure 14 below).

**Figure 14: Cumbria: Projected population aged 65 years and over living in a care home with or without nursing, 2014 – 2030.**

	2014	2015	2016	2017	2018	2020	2025	2030
<b>Cumbria</b>	3,677	3,780	3,893	4,007	4,119	4,349	5,207	6,053
<b>Allerdale</b>	804	830	856	877	905	953	1,162	1,340
<b>Barrow-in-Furness</b>	468	473	491	509	516	540	640	730
<b>Carlisle</b>	693	711	726	748	769	824	958	1,126
<b>Copeland</b>	463	483	484	506	524	565	670	779
<b>Eden</b>	369	386	389	404	423	447	557	651
<b>South Lakeland</b>	879	899	930	950	975	1,025	1,228	1,431

(Source: POPPI, 2015)

### 8.1.8 District Housing Surveys

The results from Allerdale Borough Council's Housing Survey will be available in June/July 2016.

## 9 Current services and assets including projections

Carers themselves are an asset. They provide an invaluable service to those who need them; often preventing individuals from requiring full-time care for example in residential or nursing care, by enabling individuals to stay at home by providing help and support. They help to significantly reduce the burden on services including the NHS and local authorities.

There are many services and assets available to help support the health and wellbeing of carers' across Cumbria, including provision from Cumbria County Council, other local authorities, and Carer's organisations, some of these include:

### **9.1.1 Adult Social Care**

Adult Social Care and local carers organisations work together to provide support to carers. Carers can have an assessment of their own needs as a carer rather than for the person they are caring for. Support for carers can include:

- Information and advice
- Breaks (sometimes called respite care)
- Carers' emergency card
- Emotional support
- Support at home
- Daily living equipment and adaptations to the home
- Telecare alarms
- Car badges for disabled drivers and passengers

For each carer making contact with health and social care a care pathway is followed. The initial step is the Assessment which is carried out by a practitioner/social worker, or a support worker at Cumbria's Carers organisation; carers are entitled to have an assessment of their own needs as a carer rather than the person they care for. Following an assessment the carer may then be given a care plan depending on their current situation and level of need. Throughout 2015 (January – December), a total of 2,028 support plans were completed by Carers Support Cumbria. In many cases health and social care are able to provide support in the way of information, help and advice thus further support is not needed.

### **9.1.2 Carers Organisations – Carers Support Cumbria**

Carers Support Cumbria is the consortium of local organisations partly funded by Cumbria County Council who provide support to carers. The organisations which make up the consortium are: Carlisle Carers; Eden Carers; Furness Carers; South Lakeland Carers; and West Cumbria Carers.

Carers organisations play a key role in supporting carers; they provide important help and advice and support while also helping to identify those most vulnerable and those most in need of support. Carers Support Cumbria provides support to around 15% of those known to Adult Social Care. The organisation not only supports those known to Adult Social Care but they support a significant number of other carers in the community who do not receive formal social care support. Carers Support Cumbria are pro-active in terms of reaching out to carers by being visible in the community and providing invaluable help and support.

There are a number of roles and services provided within Carers organisations including support workers, volunteers; and therapy and counselling services. In the Furness locality,

dementia support workers are subcontracted to the Alzheimers Society; while drug and alcohol support across the county is provided by CADAS.

Carers organisations are proactive in reaching out to carers; they hold regular forums across the county involving various health and social care organisations. They hold coffee mornings and drop in sessions; while some have sessions in GP surgeries.

Carers Support Cumbria are contracted to provide a range of services and have a set of key outcomes which they must deliver, as set out below:

- Outcome 1: Carers are actively sought and identified
- Outcome 2: Carers are provided with up-to-date information, advice and guidance
- Outcome 3: Carers Receive Carers Assessments
- Outcome 4: Young Adult Carers (16-25 years) are identified, engaged and supported through their transition into adulthood
- Outcome 5: Carers are engaged and supported to plan for the future
- Outcome 6: Carers feel empowered and engaged
- Outcome 7: Carers wellbeing is improved through the provision of emotional support
- Outcome 8: Health and Wellbeing Support for Carers
- Outcome 9: Increased partnership with Social Care, Health, Voluntary and Community Sectors
- Outcome 10: Increased knowledge, skills and behaviours of Carers and professionals through training and development opportunities

### **9.1.3 Employment Liaison Officers**

Supporting Unpaid Carers in Employment – There are two Employment Liaison Officers based at South Lakes Carers covering the whole of Cumbria and offer guidance for employers in Cumbria.

- Carers directory
- Advice hubs
- Specific support groups for carers e.g. carers support groups, carers associations, peer support groups organised by Age UK, condition specific support groups e.g. cancer.

Cumbria County Council works with individuals, families and communities to promote independence in the home, reducing the need for formal services and ensuring everyone can be as independent as possible. The Council has a commitment to join up the commissioning and delivery of services with the NHS wherever this will add value.

### **9.1.4 Carers Support Cumbria (Carers Organisations)**

Carers Support Cumbria is a consortium of carer services providers combining the following organisations across the county: Carlisle Carers Association; Eden Carers; Furness Carers; South Lakeland Carers; and West Cumbria Carers. Each organisation helps to deliver, on behalf of Cumbria County Council, targeted support services for: unpaid carers, young adult carers, young carers, those who are being cared for and their families. The services provided include: assessments, support plans, health and wellbeing support and associated personalised support services.

### 9.1.5 Employers for Carers

Employers for Carers is a national DWP Initiative for those aged 50+ years. It is a service for employers to help retain the 1 in 7 people in the workplace who are caring for a family member. They promote the business benefits of supporting carers and provide advice and support on carer friendly policy and practice. Employers for Carers aims to help businesses remain competitive with a healthy and productive workforce.

### 9.1.6 Reablement

The home care reablement service provided by Cumbria County Council aims to help people regain independence following illness, injury, disability or loss of personal support network by providing support at home and in their community. It is a free service provided for a short period of time, usually up to six weeks. Reablement helps people to live independently by providing support with daily tasks and encourages them to do things for themselves. Reablement may include equipment such as Telecare or assistive technology.

Reablement may help carers to continue care for by helping to reduce the burden or enable a person to be cared for at home who may otherwise need to go into residential care. Reablement can also relieve pressure on the carer and slow the speed at which they decline and ultimately need care themselves (source: Adult Carers Strategy for Cumbria, 2015, CCC).

### 9.1.7 Equipment and Assistive Technology

Equipment for the home is available for the cared for which can help the carer, through Adult Social Care or the NHS. Assistive technology such as Telecare is also available within the home. (Further information relating to assistive technology can be found in section [8.1.1](#)).

### 9.1.8 Day Services

Cumbria County Council day services are provided in purpose built day centres, residential homes and community centres, predominantly located in centres of population. There has been a decrease in the take-up of day services in recent years due to the service criteria and an increase in direct payments. There are independent day services across Cumbria also. Day Services available are:

Allerdale:	Westhouse Day Opportunities, Florence House Day Centre, Allerdale COSC. Age UK West Cumbria (Workington, Maryport, Cockermouth, Keswick)
Barrow-in-Furness:	GDSK Day Services, Mill Lane; Bevan House Day Centre, Dalton Day Centre
Carlisle:	Making Space Day Centre, Carleton Day Centre, Croftlands Trust; Petteril House Day Centre, Langrigg House Day Centre
Copeland:	Copeland COSC, Blengdale Day Centre, Powbeck Day Centre, Cross Keys Day Centre, Age UK West Cumbria (Whitehaven, Cleator Moor, Millom)
Eden:	Dementia Day Centre (Appleby and Penrith), Edington Centre; Tynefield Drive Day Centre
South Lakeland:	Cameo Day Care

### 9.1.9 Day opportunities

Many people require more personalised day services which are often based on activities provided in communities, these are known as day opportunities. They are designed around individual interests and preferences and through Adult Social Care **personal budgets** and **direct payments** an individual is given more choice. Day opportunity options include: social groups and lunch clubs; shopping; visiting cafes and restaurants; leisure, arts and crafts activities; training; volunteering and employment opportunities. This approach has been widely adopted by younger adults, but its popularity is now increasing amongst older people.

Day opportunities including a range of activities and luncheon clubs are supported to provide both the cared for and carers opportunities to maintain contacts, hobbies and interests.

Mens groups (based on the Australia Men's Shed Association models) operate in Wigton, Caldbeck, Cockermouth, Workington, Distington, Whitehaven, and Millom.

### 9.1.10 Carers' budgets

Carers budgets are payments awarded by Cumbria County Council to help carers buy services or goods in order to help them to continue to provide essential care. Eligibility of this support is identified in the carers' assessment process. Support may include services recreational activities, a short term break or practical equipment in the home.

### 9.1.11 Domiciliary care in Cumbria

Cumbria County Council currently has 47 domiciliary care providers across the county, all providing a total of more than 24,000 hours of care. The rates paid to domiciliary care providers are set by the Council; in 2015, the average weekly fee rate (per hour) £14.00. Contracts for services are reviewed on a regular basis. Age UK West Cumbria runs a help at home service which supports carers with general household activities, shopping etc. and can provide a sitting service where no personal care is needed.

### 9.1.12 Extra Care Housing (ECH)

Extra Care Housing - the county council is committed to support older and vulnerable people to live independent and healthy lives by investing in Extra Care housing across the county to enable people to live independently for longer.

Cumbria County Council has developed an Extra Care Housing (ECH) Strategy that is compatible with the Cumbria Housing Plan and Investment Strategy 2011-2015. The aim of the County Council ECH Strategy is to enable people in Cumbria to plan for their future and realise their aspirations to live independently. It will complement and support the work of our colleagues in Housing who share this aim. The ECH strategy identifies demand for ECH for older people to be 1800 units (apartments) by 2019 – currently Cumbria has approximately 377 units available for social rent. Cumbria currently has 12 ECH schemes supported by CCC (i.e. provision of care services on site.) The Number of ECH units = 377 approximately and includes some specialist provision. CCC is currently working with Registered Housing

Providers to develop a further 5 affordable rent ECH schemes due 2015 – 2016 and one mixed tenure scheme 2015, adding a further 196 units to the current figure.

### **9.1.13 Services for young carers**

Young carers need to be able to have the same life chances as other young people. Via Cumbria's carer organisations a variety of support is available to young carers.

Services available to young carers through Carlisle Carers include:

- One to one support
- Trips and social events
- A regular Youth Group
- Newsletter
- Support in school
- Signposting and referral to other support services

Eden Carers offer tailored support to young carers aged from 5 to 18, and social activities including an after school club. Furness Carers provide services to young carers that include respite breaks, one to one support, the opportunity to spend time with other young carers, and after school clubs.

South Lakeland Carers offer a support groups for a range of ages: a pre-junior group for children aged between 5 and 7 years old, a junior group for those aged between 8 and 12 years, and a senior group for young people aged between 13 and 15 years. Young carers are able to participate in a variety of day and residential trips.

West Cumbria Carers along with ensuring that young people can take part in trips and activities also offer support in the transition period from young carer to adult carer. Support workers are available to work with carers aged from 14 to 25.

### **9.1.14 Neighbourhood Care Independence**

Neighbourhood Care Independence is a place based service which has help lines in Whitehaven for West Cumbria and Penrith for North, East and South Cumbria. This enables those who require support to call for information and to enable effective signposting to relevant agencies and organisations. The Helplines are used by Carers, particularly at the beginning of their journey.

## **10 Evidence of what works**

Carers Support Cumbria is the consortium of local organisations contracted to Cumbria County Council who can provide this support. The organisations which make up the consortium are:

- Carlisle Carers
- Eden Carers
- Furness Carers



- South Lakeland Carers
- West Cumbria Carers

Carers organisations play a key role in supporting carers; they provide important help and advice and support while also helping to identify those most vulnerable and those most in need of support. Cumbria's Carers organisation provides support to around 15% of those known to health and social care. The organisation not only support those known to health and social care, but they support a significant number of other carers in the community who do not require formal social care support. Carers' organisations are pro-active in terms of reaching out to carers by being visible in the community. Information, help and support is readily available to carers through this fundamental provision.

The NHS Five Year Forward View commits the NHS to find new ways to support carers, to build on the new rights created by the Care Act and to help the most vulnerable carers – the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85. Whilst commissioners and practitioners cannot solve all of the challenges faced by carers, much more could be done to support them and help ensure that they receive the recognition and support that they need and deserve from the NHS (Source: Principles and resources to support effective commissioning for adult and young carers, NHS England, December 2014).

The Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers, is a practical tool and part of a suite of products that will help commissioners to deliver what carers say is important to them in ways that have been shown to work effectively and efficiently in practice. The Principles are based on the latest research, case-studies and best-practice and are the vital and common ingredients to deliver better outcomes for carers, patients, commissioners, practitioners and local communities. They are:

1. Think Carer, Think Family; Make Every Contact Count
2. Support what works for carers, share and learn from others
3. Right care, right time, right place for carers
4. Measure what matters to carers
5. Support for carers depends on partnership working
6. Leadership for carers at all levels
7. Train staff to identify and support carers
8. Prioritise carer's health and wellbeing
9. Invest in carers to sustain and save
10. Support carers to access local resources

The Commissioning for Carers Principles form part of NHS England's Commitments to Carers, published on 7 May 2014, and the RCGP Supporting Carers in General Practice

Programme, to help in identifying, supporting and recognising the vital roles that carers play to support them to provide better care and to stay well themselves. This report noted that the improving support for carers was a journey and the Commitments represented a first step in this journey.

**Fit for the Future** – is a programme designed to help a person lead a more active and healthy lifestyle and fulfilling life. A Fit for the Future Support worker will visit a person at home to discuss their needs and issues which are important to them and help them to identify areas of their life where they would like support e.g. socialising, eating more healthily, physical exercise Etc. They will be given support to explore local opportunities and their support worker will agree with them a plan of action and set achievable goals. Ongoing support and encouragement will be given to the client to help them follow their plan and they will link the client up to other service to meet any additional needs they may have. This is a free service for anyone age 55 + living in the Workington and Maryport areas. The service is for those with long term health conditions (e.g. diabetes, high blood pressure, COPD) and those who want a more socially included and active later life. A person can refer themselves or be referred by a family member or friend (with their permission). They can also be referred by a GP, Health or Social worker. This programme ended in March 2015 but subsequent funding now means that it will operate across all of Allerdale and Copeland from April 2016.

**Peer Support Groups** – Age UK South Lakeland and West Cumbria provide a series of dementia peer support groups in Kendal, Milnthorpe and Ambleside. The purpose is to provide information, advice and coping strategies and to promote self-care, independence, wellbeing and choice for people with dementia and their carers. Funding for these groups has now come to an end however, in 2016, Age UK South Lakeland aim to support Alzheimer's Society, Dignity in Dementia and South Lakeland Carers in their work.

**Dementia Awareness** - Age UK deliver dementia awareness training sessions to groups as diverse as local councillors, residents and staff at sheltered housing schemes, local retailers and also to three groups of young people participating in the National Citizens Scheme.

**Dementia Friends programme** - dementia cafes facilitated by the Alzheimers Society are established in the Furness area: Askam-in-Furness, Barrow-in-Furness, Dalton-in-Furness, Ulverston, and Walney Island.

**Cumbria Deaf vision** - provide services, advice and support for people who are deaf in Cumbria.

**Sight Advice South Lakes** - provide services, advice and support for people with sight problems in Cumbria.

**Parent Carers** - The Cumbria Parent Carer Forum provides parents, carers, grandparents and foster carers in Cumbria with a way to work with local authorities, education, health and other service providers in order to influence and to have a say in the commissioning and delivery of services so that they meet the needs of children and families.

**Mind Cumbria** provides support and advice to people (and carers) who are experiencing a mental health problem. The organisation is a consortium of:

- Carlisle/Eden Mind

- Mind in West Cumbria
- South Lakeland Mind
- Ulverston Mind
- Mind in Furness

## 11 User views

### 11.1 Adult carers

The Caring for Others Survey 2012-2013 was carried out by Cumbria County Council's Adult Social Care team to investigate the views of carers in the county. Surveys were circulated to 900 carers identified via the county's carer organisations and represented all groups receiving services from Adult Social Care, and were carers who had received an assessment or review of their caring needs in the 12 months prior to September 2012.

Almost half the surveys were returned (48.5%) and the views of carers known to Adult Social Care are summarised below.

Three main areas were identified by carers as being of the greatest importance to them. These are:

- being involved or being consulted in discussions relating to the person that they care for;
- the availability of support or services in the event of any emergency or crisis situation;
- having their needs as a carer recognised and appropriate support or services identified.

The majority of responding carers (80%) reported that that were always or usually involved or consulted in discussions relating to the person they care for. However, this indicates that one in five feel ignored, and consider that their views are not taken into account.

Cumbria's carers also consider communication to be important. They report that it is important to receive good quality, consistent information and advice from professionals to help them carry out their caring role. In particular, carers require information and advice about the illness or condition affecting the person that they care for. The preferred mode of receiving information and advice is face to face, by telephone or via leaflets. The respondents to the survey do not appear keen to access information and support on line; this could be due to the older profile of the carers.

Almost three quarters (73%) report that it is either very or fairly easy to find information; this indicates that just over a quarter (27%) experience some degree of difficulty. Some of the comments around communication relate to the awareness of staff and organisations (mainly Adult Social Care and health) about the support available for carers; carers find it frustrating not being provided with information that they later find out from other sources, or being provided with conflicting information from different organisations. Carers also outlined other communication issues such as lack of contact, poor follow up and the length of time it can

taken for information and advice to be provided, sometimes resulting in information being delivered too late.

Quality of life is important to carers. The highest level of need amongst carers is around being able to participate in activities outside of caring that they value and enjoy, and having control over their daily lives. Respite care, even if only for a few hours to provide a break, can help to facilitate this and is considered important by carers.

Other issues brought up by carers include concerns about the number of agencies and organisations involved, and the feeling of being passed around between different organisations. Procedures, information and forms can also appear over complicated to carers, and could be a barrier to accessing services; in particular comments were received around the eligibility for support, the cost of support and who will pay for what.

The three areas that Cumbrian carers considered to be of least importance are:

- support to help carers stay in employment;
- gaining new skills or qualifications;
- training on the emotional and physical aspects of caring.

The lack of interest in support for employment, or accessing training may well be because the majority of carers supported by Cumbria Adult Social Care are of an older profile and many are retired or not working (46% of those surveyed were aged 65 or over; 25% aged between 55 and 64 years). Of those who are currently in work, around three quarters (76.9%) felt that their employers were supportive.

The carers surveyed by Adult Social Care appear to be relatively satisfied with the support services they receive. Just over half (51%) reported being extremely or very satisfied, 31% were quite satisfied. Some degree of dissatisfaction was reported by 8% of respondents.

## 11.2 Parent carers

Views of parent carers in the south of the county were captured during a Carers Forum, held in September 2015 and hosted by Furness Carers (Source: Carers Forum - Carers Views, Furness Carers, 29 September 2015).

Communication and the provision of information are also considered of importance to parent carers. Parent carers feel that there is often a lack of communication between professionals and parents; parent carers feel that clinicians are not listening to them and not understanding the issues they face.

Parent carers report that finding a service and being involved with services can be stressful. Examples of why parent carers find involvement with services stressful include having to retell their story multiple times because of inconsistency between services, not knowing who to contact, no single point of contact, confusion over service criteria being a barrier to accessing services for the child they care for, feeling that staff they do contact do not care or do not listen to them.

The requirement for good, consistent support for children during term time and school holidays is considered important by parent carers. They feel that there is a gap in the support provided for 16-18 year olds and worry that there is poor quality of transition into adult services. Parent carers also feel that they are often passed from one service to another and that there is a lack of a joined up, consistent approach.

Parent carers feel that there is a lack of support from schools, and that teachers do not understand how to deal with situations. There is also feeling that there is a lack of crisis support for families. Lack of bereavement support for families is also an issue (Source: Carers Forum - Carers Views, Furness Carers, 29 September 2015).

## 12 Equality Impact Assessment

Protected characteristics of adult carers and at risk groups are taken into consideration within Cumbria County Council's *Carer Service Equality Impact Assessment, 2014*. The Equality Impact Assessment aims to ensure that a fair range of services are provided to all adult carers across the county. Characteristics taken into account include ethnicity, disability and health and wellbeing, gender, sexual orientation, age, religion or belief, and socio-economic status.

Particular issues that require action are identified within the EIA, along with the relevant actions required. One issue is the need to ensure that hidden carers and those who do not necessarily see themselves as carers are not overlooked, and that they are able to receive assessments and be offered the same services as all carers. It is also recognised that services provided by relevant specialist services should meet the needs of all carers, including those supporting people with mental health problems.

A further issue raised is support for parents who are the carers of a child with a disability in order to ensure that they can continue caring. The final issue raised within the EIA as requiring action is that of the transition of young carers (those aged under 18) to adult carers, in order to ensure their needs are not overlooked (Source: Carer Service Equality Impact Assessment, CCC, 2014).

## 13 Key contacts

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## 14 Links to data sources

Adult Carers Strategy for Cumbria, 2015, Cumbria County Council:  
[julian.legat@cumbria.gov.uk](mailto:julian.legat@cumbria.gov.uk)

Care Act 2014, Factsheet 8: <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets>

Census 2011: <http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/index.html>

Children and Families Chapter, 2015, Joint Strategic Needs Assessment:  
<http://www.cumbriaobservatory.org.uk/health/JSNA/previous/Children.asp>

The Commissioning for Carers guide, 2013, Royal College of General Practitioners:  
<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

Facts about carers 2014, Carers UK: <https://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2014>

Population Chapter, 2015, Joint Strategic Needs Assessment:  
<http://www.cumbriaobservatory.org.uk/health/JSNA/2015/population.asp>

Projecting Adult Need and Service Information (PANSI): [www.pansi.org.uk](http://www.pansi.org.uk)

Projection Older People Population (POPPI): [www.poppi.org.uk](http://www.poppi.org.uk)

Public Health Outcomes Framework (PHOF): <http://www.phoutcomes.info/>

State of Caring 2015, Carers UK: <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015>

Survey of Carers in Households – England, 2009-10, Health & Social Care Information Centre: <http://www.hscic.gov.uk/pubs/carersurvey0910>

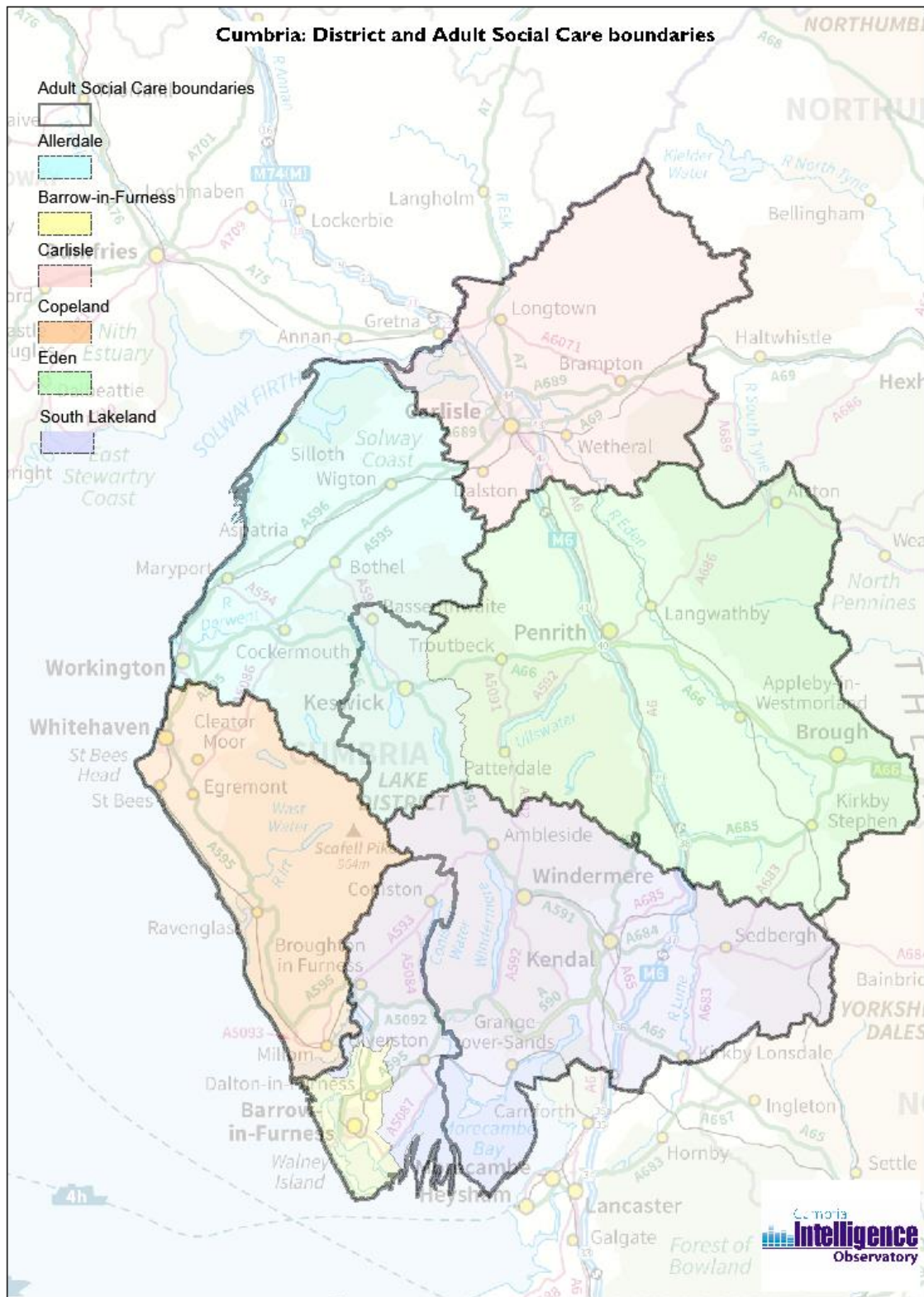
Valuing Carers 2015 – the Rising Value of Carers Support, 2015, Yeandle, S. & Buckner, L:  
<http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

Deprivation of Liberty Safeguards (DoLS), Law Commission:  
<http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/>



# 15 Appendix 1

## Map 1: District and Adult Social Care locality boundaries



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