Respite Care in Wales

Final Report

to Welsh Assembly Government

Prepared by

LE Wales

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About LE Wales

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We advise clients in both the public and private sectors on economic and financial analysis, policy development and evaluation, business strategy, and regulatory and competition policy. We are able to use a wide variety of analytical techniques to assist our work, including cost-benefit analysis, multi-criteria analysis, policy simulation, scenario building, statistical analysis and mathematical modelling. We are also experienced in using a wide range of data collection techniques including literature reviews, survey questionnaires, interviews and focus groups.

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Data source: Census 2001, National Statistics

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Introduction

This research was undertaken by LE Wales under contract to the Welsh Assembly Government during 2010.

The main aims for the research were set out in the contract specification as follows.

- To collect evidence on and consider and assess the existing usage, capacity and range of respite care provision commissioned through public funding (including the NHS, social services and community care direct payments) across Wales;
- To collect evidence on and consider and assess the patterns and volume of existing and future demand for respite care services; and
- In the light of all the views, evidence and information that are gathered and assessed by the successful contractor, to reach conclusions and make recommendations about priorities for future respite care provision in Wales including an assessment of the implementation costs associated with any recommendation.

The research covers respite care for both children and adults.

The Carers Strategies (Wales) Measure 2010 was approved by the National Assembly for Wales on 21 September 2010 and received royal approval on 10 November 2010. One of the reasons for the commissioning of this research was to assist the Welsh Assembly Government in making informed decisions about the development and implementation of that Measure.

In undertaking the research we have reviewed existing data on respite services; we have collected additional data from the local authorities and local health boards; we have reviewed the literature on respite care; we have held telephone interviews with a range of stakeholder organisations in Wales; we have met with groups of carers and care recipients; and we have conducted an online survey of carers in Wales.

For the purposes of this research we use the term ‘respite care’ to mean any services that enable carers to have a break from caring. These types of services are also sometimes known as ‘replacement care’ or ‘short breaks’. We use the term ‘carer’ to mean someone whose caring role is unpaid – generally they are caring for a relative or a friend. Such carers are also sometimes known as informal carers.

Respite services in Wales

According to the 2001 Census data, about one in twenty people in Wales (132,000) self-identified as providing more than 20 hours of care per week. This included 3% (90,000) of people in Wales who provided more than 50 hours of care per week. WAG estimates that the number of carers in Wales that provide substantial and regular care could reasonably be considered to be in the range 60,000 to 90,000. LE Wales undertook some simple modelling that showed the numbers of carers rising from a starting point of around 75,000 in 2008 to just over 90,000 in 2030. The projections also suggest that the gap between the numbers needing care in Wales and the numbers of informal carers will have almost doubled from around 40,000 people in 2008 to around 75,000 in 2030.

Based on information sent to us by the local authorities, we estimate that over the last year they funded respite services that benefited 11,000 – 15,000 carers in Wales. We were also provided with evidence of just over £7.5m spent specifically on respite services by the local authorities. However we are aware of many cases where a service is provided for which we have no expenditure data. Actual expenditure is likely to be considerably more than this, though it is very hard to judge exactly how much more.

Based on the information sent to us by the local health boards, we estimate that over the last year they funded respite services that benefited 500 – 1,000 carers in Wales. We were provided with evidence of just under £2m spent specifically on respite services by the local health boards. Actual expenditure on respite services will be higher than this because separate estimates of spend on the respite elements of many services were not available. It is very difficult to judge how much additional expenditure there may be on respite services, though we believe that the total is unlikely to be more than £5m.

Views of stakeholders

The views of stakeholders on issues around publicly funded respite care in Wales were accessed through a number of different means:

- Telephone interviews with a range of organisations active in respite care;
- Face to face discussions with a number of different groups of carers and care recipients;
- An online survey of carers.

We did not speak to all of the organisations who are active in the area of respite care and we did not speak to a statistically representative sample of carers. Nevertheless we accessed the views of a large number of people and these discussions provided a useful insight into the range of views held by stakeholders on a number of issues important for respite care policy.

Many carers and care recipients had high praise for individual care workers that had provided them with respite care and for specific respite care facilities and organisations that they had had experience with. Individuals and organisations that took the time to listen to, and to respond to, the individual needs of carers and care recipients were the ones that were most appreciated.

The value of respite services

Many carers, particularly those with heavier caring burdens, lead very busy, stressful lives. Stakeholders used many phrases to describe how useful respite care services are, including:

- Critical - they provide carers with the means to continue caring
- Improve quality of life and reduce isolation for carers
- Increase quality of life for care recipients through developmental activities based on individual needs
- Allow carers to get on with their own lives – chores, family life, employment, education etc
- Young carers can be children again
- Reduces stress for carers and allows them to recharge batteries

- Helps prevent deterioration in health of carers
- Allows carers to maintain relationships with friends and family
- Care recipients can feel less guilty about the burden they are placing on their carer

Some stakeholders felt that appropriate respite care could and should have a value for the care recipient as well as the carer. They felt that respite care was an opportunity for the care recipient to interact with different people, to experience activities that they do not normally experience and also for them to access therapies that are more difficult to access whilst they are at home.

Respite care can lead to conflict between carers and care recipients. Care recipients can feel vulnerable when they are in unfamiliar surroundings or when they are being cared for by someone who is not their usual carer, and perhaps someone they have not met before. Some care recipients can get very upset and agitated in such situations. This can make it very difficult for carers to seek respite. Some suggested that one approach to ameliorate this problem would be to aim to build up a long term relationship between the care recipient and an alternative carer, noting that this was often difficult when there were high levels of turnover for care staff.

Quantity and range of available respite services

In our discussions with stakeholder organisations one of the most consistent messages that we had from them was the need for a greater quantity of respite services to be available to carers. This message also came across strongly in our face to face discussions with carers and in the responses to the online survey. Some people told us that the availability of services was "patchy" across Wales and referred to a postcode lottery. Some told us that there were long waiting lists for respite services in some areas.

A large number of respondents to our online survey wanted a respite service but did not receive one at all. The large majority of respondents of all types thought that the volume of respite services available to them was too low.

From our discussions, it became clear that the needs of individual carers and care recipients can vary tremendously and so it is very difficult to generalise about the needs of carers and which services are most useful. Stakeholders suggested to us that carers need to be able to access a wider range of service types, beyond the traditional provision of overnight stays in residential homes or 'sitting' services in the care recipient's home and that they needed to have some flexibility to choose which service most suited their needs at the time. Whilst a wider range of services was becoming available, these were still limited compared to the needs of carers. Many stakeholders told us that in practice carers tend to be offered a very limited menu of service options on a take it or leave it basis. The scarcity of any type of respite service means that they often take what is offered even where it does not match their needs very closely.

Quality of respite services

Many of the stakeholder organisations that we spoke to were clear that the quality of respite services was nowhere near as big an issue as the quantity of available respite services. Many said something to the effect that "carers are so relieved to get a service, they don't complain much about quality".

The carers we spoke to had more to say about quality issues. The quality of care received by their loved ones was a key issue for them. Many felt that, inevitably, nobody would be able to provide the same quality of care for their loved one as they did. This meant that they often felt guilty about requesting respite care.

In order for carers to overcome these feelings and arrange respite care they needed to feel that the care provided would be of high quality. Some spoke to us of very positive experiences that they had had of respite care. Others talked about bad experiences which meant that they would never again consider the possibility of using respite services.

Barriers to take up of respite care

In addition to the limited availability of respite services and possible issues around the quality of respite services, different views of care recipients and feelings of guilt for carers, discussed above, carers mentioned a number of other barriers to take up.

One issue that was raised over and over again by carers and by stakeholder organisations was the lack of accessible information about respite care services. Many carers told us that they did not know how to find out about available respite services.

Stakeholders also told us that often the respite care that carers were offered was not suitable for their needs. Other barriers included cultural barriers for BME carers, financial barriers and other barriers specific to the take up of direct payments.

Policy issues and recommendations

In our view, the three key issues for policy-makers in the respite arena are the quantity of publicly funded respite services; the need for any system that provides respite services to address carers' individual needs; and the need to improve information flows to carers about respite services. We make recommendations in these three areas and also in relation to data collection for policy development and training on respite care issues for formal carers.

Recommendation 1

Given the high value placed on respite services by carers and other stakeholders, the likely future increases in the need for care and given what appear to be the relatively small amounts of expenditure on respite services at present, we believe that there is a strong case for funding more outcome focussed respite services in Wales, ensuring that those services are appropriate to the needs of carers and care recipients.

Recommendation 2

Throughout our work in the care sector in Wales it has been clear to us that the needs of individual carers and care recipients can vary tremendously. It can be very difficult to generalise about the needs of carers. Each individual carer is in their own unique situation with their own particular set of needs.

We propose that WAG take further action to ensure that the process of better addressing carers' individual needs continues to move forwards. We suggest that this happens in three ways:

i. WAG take further action to make direct payments easier for carers to use.
ii. WAG extend the use of direct payments to respite services provided through the healthcare system.
iii. WAG work with local authorities and the NHS to ensure that carers not using direct payments have access to a wider range of appropriate services in a more flexible way.

Recommendation 3

Where policies to implement the Carers Strategies (Wales) Measure are being developed we recommend that WAG or, if more appropriate, local authorities, local health boards and others:

i. Use varied means of providing information to carers
ii. Ensure that carers have access to comprehensive information relating to all types of respite services, across Wales and regardless of provider.
iii. introduce a general presumption that strategies under the Measure will be developed jointly between individual local authorities (social services and education functions) and the local health boards unless there are strong reasons why this should not be the case.
iv. Explore mechanisms for making available better information about respite services available at short notice.

Recommendation 4

We recommend that the Welsh Assembly Government work with the local authorities and the NHS to:

i. consider whether there is sufficient value, given the costs, in collecting a common set of data on respite care services for the purposes of policy development; and
ii. if so, to develop a common definition of respite care for data collection purposes and to agree a common approach to linking a respite service with the carer, as well as the care recipient.

Recommendation 5

We recommend that WAG consider the development of best practice standards for quality assurance purposes in relation to respite care; and an accompanying training module for social and health care staff who may interact with carers. We envisage that the best practice standards would be aimed at practitioners and providers and adherence with the best practice standards would be monitored by commissioners. We also suggest that such an approach be considered in consultation with key stakeholders including carers, care recipients, service providers and training providers.

1 Introduction

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Our report is structured as follows:

- In Section 2 we summarise the data available on carer numbers; we provide a projection of carer numbers and those needing care to 2030; and we summarise information on the current provision of respite services in Wales, including the numbers of carers receiving respite services and public expenditure on respite services. Much more detail on current service provision is provided in Annexes 1 and 2. More detail on our projections to 2030 are provided in Annex 3.
- In Section 3 we summarise the views of stakeholders, based on our telephone interviews, online survey and face to face discussions with carers and care recipients. Further details on our online survey are provided in Annex 4, including carers' views of respite services in their own words. Further details on our programme of stakeholder consultation are provided in Annex 5.
- In section 4 we discuss what we see as the main policy issues and we provide a series of recommendations for next steps.

2 Respite services in Wales

2.1 Definitions

For the purposes of this research we use the term ‘**respite care**’ to mean any services that enable carers to have a break from caring. These types of services are also sometimes known as ‘**replacement care**’ or ‘**short breaks**’. Typical policy usage of these terms tends to distinguish between whether the carer is an adult or a child, and (if the carer is an adult) whether the care recipient is an adult or a child:

1) Adult carer of an adult: respite care
2) Cared-for young person, or young carer: short break

Short breaks may mean slightly different things depending on whether the young person involved is a care recipient or is a carer. Short breaks for cared-for children tend to be viewed as services provided to the child, whereas short breaks for young carers tend to be viewed as services provided to the young carer (not to the young carer’s care recipient).

We use the term ‘**carer**’ to mean someone whose caring role is unpaid – generally they are caring for a relative or a friend. Such carers are also sometimes known as informal carers.

We were asked by the Welsh Assembly Government to focus our research on publicly funded respite services aimed at informal carers who provide “a substantial amount of care on a regular basis to a child who is disabled within the meaning of part 3 of the Children Act 1989 or to an individual aged 18 or over”. In practice this means that we are interested in three distinct groups of carers in our study (though it would be possible for an adult to simultaneously fall into both of the first two categories):

1) Adult carers of adults
2) Adult carers of (disabled) children
3) Young carers of adults or of (disabled) children

Our research focuses on respite care that is funded by public authorities – mainly by the local authorities and the local health boards.[1] It includes services that they provide directly themselves and services from third parties that are funded by those public authorities. It also includes direct payments. WAG asked us to focus, if possible, mainly on services whose principal aim was to benefit carers, rather than on services whose main aim was to benefit care recipients but which might have beneficial effects for carers. In practice, the boundary is fuzzy and it is difficult to make a clear distinction between services with these differing aims.

When collecting or collating data about respite services it is difficult to find measures that clearly distinguish between services for carers who provide “regular and substantial” care and carers who do not. WAG recognise that “regular and substantial” is not defined by reference to numbers of hours of care or how frequently care is provided and consequently that there is no specific data on

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– [1] JobCentre Plus also offer to fund ‘replacement care’ in certain circumstances for carers who are seeking employment.

the number of carers across Wales that would meet this definition of a carer.[2] As a result, the information that we have collected will tend to relate to a wider definition of a carer than this, though we have noted where possible, any indicators of the intensity of care provided (e.g. numbers of hours).

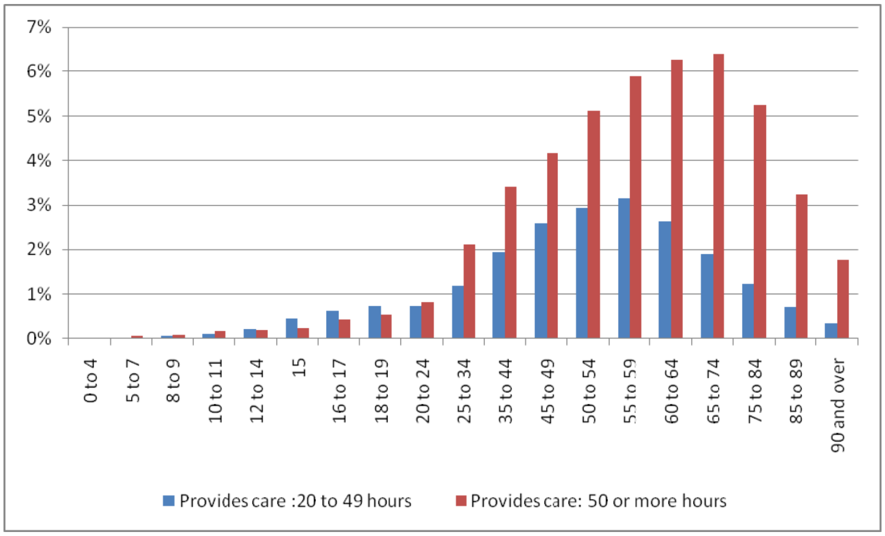
2.2 Number of carers

There are a number of different sources of data about the number and characteristics of informal carers in Wales. The issues around definition, discussed above, in particular the meaning of "substantial and regular care", mean that none of the data sources can necessarily match the requirement precisely. The most comprehensive of the data sources is the Census. The main data sources are discussed below, starting with the Census data.

2.2.1 Census data

According to the 2001 Census data, about one in twenty people in Wales (132,000) self-identified as providing more than 20 hours of care per week. This included 3% (90,000) of people in Wales who provided more than 50 hours of care per week. The share within each age group increases with older ages, with the peaks being in the years surrounding retirement age (55-59 years old for 20-49 hours of care per week and 65-74 years old for more than 50 hours of care per week).

Figure 1: Self-identified carers, by age band and time spent providing care



Source: LE Wales calculations on data from 2001 census

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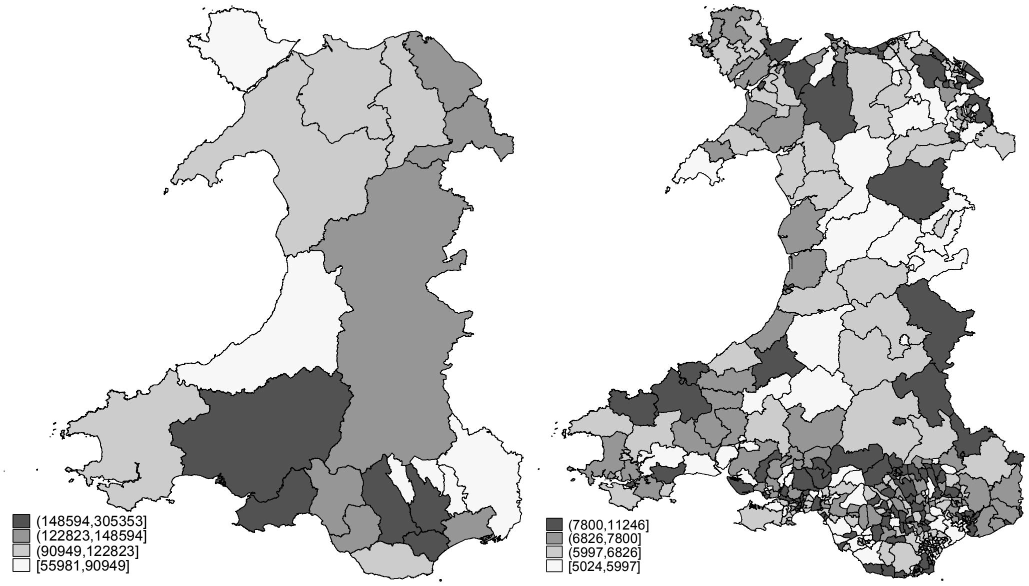
[2] Deputy Minister for Social Services "Proposed Carers Strategies (Wales) Measure" Paper for the National Assembly for Wales Finance Committee, FIN(3)-06-10: Paper 2.

The following figures show the geographic distribution of carers. The first figure shows all carers who report that they spend 20 or more hours per week caring. The second and third figures show the split between those carers who report spending 20-49 hours per week and those spending 50+ hours per week caring. In each figure, the left hand map shows the data by local authority and the right hand map shows the data at a more disaggregated level.[3]

Figure 2: Numbers of people in Wales, by local authority and by Middle Super Output Area



Note: The key shows the range for the number of people represented by each shade. For example, [55981, 90949] after a shaded box in the key means that areas represented by that shade include between 55,981 and 90,949 people.

Source: LE Wales calculations on data from 2001 census

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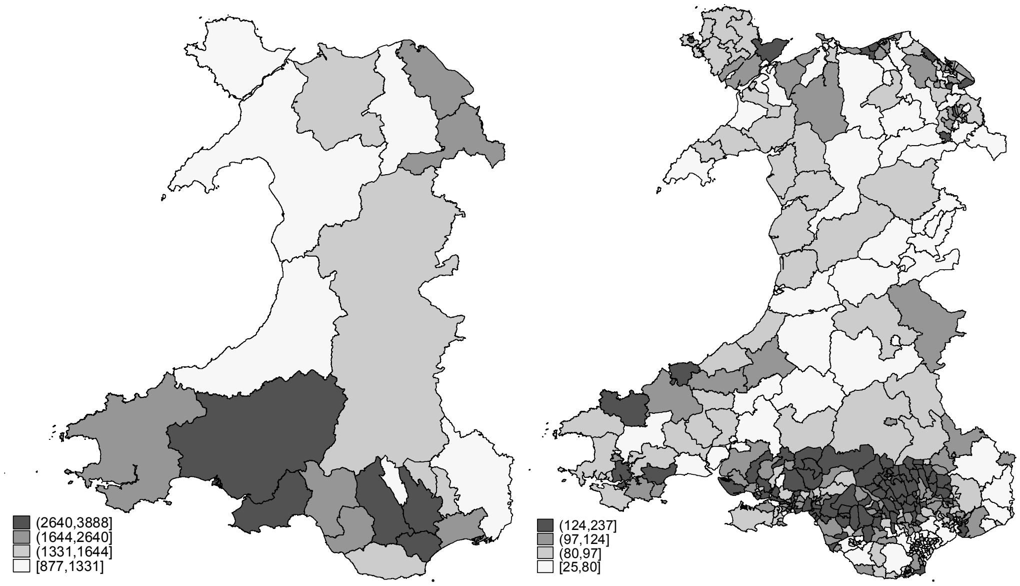
[3] There is also a paper from the ONS ("Who cares? Geographic variation in unpaid care giving in England and Wales: evidence from the 2001 Census" in Population Trends, Summer 2005)[3], which explores some of the demographic (geography, ethnicity, health, index of multiple deprivation) characteristics that can be analysed using the census 2001 data. The paper provides data at local authority level and so it is possible to view some detail for LAs within Wales.

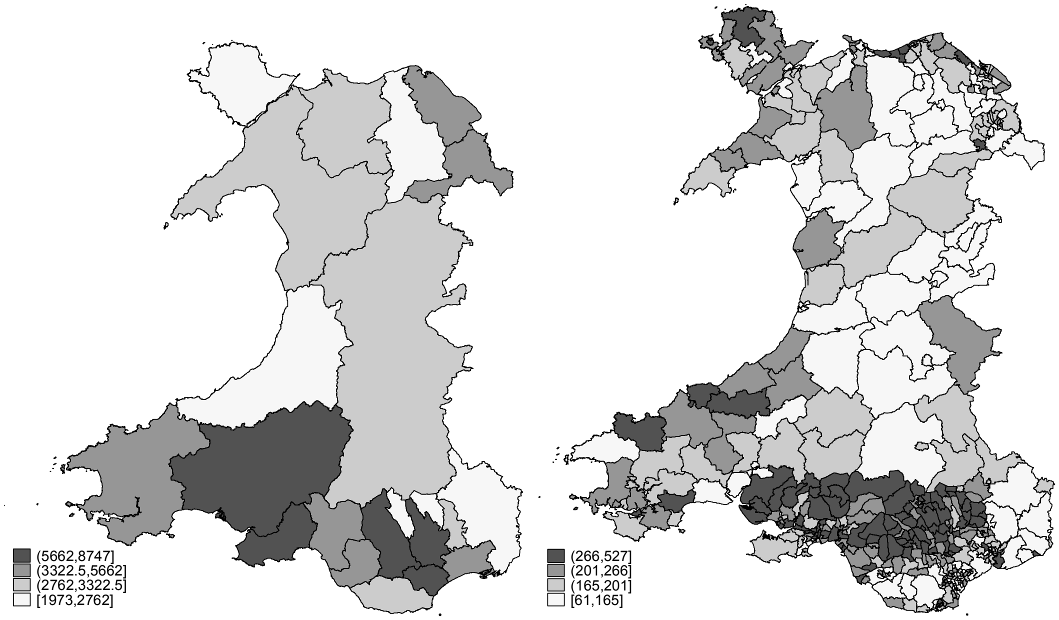
Figure 3: Numbers of people providing 20-49 hours of care per week, by local authority and by Middle Super Output Area



Note: The key shows the range for the number of people represented by each shade. For example, [55981, 90949] after a shaded box in the key means that areas represented by that shade include between 55,981 and 90,949 people.

Source: LE Wales calculations on data from 2001 census

Figure 4: Numbers of people providing 50+ hours of care per week, by local authority and by Middle Super Output Area



Note: The key shows the range for the number of people represented by each shade. For example, [55981, 90949] after a shaded box in the key means that areas represented by that shade include between 55,981 and 90,949 people.

Source: LE Wales calculations on data from 2001 census

2.2.2 More recent data

Welsh Health Care Survey 2008

A 2008 Welsh Health Care Survey repeated the question asked in the census 2001, and found a similar distribution of carers who provided more than 20 hours of care per week.

Table 1: Percentage of people aged 16 & over who reported being carers, by carer workload (a)

Carer workload	Welsh Health Survey 2008	Census 2001
Carer, less than 19 hours a week	11	9
Carer, 20-49 hours a week	3	2
Carer, 50+ hours a week	4	4

Note: (a) Time spent (hours) in a typical week

Source: Welsh Health Survey 2008 & 2001 Census of Population

The survey also found that younger adult carers (16-44 years old) tended to report worse health characteristics than their peer group (same age group non-carers). In contrast, older adult carers did not report statistically different health characteristics from their corresponding peers. The health problems reported included being treated for illnesses, including mental illness and limiting long-term illnesses, smoking and increased propensity to have recently visited their GP. There was also a correlation of poorer health with higher carer workloads. On the positive side, though, young carers were more likely than young non-carers to report having eaten five portions of fruit and vegetables the previous day, and having met the guidelines for physical activity in the previous week.

Living in Wales survey 2007

A smaller-scale survey, which asked similar questions to those in the Census is the Living in Wales survey. However, data from this survey are of limited use for these purposes, since it interviewed only adults (over 16 years old) and only one person from each household. Therefore, we cannot be sure of the completeness with which it represents the distribution of carers.

The findings from the Living in Wales survey[4] were that about 3% of respondents provided 20 or more hours of special care to at least one person who had long-term physical or mental ill-health, or disability, or problems related to old age. The proportion of respondents who reported providing more than 12 hours a day was 1% of the total, and only one in eight of these carers reported receiving respite support.

Carer's Allowance – administrative data

Carer's Allowance is a non-devolved UK benefit available to carers though eligibility for Carer's Allowance is restricted. For instance, pensioners are excluded from receiving Carer's Allowance, as it is intended as a social security benefit to counter loss of earnings.

There were 29,000 recipients of Carer's Allowance in Wales in August 2009. This has increased by about 12% since 1999, with more rapid increases since 2007. The age distribution amongst

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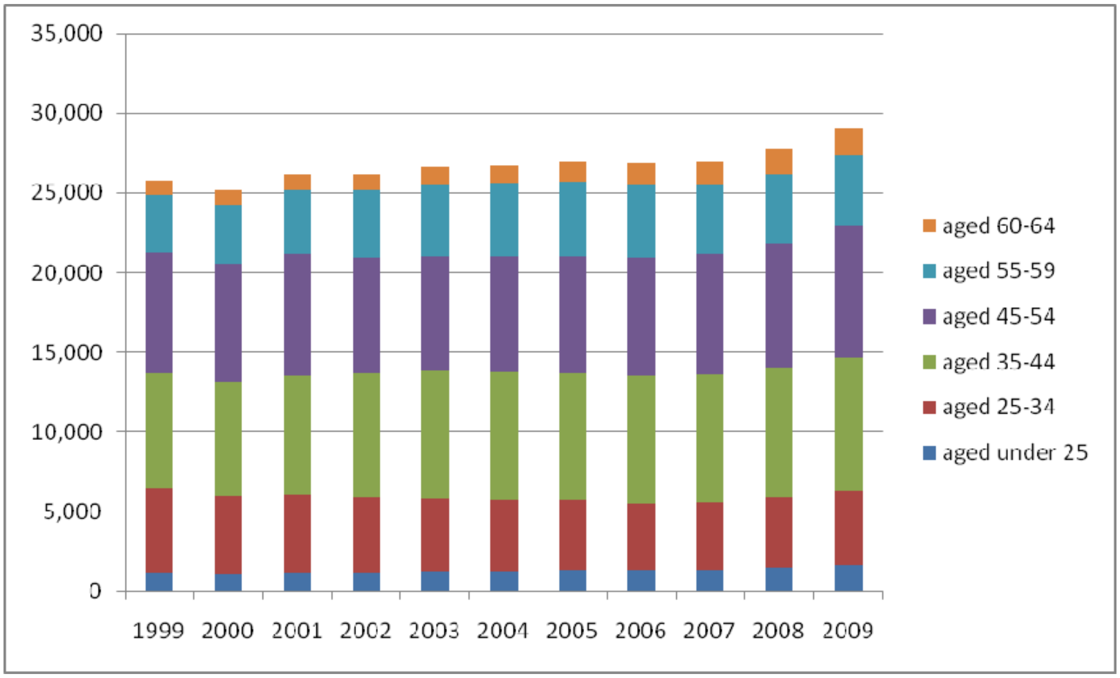
– [4] http://wales.gov.uk/topics/statistics/headlines/health2008/hdw200811255/?lang=en recipients has remained fairly stable and is approximately symmetrical either side of 45 years of age. Most recipients fall within the age brackets 35-44 and 45-54 years old (about 30% each), with ages either side (25-34 and 55-59 years old) accounting for about 15% and 5% each for those under 25 and 60-64 years old.

About two-thirds of recipients receive Carer's Allowance only, with the remaining third also receiving Income Support or Pension Credit. There is a slightly stronger prevalence of joint receipt of Carer's Allowance and Income Support amongst younger age groups than is suggested by the overall distribution (where the distribution is dominated by the majority who receive Carer's Allowance only).

Figure 5: Numbers of people in Wales in recepit of Carers' Allowance, by age band



Note:

Source: LE Wales calculations on data from NOMIS

2.2.3 Estimates used for policy development

As a part of the process for the Proposed Carers Strategies (Wales) Measure, the Welsh Assembly Government's Deputy Minister for Social Services produced a policy paper for the National Assembly for Wales Finance Committee (FIN(3)-06-10 : Paper 2). The paper states the following in relation to carers:

"... a 'carer' means an individual who provides or intends to provide a substantial amount of care on a regular basis to a child who is disabled within the meaning of part 3 of the Children Act 1989, or to an individual aged 18 or over. The use of the words 'substantial and regular' reflect what is in the Carers LCO and also more broadly reflect the provisions of the Carers (Recognition of Services)

Act 1995 and Carers and Disabled Children Act 2000. It is not defined within the Carers LCO or the 1995/2000 Acts by reference to the numbers of hours of care or how frequently the care is provided. The key issue is the impact of the caring role on the individual carer. The 1995/2000 Acts definition is well established and understood."

The paper notes that since the definition of a carer is not quantifiable purely objectively, there are "no specific data on the number of carers across Wales who would meet the definition of a carer". The paper nevertheless estimates that the number of carers in Wales that meet the above definition of a carer (e.g. providing substantial and regular care) would reasonably be in the range 60,000 to 90,000. This is based on the 2001 Census estimate of 90,000 carers providing 50 or more hours of care per week and an estimate based on the numbers providing more than 35 hours caring per week.[5]

2.3 Projections of the demand for informal carers to 2030

In order to provide an indication of how the demand for respite care services might evolve in future, we have made projections for Wales of the future need for informal carers. The projections are based on a large number of assumptions and so there is a considerable amount of uncertainty associated with them.

Fuller details of the methods we used are provided in Annex 3. In essence the projections of people in need of care are based on the population projections for Wales that are published at StatsWales. We assume for Wales the same proportion of people needing care in each age band that is used by Pickard (2008) in her work on England. For our main scenario, we also follow Mayhew (2009) in assuming that as general life expectancy increases, the length of life spent with a physical disability will also increase. We apply his estimates of the effects of this factor to produce our projections of the number of people in need of care, illustrated below.

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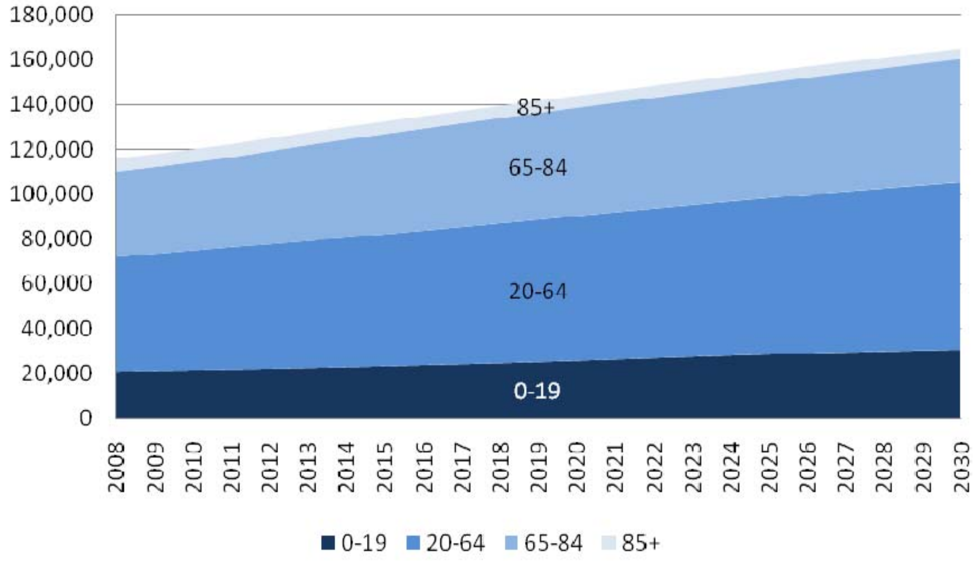
[5] This is based on 32,000 people in Wales claiming Carer's Allowance (which has an eligibility threshold of 35 hours per week) and an estimate that there are a further 30,000 people who may exceed 35 hours per week caring but who do not meet the other eligibility criteria for Carer's Allowance (e.g. relating to income and benefits).

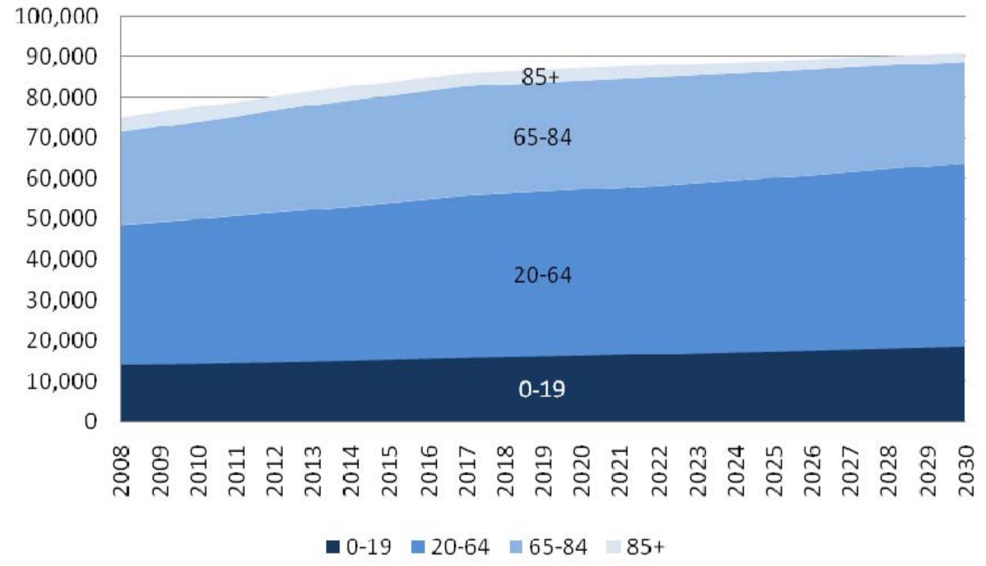
Figure 6: Number of people in need of care, by age of care recipient



Note: The ages in the graph above are the ages of those cared for rather than the carers.
Source: Mayhew, StatsWales, ONS, LE Wales estimates

Our model starts with an estimate of about 116,000 people needing 20 or more hours of care per week in 2008. Over time, we see (Figure 6) that all age groups have a growing need for care over time, except for the 85+ age group which remains relatively stable. The increase is most profound for those aged 20-64. The total projected number of people needing care by 2030 is around 165,000. These changes derive from increases in healthy life expectancy rising at a lower rate than increases in life expectancy. If we use Pickard's assumptions about the ratio of informal carers to those who need care (based on data for England) then we can derive a projection of the number of informal carers. This is shown in Figure 7.

Figure 7: Number of people providing care, by age of care recipient



Note:

Source: StatsWales, Mayhew, LE Wales estimates

The figure shows the numbers of carers (by age of care recipient) rising from a starting point of around 75,000 in 2008 to just over 90,000 in 2030. Much of the increase in carers is for those caring for people in the 20-64 age band. The starting point of 75,000 is broadly consistent with the range of 60,000 to 90,000 that WAG refer to in their paper to the Finance Committee that is referenced above.[6]

The two projections above suggest that the gap between the numbers needing care in Wales and the numbers of informal carers will have almost doubled from around 40,000 people in 2008 to around 75,000 in 2030.

We have used a simple approach for illustrative purposes. It relies on some assumptions that were developed for England, though it is calibrated on population projections for Wales. There is a number of potential future developments that these projections do not take into account. These include changes in the characteristics of those who are willing and able to be informal carers.[7] This means that the projections should be treated with some caution and developing them further may be a potential avenue for further useful research. These projections do provide an illustration of the potential for future pressures in respect of the need for informal care and hence the need for respite care.

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[6] Though underlying assumptions about the number of hours per week consistent with 'substantial' care are different (20hrs versus 35/50 hrs).

[7] Relevant characteristics may include age, gender, marital status and educational qualifications.

2.4 Current respite provision

2.4.1 Existing data sources

The main source of existing published data on the respite care services provided in Wales is the data collected by Data Unit Wales from the local authorities and available from the Data Unit's website. There is no equivalent source of data for respite services funded by the local health boards.

This data on respite services includes information on the numbers of adults and children receiving respite services, disaggregated by local authority, by age band of the care recipient (for the adults) and by health condition of the care recipient. These data are limited to respite services that include at least one overnight stay and so have a much narrower focus then this research. Some members of the Carers Learning and Information Network,[8] who we met in April 2010, did not have a high degree of confidence that this data provided a good overall picture of respite services in Wales.

These data suggest that over the year 2008-09 local authorities funded overnight respite care for 7,000 adult care recipients and 705 short-break (respite) placements for looked after children in Wales. Further details are provided in Annex 2.

2.4.2 LE Wales data collection

In order to provide a fuller picture of the respite care services currently provided across Wales we approached the local authorities, the local health boards and JobCentre Plus to ask for information about the respite services that they fund.

The local authorities and local health boards all operate independently and they collect data on their services in different ways, reflecting their own needs. For most of these organisations, consistent comprehensive data on the respite services they provide is not collected centrally. In some cases there is no separate central record kept of respite services provided. For some of the local health boards, for example, respite services are provided as part of a wider package of care and information about each patient's package of care would need to be accessed and analysed separately in order to build up an aggregate picture of the respite services provided.

All of these issues mean that it has not been possible for us to build a clear and consistent set of aggregate data covering all of the publicly-funded respite services that are provided in Wales. The data we have collected is not complete and has not been provided in the same format by each of the organisations we approached. Whilst this means that it is difficult to be precise about exactly how much respite care is provided across Wales, we believe the information we have collected does provide, for the first time, a good indication of the range and volume of respite services provided.

An overview of these services is provided below, whilst fuller details are available on services funded by local health boards in Annex 1 and on services funded by local authorities in Annex 2.

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[8] Representatives of Welsh local authorities who work with carers, mainly from adults services.

Services funded by local authorities

Based on the information sent to us by the local authorities, we estimate that over the last year they funded respite services that benefited 11,000 – 15,000 carers in Wales. This is about 15% of the number of carers whom WAG believe may provide ‘regular and substantial’ care.

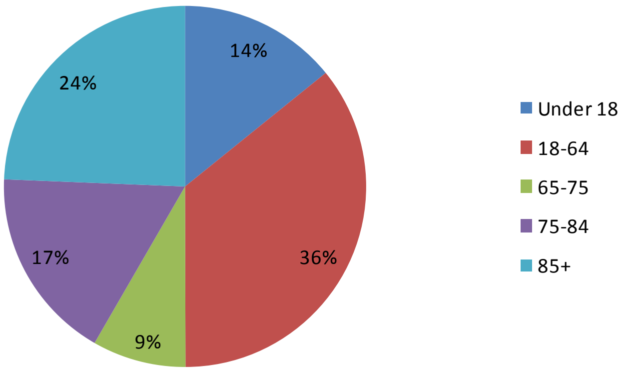
The data that they sent us provides evidence relating to just under 12,000 carers (about 1,000 young carers, 1,900 adult carers of children and 9,000 adult carers of adults). We believe that there may be some small amount of overlap within these numbers (i.e. where one carer benefits from more than one respite service within a local authority). That accounts for our lower bound estimate of 11,000.

These figures include all services that local authorities have described to us as respite care, though we have excluded all provision at day care centres. Some local authorities told us that they thought some, though not all, provision at day care centres could be considered as respite care. One or two indicated that they thought that this might be around half or a third of day care centre provision, though they had no firm data for this. Data from local authority PM2 returns to Data Unit Wales suggests that over 15,000 people used day care centre services in 2008-09.

We also know that local authorities were not able to provide us with information about numbers of beneficiaries for some of the services that they provide. This missing information affects all three types of carer, but it affects adult carers of children and young carers more than it does adult carers of adults. This means that the numbers quoted above are likely to give a misleading picture of the balance between services for the three types of carers. Three local authorities were not able to provide us with data on the numbers of carers benefiting from respite services that they fund. It is difficult to put an upper bound on our estimate of the number of carers receiving publicly funded respite services but it seems to us to be highly unlikely that as much as half again of carers are missing from the data that we received, hence our upper bound estimate of 15,000.

We have information on the age of service users for about 4,600 users. This is presented below. About half are aged over 65, though for the reasons outlined above we believe that the data available to us is likely to exaggerate the proportion of service users that are at the higher age levels.

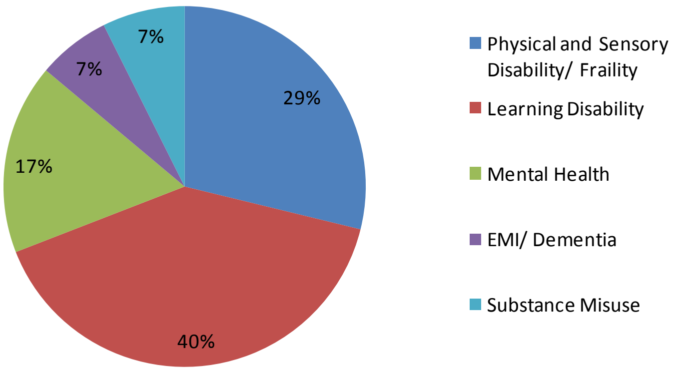
Figure 8: Age of services users (where data available)



Note: This information was available for about 4,600 service users
Source: Welsh local authorities, LE Wales analysis

We also have information about the type of service user associated with respite care services – for about 3,900 service users. This is presented in Figure 9.

Figure 9: Service user type (where data available)



Note: information was available for about 3,900 service users
Source: Welsh local authorities, LE Wales analysis

There is a wide range of respite services funded by local authorities. Some are provided directly by local authorities and some are purchased from other organisations. There is a wide range of private sector and voluntary organisations active in providing respite services funded by the public sector. The information provided in Annex 2 provides an indication of the types of services funded by the local authorities.

We were provided with evidence of just over £7.5m spent specifically on respite services by the local authorities. However we are aware of many cases where a service is provided for which we have no expenditure data. Actual expenditure is likely to be considerably more than this, though it is very hard to judge exactly how much more.

Services funded by the local health boards

Based on the information sent to us by the local health boards, we estimate that over the last year they funded respite services that benefited 500 – 1,000 carers in Wales.

The data that we received provides evidence relating to services provided to just under 500 carers. However in many cases local health boards were able to describe respite services to us for which they were unable to supply numbers of service users. In many cases respite is provided as part of a package of care and details of the respite element are not collected centrally and so were not provided to us.

We were provided with evidence of just under £2m spent specifically on respite services by the local health boards. Actual expenditure on respite services will be higher than this because separate estimates of spend on the respite elements of many services were not available. It is very difficult to judge how much additional expenditure there may be on respite services, though we believe that the total is unlikely to be more than £5m.

The local health boards fund a range of respite services, often through Continuing Health Care funding, some of which they provide directly themselves and some of which they purchase from other organisations. The information in Annex 1 provides more details of the types of respite services that are funded by the local health boards.

Services funded by JobCentre Plus

Since December 2009 Jobcentre Plus has been in a position to fund replacement care services under certain circumstances for those who are undertaking approved activities as a step towards taking up paid employment.

Funding for replacement care is available for adult carers who are not working or who are working less than 16 hours per week and who provide significant levels of unpaid care to friends or relatives. To receive funding carers must be participating in a Jobcentre Plus approved activity (such as job-related training) or be attending an interview (with previous agreement from Jobcentre Plus). Jobcentre Plus makes the agreed payments for replacement care directly to the care provider on behalf of the carer.

A network of Jobcentre Plus Care Partnership Managers is in place across Wales. Their role is to act as a link between carers/carers' organisations and Jobcentre Plus frontline staff. They aim to contribute to build up an understanding of carers' needs and existing provision to meet those needs; to ensure that Jobcentre Plus frontline staff understand those needs; and to ensure that carers and carers' organisations understand what Jobcentre Plus is offering

By the end of September 2010 there had been no uptake of replacement care in Wales through this route.

3 Views of stakeholders

3.1 Introduction

The views of stakeholders on issues around publicly funded respite care in Wales were sought through a number of different means:

- Telephone interviews with a range of stakeholder organisations;
- Face to face discussions with a number of different groups of carers and care recipients;
- An online survey of carers.

Some further details on the telephone interviews and the face to face discussions are provided in Annex 5. Further details on the online survey are provided in Annex 4. Annex 4 also includes the anonymous views of survey respondents on respite care services in their own words

We did not speak to all of the organisations who are active in the area of respite care and we did not speak to a statistically representative sample of carers. Nevertheless we accessed the views of a large number of people and these discussions provided a useful insight into the range of views held by stakeholders on a number of issues important for respite care policy.

In the remainder of the text in this section we have tried to capture the main points that stakeholders made to us - we have not included reference to every single opinion on every issue that was discussed.

The points recorded below tend to focus on the negative more than on the positive but many positive points were made to us by stakeholders, particularly in relation to the respite services that are provided. Many carers and care recipients had high praise for individual care workers that had provided them with respite care and for specific respite care facilities and organisations that they had had experience with. Individuals and organisations that took the time to listen to, and to respond to, the individual needs of carers and care recipients were the ones that were most appreciated.

3.2 The value of respite care

For many working in the care sector, the value of respite care seems obvious - many carers, particularly those with heavier caring burdens, lead very busy, stressful lives and they both need and deserve to have breaks from their caring responsibilities. We heard a number of individual stories of carers going night after night after night with severely disrupted sleep and little interruption to the caring demands on their time throughout the daytime either.

Stakeholders used many phrases to describe how useful respite care services are, including:

- Critical - they provide carers with the means to continue caring
- Improve quality of life and reduce isolation for carers
- Increase quality of life for care recipients through developmental activities based on individual needs
- Allow carers to get on with their own lives – chores, family life, employment, education etc
- Young carers can be children again

- Reduces stress for carers and allows them to recharge batteries
- Helps prevent deterioration in health of carers
- Allows carers to maintain relationships with friends and family
- Care recipients can feel less guilty about the burden they are placing on their carer

What do carers do when their loved one is in respite care? It varies considerably and depends to some extent on the nature of the respite care – how long is it for and is it in the care recipient or carer's home or is it elsewhere? Many carers told us that whilst respite offered a break from caring this did not mean that they were free to put their feet up – they take the opportunity do all of the other chores that they don't have time to do whilst they are caring. Some have other caring responsibilities – parent carers, for example, can use the break to spend more time with their other children who often receive much less attention whilst the parent is caring for their sibling. This is another source of guilt for many parent carers.

Some carers do also take the opportunity to relax, meet friends and other family members. Many carers told us that heavy caring responsibilities have an isolating effect, making it very difficult to keep up with networks of friends and other family members. This can be because of the heavy time demands of caring but also because friends, relatives and neighbours can sometimes be uncomfortable with or even hostile towards the care recipient. We heard of such examples where the care recipients had behavioural problems, complex physical impairments and dementia. A number of the carers we spoke to spoke of losing touch with family and friends and others spoke of being verbally abused by neighbours. By allowing them time apart from their caring responsibilities, regular respite can sometimes help carers to maintain their social networks.

Some stakeholders also felt that appropriate respite care could and should have a value for the care recipient as well as the carer. They felt that respite care was an opportunity for the care recipient to interact with different people, including other care recipients in similar situations to themselves, it could also be an opportunity for some care recipients to experience activities that they do not normally experience and also for them to access therapies that are more difficult to access whilst they are at home. We heard of positive experiences where care recipients had built up a network of like-minded friends through regular visits to the same respite centre, but we also heard of more negative experiences where care recipients, at best, did not gain any additional benefit from respite periods.

Respite care can also lead to conflict between carers and care recipients. Care recipients can feel vulnerable when they are in unfamiliar surroundings or when they are being cared for by someone who is not their usual carer, and perhaps someone they have not met before. Some care recipients can get very upset and agitated in such situations. This can make it very difficult for carers to seek respite. Some suggested that one approach to ameliorate this problem would be to aim to build up a long term relationship between the care recipient and an alternative carer, noting that this was often difficult when there were high levels of turnover for care staff.

3.3 Quantity and range of available respite services

In our discussions with stakeholder organisations one of the most consistent messages that we had from them was the need for a greater quantity of respite services to be available to carers. This message also came across strongly in our face to face discussions with carers and in the responses to the online survey. Some people told us that the availability of services was "patchy" across Wales and referred to a postcode lottery. Some told us that there were long waiting lists for respite services in some areas.

A large number of respondents to our online survey wanted a respite service but did not receive one at all. The large majority of respondents of all types thought that the volume of respite services available to them was too low.

When we asked stakeholders about which types of care recipient had respite care needs that were particularly poorly addressed we were provided with a very wide range of responses, which in part reflected the range of stakeholders that we spoke to. Some of the areas where carer needs are particularly poorly addressed that were mentioned most frequently to us were:

- Those living in rural areas;
- Emergency respite services;
- Services for carers of those with mental health and dementia problems;
- Services for carers of those with complex needs;
- Services for carers of those with Autism Spectrum Disorder;
- Services for carers of younger adults (aged 25-40);
- Services for BME carers;
- Services for young carers;
- Services for carers of children and young people, particularly:
    - The transition to adulthood;
    - Those at the lower end of the learning disability spectrum and those with challenging behaviour;
    - Day centre provision;
    - Provision for families to have short breaks together;
    - Asylum seeker/refugee children;

From our discussions, it became clear that the needs of individual carers and care recipients can vary tremendously and so it is very difficult to generalise about the needs of carers and which services are most useful. Whilst there are clearly overlaps between the needs of different carers and sometimes these overlaps may be large, each individual carer is in their own unique situation with their own particular set of needs and those needs vary over time as individual circumstances change.

Stakeholders suggested to us that carers need to be able to access a wider range of service types, beyond the traditional provision of overnight stays in residential homes or ‘sitting’ services in the care recipient’s home and that they needed to have some flexibility to choose which service most suited their needs at the time. Whilst a wider range of services was becoming available, these were still limited compared to the needs of carers. Many stakeholders told us that in practice carers tend to be offered a very limited menu of service options on a take it or leave it basis. The scarcity of any type of respite service means that they often take what is offered even where it does not match their needs very closely.

In order to illustrate the relationship between the services that carers receive and the services that carers would like to receive we have drawn from responses to our online questionnaire to produce the tables below.

There are three main features to the responses in these tables.

First, the percentage of respondents indicating each of the most useful services received in the first table is much lower than the percentage of respondents indicating each service that they would like to have in the second table. This is because a large percentage of respondents (44%) do not receive any service at present and so relatively low percentages receive each individual service. This is the biggest gap between the most useful services received and the services that respondents would like to receive. 56% of respondents said that they had received a respite service whilst 96% said that they wanted to receive a respite service.

Second, the list of services in each of the two tables is very similar. Broadly, the top 5 services that respondents wanted to receive were the top 5 most useful services that they had received. The exception to this is 'overnight care in the cared for person's home' – 4% listed this as the most useful service that they had received.

Third, the two services that most people ranked highest as services that they wanted to receive were 'activity days out and holidays' (27% of respondents) and 'direct payments' (18% of respondents). Direct payments was also the service most often ranked as the most useful service received (by 11% of respondents).

Table 2: Most useful service received – Top 6

Service	% of respondents describing as most useful service received
Direct payments	10.98
Daytime care in cared-for person's home	8.54
Day care centre	7.32
Activity days out or holidays	6.1
Residential care centre (overnight care)	6.1
Overnight short breaks for disabled children	6.1

Note: 44% of respondents received no respite service at present

Source: LE Wales online survey

Table 3: Service most wanted – Top 5

Service	% of respondents describing as service they most wanted
Activity days out or holidays	26.71
Direct payments	18.01
Residential care centre (overnight care)	11.18
Daytime care in cared-for person's home	9.94
Overnight care in cared-for person's ho	7.45

Note: In response to this question respondents were asked to include services they already received as well as those they did not already receive. 4% of respondents did not want any respite service.

Source: LE Wales online survey

There is a wide range of types of respite service available across Wales, but many of these are only available in some areas and/or for some types of care recipient. The capacity of the services is also limited. This means that in spite of the wide range of services that exists, the choice available to any individual carer in practice can often be very limited.

The range of physical and mental health conditions faced by care recipients is very wide and their care needs can often be very specialised. This means that even if an 'activity day out' type service is widely available geographically, there may be many types of care recipient for whom it is not suitable because their particular care needs are not met by the service.

One point that was made to us on more than one occasion was that ancillary services not normally regarded as respite care may sometimes be more useful for carers than more traditional respite care services. Often, during periods of respite care the usual carer may be having a break from caring for the care recipient but they are certainly not resting. They use the time to do the many chores that they are not able to do whilst caring, sometimes they are in employment and they may also have other caring role such as bringing up (other) children. Some carers felt that assistance with some of their chores (e.g. cleaning, gardening, shopping) would be more useful in practice than respite care. This was particularly the case in situations which meant that the informal carer was at a particular advantage in providing care compared to potential replacement carers. The two main examples of this that were presented to us were: where the care recipient had dementia and was very upset by being cared for by anyone other than the usual carer; and for BME care recipients where potential replacement carers may not have relevant language skills or sufficient understanding of cultural sensitivities.

3.4 Quality of available respite services

Most of the stakeholder organisations that we spoke to were clear that the quality of respite services was nowhere near as big an issue as the quantity of available respite services. Many said something to the effect that "carers are so relieved to get a service, they don't complain much about quality". This was repeated to us many times and emphasises the size of the problem with the quantity of respite services.

The carers we spoke to had more to say about quality issues. The quality of care received by their loved ones was a key issue for them. Many felt that, inevitably, nobody would be able to provide the same quality of care for their loved one as they did. This meant that they often felt guilty about requesting respite care. This can particularly be the case were the care recipient might have difficulties in describing their views and feelings about respite care, such as some who have had a stroke or who have dementia. For some carers it meant that they had never tried to access respite care.

In order for carers to overcome these feelings and arrange respite care they needed to feel that the care provided would be of high quality (whilst accepting that it could not match the quality of care that they provided). Some spoke to us of very positive experiences that they had had of respite care. Others talked about bad experiences which meant that they would never again consider the possibility of using respite services. The poor experiences that were mentioned to us related mainly to residential care for the elderly and care for those with mental health problems.

Some carers said that they had accepted services that were not really suitable because that is all that was on offer.

There was a general feeling that many replacement carers lacked a sufficient understanding of the care recipient's individual needs. Sometimes these needs related to that care recipient as an individual, sometimes they related to a knowledge and understanding of the effects of the care recipient's particular condition. High levels of staff turnover were mentioned as a particular problem in this regard. Inadequate training of formal carers was also mentioned by some.

A number of suggestions were made to us for ways of improving the quality of existing respite care services. Some of these are listed here.

- There should be more consultation with carers and care recipients including regular reviews of service provision through user feedback.
- Outcomes-based approaches to monitoring services should be used.
- WAG should provide guidance on what constitutes high quality respite care. The standards in Scotland were provided as an example.
- Provide advice to carers on how to navigate the system and on how to make complaints about service quality.
- Provide respite services to carers in a way that is more predictable for them. If they are confident of long term support, this is more likely to enable them to take up long term opportunities such as part-time employment. One way of doing this would be having longer term contracts for services providers, e.g. five year contracts instead of one year contracts.
- a more regular inspection regime for care homes.
- Good communication between service providers and carers.
- More specialist training for care workers on the needs associated with specific conditions e.g. autism, behavioural problems.
- Reduce turnover of care staff to allow care recipients to build up long term relationships with their replacement carers.

3.5 Barriers to take up of respite care

In addition to the **limited availability** of respite services and possible issues around the **quality** of respite services, different **views of care recipients** and **feelings of guilt** for carers, discussed above, we explored what other barriers to the take up of respite care exist for carers. In this section we discuss these barriers and indicate the measures suggested by stakeholders for overcoming them.

3.5.1 Insufficient information about services

One issue that was raised over and over again by carers and by stakeholder organisations was the lack of accessible information about respite care services. Many carers told us that they did not know how to find out about available respite services. Some told us that they had not heard of direct payments – and most of them sounded very interested in the idea. Some service providers felt a certain amount of frustration with these views because they felt that good information was available and provided, including information about direct payments.

One of the difficulties in this policy area is that care recipients have a wide range of physical and mental health problems which can need very different types of care. Many conditions are not very common in the population and so care services are very specialised. In response to this there is a large number of organisations providing respite care, some of it very localised and some of it very specialised. The appropriate specialised respite care services may not be available in Wales and so some families in Wales make use of residential respite services in England. This plurality of services makes it more difficult for carers to access and digest information about available services that are suitable for their needs, though many of the voluntary organisations active in this area do provide signposting services for carers. Some said that social workers were not fully aware of the range of potential services available, especially where services were specialist in nature and not located locally. Many carers talked of travelling long distances to access respite services.

A number of stakeholders did point out that making more information available was a two-edged sword – it might just serve to further highlight the lack of availability of respite services compared to the demand for those services.

3.5.2 Unsuitable provision

Stakeholders told us that often the respite care that carers were offered was not suitable for their needs. There were a wide range of reasons for why the available respite care was viewed as unsuitable. Some examples are:

a. Periods of domiciliary care offered are too short (e.g. one or two hours). For those living in rural areas the additional travel times means that this period can often leave insufficient time for the carer to do other things away from the home, e.g. attend a dentist's appointment, do the shopping etc.
b. Many centre-based respite services (day or overnight services) are aimed mainly at older people and are not suited to the needs of younger adults.
c. For care recipients with less common needs care staff were not considered to have sufficient expertise to look after them properly.
d. Respite services were not available at sufficiently short notice in order to accommodate unexpected events.
e. Young disabled children sometimes go to specialist respite placements a long way from home – this is far from ideal as it makes family visits more difficult.
f. Very few services are suitable for 16-25 year olds. Services are usually aimed towards children or adults (often older adults) and this age group does not fit easily into either category. In general there is a big step down in available services in the transition between childhood and adulthood.
g. Many respite services do not include any therapeutic element. This would be ideal for many types of care recipient and it also benefits the carers in the long term.

3.5.3 Cultural barriers

Many of the provider organisations we spoke to had little or no experience of providing respite services to BME carers and their families. Many did not have significant experience of Welsh language services either. Most people we spoke to felt that there were not large problems with the availability of Welsh language services but many thought that there were particular problems with the availability of appropriate services for BME carers.

We spoke with one group of BME carers and with a voluntary sector organisation working with BME children and young people and their families in Wales. Many of the BME carers' concerns were similar to the concerns of other carers, but they also had other concerns. Like some other carers we spoke to, many of them were not aware that respite services might be available to them, but they were attracted by the idea of respite services. Some had experience of respite services and spoke of the struggle it was to access respite. One case was mentioned where it had taken over a year to be offered respite, by which time the care recipient had already died.

There was a general feeling that services were often not culturally appropriate, examples were given of the use of male staff for female care recipients and of meals that were not religiously appropriate. It is not culturally acceptable in many BME communities for females to mix with males in some circumstances and so the lack of single sex provision was a barrier

Language skills was a key issue with many care recipients not able to speak English (or Welsh). There was a feeling that social services departments relied too much on family members, often children, to provide translation. Many care recipients were reluctant to discuss their health problems in front of children. Many carers who speak English as a second language may not be able to understand written English and so access to information is a problem. Many may not be literate in their mother tongue either and so information written in their own language may not be accessible either.

A number of suggestions were made for improving respite services for BME communities. These included:

a. Improving the cultural and religious awareness of social services staff and the staff of other service providers. The best way to do this would be to recruit more care staff from within BME communities. There was a feeling that sometimes a lack of qualifications was a barrier to this, but that where skill levels were high, the lack of qualifications was an unnecessary barrier. Better training for other care staff on cultural and religious issues was also required.
b. Care workers should rely more on independent interpreters and less on family members. Recruiting care workers from within the BME sector could also help with language barriers, but the multiplicity of languages spoken within BME communities might limit this contribution.
c. In some cases other services could be at least as valuable to carers as respite services. Often respite services enable carers to spend time doing all of the other household chores that they have to do. If they had assistance with these chores instead, then they would spend that time caring and could avoid many of the issues around having culturally and religiously appropriate care and issues around language skills. Assistance of this kind could include help with household chores and/or assistance with the purchase of household labour saving devices, such as dishwashers, washing machines and tumble driers.
d. Consult more with BME communities about their needs.
e. Fund more respite services specifically for BME communities.
f. More short break facilities that are suitable for large families that are common to many BME communities.
g. Provision of verbal information on respite care services to BME communities is best. Either one-to-one, within group settings (e.g. focus groups) or presented on a dvd. Sometimes even interpreters may not be able to get across information because there can be many dialects within BME community languages and the interpreter may not speak the

> appropriate dialect. That’s why it’s important to have contact with wide variety of organisations which have interpreters. This increases probability of finding an appropriate interpreter.

The BME carers we spoke to felt that there were more BME-specific respite services available in England (citing Bristol as an example), Scotland and Ireland than was the case in Wales. Such services were particularly scarce in North and mid Wales.

Dementia sufferers often revert to the language of their childhood and so may need a carer who speaks their mother tongue. This issue was raised with us a number of times in the context of Welsh language services, though it is relevant to speakers of other languages too.

3.5.4 Financial barriers

Many stakeholders that we spoke to felt that financial barriers were not a major issue because respite services were fully funded for the carers that they dealt with. Others felt that this was an important issue, particularly as the high eligibility thresholds for services from local authorities meant that many carers who need respite, are not able to receive publicly funded respite services and so have to pay for it themselves, if they can afford it, or do without.

Many stakeholders pointed out that respite services were usually provided following an assessment of the needs of the care recipient rather than following a carer’s assessment. This means that the service is means tested. It also means that if the care recipient is having to pay towards the cost of respite care (which benefits the carer) that this can lead to conflict between the carer and the care recipient. Sometimes the care recipient will refuse to pay.

There are often hidden costs to carers of respite care. The most frequently quoted cost was transport costs when respite facilities were a long way from home. This could be a particular issue for carers with large families. The cost of providing snacks and meals for children on activity days out was also referred to a number of times. Respite services that allow the carer to go on holiday were often only finalised relatively shortly before the holiday dates which meant that carers had to pay more for their holidays as cheaper advanced deals were harder to get.

3.5.5 Barriers to the use of direct payments

Many carers were not aware that direct payments existed as a possible option. That is clearly a key barrier to take up of direct payments.

Many stakeholders referred to the benefits of direct payments in terms of flexibility and the ability to commission services that meet individual needs. A number of stakeholders referred to take up of direct payments in Wales being relatively low. Carers/care recipients can lack confidence in finding the right kind of service/carer and can be daunted by the paperwork involved, particularly if they have literacy and/or numeracy problems. Some are offered assistance in using and managing direct payments.[9]

– [9] Dewis CIL and the Coalition for Disabled People were two organisations mentioned that offer assistance in this area. Some local authorities (e.g. Conwy) also offer direct assistance with the paperwork involved in employing somebody and others have supported user support groups (e.g. Neath Port Talbot).

Some stakeholders thought that the use of direct payments can entail more risk for carers both in terms of the suitability of the person/service being employed and in the sense that if a personal assistant is ill and unable to provide the service for a period there is no back up as there would be under a local authority provided service. One stakeholder suggested that a single system for direct payments across Wales, together with training for carers/care recipients in the use of direct payments could significantly reduce barriers to take up.

Stakeholders recognised that direct payments were not suitable for everybody. Some people do not want the responsibility that goes with using direct payments, e.g. managing the payments and in some cases employing carers, personal assistants etc. Direct payments can also be less useful in rural areas, where it can sometimes be very difficult access services, e.g. to find anyone willing to be a personal assistant.

4 Policy issues and recommendations

4.1 Introduction

In our view, the three key issues for policy-makers in the respite arena are the quantity of publicly funded respite services; the need for any system that provides respite services to address carers' individual needs; and the need to improve information flows to carers about respite services. Our discussion and recommendations in the remainder of this section focuses on these three areas.

Two other issues that have arisen in the course of our review are: the relatively poor quality of data on respite provision that is currently available for policy-making; and the need for more and better training for formal carers.

4.2 The quantity of available respite services

The limited availability of publicly funded respite services relative to the demand for those services was one of the key issues to arise in our stakeholder consultation. There is also wider evidence of this in the literature.[10] Clearly, the current climate for public finances makes it difficult to propose increasing expenditure in any policy area. In this section we set out, at a high level, what we see as some of the benefits of making more respite services available in future and we provide an estimate of the costs of three options for increasing the level of services.

4.2.1 Benefits of increasing the quantity of respite services

When we spoke to stakeholders about the value of respite care many felt that it was vital in order to give them a break from the stress of heavy caring responsibilities and to avoid deterioration in the health of carers. Others referred to the opportunity for carers to maintain social networks and avoid isolation and loneliness. Some carers also referred to benefits for care recipients, where respite services were appropriate for the care recipients needs and enabled them to have new experiences, widen their social networks and take advantage of therapeutic benefits.

The literature in this area provides a less conclusive picture of the benefits of respite care. Studies that ask carers about the value of respite care suggest, like our work with stakeholders, that respite care is very valuable to them.[11] However, studies that try to find a more 'objective' measure of the value of respite care through trying to link periods of respite care with measured improvements for the carer (such as reduced stress levels, improvements to health) or through delayed entry of the care recipient into formal care provide more mixed results and no clear picture emerges. Some studies show positive impacts on carers and some studies fail to find any positive impacts.

Following a systematic review, McNally et al (1999) for example conclude – "*The search yielded 29 studies, from which there was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being. This may be due in part to the fact that the majority of the work conducted has been methodologically poor. Also significant, however, might*

- [10] For example, a survey of short break schemes for disabled children across the UK found that 90% of schemes that responded to the survey had a waiting list, with a total of 2,239 children recorded as being on a waiting list (Shared Care Network, 2007).
- [11] For a UK example see Ashworth and Baker (2000).

be that the findings suggest respite care often fails to facilitate the maintenance of socially supportive relationships." They suggest that the latter point may explain why enduring positive impacts on carers are often not found after respite periods have ended, suggesting that a more carer-centred approach is required.

In another review of the literature on respite care for frail elderly people, Mason et al (2007) concluded "*The literature review provides some evidence that respite for carers of frail elderly people may have a small positive effect upon carers in terms of burden and mental or physical health. Carers were generally very satisfied with respite. No reliable evidence was found that respite either benefits or adversely affects care recipients, or that it delays entry to residential care.*" The authors also commented on the methodological failings of much of the research that they examined.

The general problems with robust quantitative analysis in this area include the fact that it is difficult to accurately measure the impacts of respite care; there may be methodological problems around linking impacts to the respite care; or the respite care provided may not always be suitable and so the positive impacts are fewer than they would be with more appropriate respite care. There is plenty of scope for more primary research to try and understand these issues better.

4.2.2 Costs of increasing the quantity of respite services

We provide here three illustrative examples of the potential costs of increasing the quantity of respite services provided. Each example is based on a different respite service and derives from the results of our online survey of carers. Our assumptions about unit costs derive from the limited cost data that were submitted to us by the local authorities and should be considered as illustrative examples of unit costs.

Increasing provision of activity days out and longer breaks

In our online survey 26% of respondents said that the respite service that they most wanted was 'Activity days out or holidays', significantly more than any other service. 6% of respondents said that this was one of the top three most useful respite services that they already receive. We have estimated the cost of providing this service to the carers who say that it is the service they most want but who do not receive it – we have assumed that this is 20% of carers.

Our analysis suggests that providing each of those 16,000 carers (the 20%) with a respite service involving one activity day a month plus a one week break per year would cost around £22m in 2010. This is based on a unit cost of £35/day for the activity days and £1,000/week for the longer break, which includes residential care costs. The increase in the number of carers over time (see Annex 3) would imply that this annual cost increases to about £25m by 2030 (in constant price terms).

Increasing provision of overnight care at a residential care centre

Using a similar approach, based on results from our online survey of carers, we have estimated the cost of providing 5% of carers with a respite service involving additional overnight care outside the home. This represents 4,000 carers in 2010. Our analysis suggests that providing each one of those carers with one respite week of residential care every three months would cost around £6.5m in

2010. Based on our projections of carer numbers, this would rise to £7.6m by 2030. These figures are based on a unit cost of £420/week for residential care.

Increasing provision of daytime care in the care recipient's home

Again, using a similar approach, based on results from our online survey of carers, we have estimated the cost of providing 1.5% of carers with a respite service involving additional daytime care in the home. This represents 240 carers in 2010. Our analysis suggests that providing each one of those carers with respite of 2 hours each week day for 50 weeks a year would cost around £11.0m in 2010. Based on our projections of carer numbers, this would rise to £13.0m by 2030. These figures are based on a unit cost of £19/hour for daytime care in the care recipient's home.

4.2.3 Discussion

Clearly these cost estimates are heavily dependent on the assumptions about frequency/length of service provision, unit costs and carer numbers, but they indicate the order of magnitude of potential costs. Whilst each of the above sums (£22m, £6.5m and £11m; just under £40m in total) is not a large sum compared to total public expenditure in Wales it is large compared to the data that we collected on confirmed expenditure on respite care in Wales at present which totals £9.5m (though we believe that actual expenditure may be considerably more than this).

It is also important to note that these calculations assume that there is capacity in existing facilities and services to accommodate the extra service provision. If this is not the case (and it may well not be) then it may not be feasible to provide these additional services immediately as new staff need to be recruited and trained and new facilities need to be built. Unit costs may also be greater than assumed here, though the extent to which that is the case depends on the extent to which capital costs are already apportioned in existing charges.

By way of illustration, we show in the table below the results outlined above (as Scenario 1) together with two alternative scenarios that reduce these levels of service provision, leading to lower costs.

Table 4: Scenarios for increased service provision – annual cost in 2010

		Scenario 1		Scenario 2		Scenario 3	
	Unit costs	Service	Cost £m	Service	Cost £m	Service	Cost £m
Activity days/longer breaks	£35/day + £1,000/week	1 day/month +1 week/year	22	1 day/2 months +1 week/year	19	1 day/month +no longer break	6.5
Overnight residential care	£420/week	1 week/3 months	6.5	1 week/4 months	4.9	1 week/6 months	3.3
Daytime care at home	£19/hour	10 hrs/week – 50 weeks/year	11	4 hrs/week – 50 weeks/year	4.4	4 hrs/week – 40 weeks/year	3.5
Totals			39.5		28.3		13.3

Note:
Source: LE Wales calculations; LE Wales online survey, local authorities

Provision of all three of the additional services outlined above (under any of the scenarios) could, on our assumptions, mean that up to 4,240 additional carers receive a respite service (if each recipient of the new services were not already benefitting from other respite services). This compares to 10,000 - 15,000 carers currently receiving respite services from local authorities.

4.2.4 Recommendation 1

Given the high value placed on respite services by carers and other stakeholders, the likely future increases in the need for care and given what appear to be the relatively small amounts of expenditure on respite services at present, we believe that there is a strong case for funding more outcome focussed respite services in Wales, ensuring that those services are appropriate to the needs of carers and care recipients.

In the current climate of public expenditure restraint then there is of course a question of priorities for public spending faced by WAG, the local authorities and the local health boards. We are not in a position to advise on the relevant merits of alternative options for public expenditure on the basis of this research. Some stakeholders that we spoke to felt that any spending on respite care inevitably reduces spend on care recipients and when finances are tight, that priority should be given to care recipients. There is evidence however that in Wales in 2008, the general satisfaction of carers with the services they received was lower than the general satisfaction of care recipients with services (CSSIW/WAO, 2009).

Informal carers play a significant role in caring for those in need of care.[12] It is also likely that they provide relatively high quality care. Even with much higher levels of support for informal carers it is likely that they would be a very cost effective means of meeting the increasing care needs of the future. In our view there is a clear case for continuing to spend on respite care during the current financial climate. This does not necessarily have to be at the expense of care recipients.

4.3 Addressing carers' individual needs

Throughout our work in the care sector in Wales it has been clear to us that the needs of individual carers and care recipients can vary tremendously. It can be very difficult to generalise about the needs of carers. Each individual carer is in their own unique situation with their own particular set of needs. There are clearly overlaps between the needs of different carers and sometimes these overlaps may be large, but they each remain an individual with individual needs.

Traditionally, it's fair to say that services to carers have typically been provided through offering a menu (sometimes a very limited menu) of standard services on a take it or leave it basis. These 'traditional' services have included overnight residential care in care homes; overnight care at home; daytime care in the home; and daytime care at day centres. Other services are being provided now and there appears to be more recognition of the individual needs of carers (and care recipients). Some stakeholders that we spoke to felt that the carers they were in contact with already had access to a sufficient range of services, but many felt that that there needed to be a wider range of services and that service provision needed to be more flexible. The carers we spoke to tended to agree with the latter point of view.

One way to address this issue is to provide the funding directly to carers and care recipients and allow them to buy whichever services suit them best. Direct payment are a step in this direction

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– [12] WAG estimate that unpaid carers provide around 70% of care in the community. (Explanatory Memorandum to the Proposed Carers Strategies (Wales) Measure, September 2010).

though the recipients of direct payments need the agreement of social services departments on how they are going to spend the money. Direct payments require significant input from the carer/care recipient in terms of taking decisions about how to spend the money and managing the associated paperwork, which can be considerable in some instances, e.g. where employing a personal assistant. Direct payments are not for everyone, though there should be scope for taking further action to make them more accessible.

In England, personal budgets for carers are being introduced. Personal budgets incorporate direct payments, but also offer other options such as holding an ‘account’ which is managed by the local authority in line with the services user’s wishes.[13] The Welsh Assembly Government have no current plans to take this approach, though they continue to support an approach that puts services users at the centre of the care assessment and care services delivery processes.

4.3.1 Recommendation 2

Given this policy, we propose that WAG take further action to ensure that the process of better addressing carers’ individual needs continues to move forwards. We suggest that this happens in three ways:

i. **WAG take further action to make direct payments easier for carers to use**. Any further action is likely to involve providing more support for carers both in taking decisions about what services to purchase and with consequential paperwork, particularly where employing a carer is involved. In the case of the former the greater availability of information about respite services, discussed in the next section, should contribute to this.
ii. **WAG extend the use of direct payments to respite services provided through the healthcare system**. Local authority social services departments and local health boards are already working together to coordinate carer services in many parts of Wales. Following the introduction of the Carers Strategies (Wales) Measure coordination is likely to become more widespread and more formalised. Many of the respite services funded by both local authorities and by the local health boards are provided by third parties (e.g. Crossroads). From the carer’s perspective, a respite service that they receive via Crossroads may seem much the same whether it’s funded by the local authority or by the health board. In these circumstances the possibility of using direct payments in place of respite services funded by the local authorities but not in place of respite services funded by the NHS seems anomalous. In 2006, WAG issued a statement indicating their view that existing legislation did not allow for the provision of direct payments in lieu of NHS funded services.[14] In England the use of personal health budgets is being piloted.[15] The Health Act (2009) allows selected primary care trust sites in England to pilot direct payments. The UK Department of Health consulted on proposals for regulations and guidance to govern how direct payments would work in healthcare in 2009 and regulations that allow the use of direct payments in pilot schemes approved by the Secretary of State came into force in June 2010.[16]

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[13] For a guide to personalisation policy in England see Carr (2010).

[14] Available at:

http://wales.gov.uk/topics/health/publications/socialcare/guidance1/usedirectpayments;jsessionid=HWnXMyVNyGgX9g14n3PxKl1QVQPsYyBpypTvlF7LcHwb1tlYwwQT!-450303615?lang=en

[15] See Carr (2010) for more details.

[16] For more details, see: http://www.dh.gov.uk/en/Healthcare/Personalhealthbudgets/DH_109429.

iii. **WAG work with local authorities and the NHS to ensure that carers not using direct payments have access to a wider range of appropriate services in a more flexible way**. In this report we have highlighted some services to which carers would like to have more access, such as activity days and holidays, services that have more therapeutic benefits for care recipients, and services that help with household chores such as help with gardening. Nevertheless we are not proposing that these services should be added to a longer list of 'standard' services which carers are able to choose from. We are proposing that services should be offered in a much more flexible way. Rather than saying to carers "Here are five respite services that we offer, which one do you want?", social services departments need to be saying to carers "What aspects of your caring role are most difficult? How can we help you make the role less difficult, stressful, tiring etc.?" This type of discussion needs to be held in the context of which services could be available at a reasonable cost, of course, but the key is to be moving away from rigid formats for services. Some local authorities have small amounts of money which they can allocate very flexibly for respite services. We heard examples of payments towards flight tickets for a care recipient to go away and be looked after by family members overseas and of payment to purchase a computer and an internet connection for a carer to be able to participate in more social interaction. For some, this type of flexibility can enable more cost effective achievement of positive outcomes for carers than more traditional respite services.

4.4 Information for carers

In order for carers to be able to access respite care services they need to know that those services exist and how to access them.

It is also unlikely that they will use any respite services that they are aware of unless they know that those services are appropriate for them and for the person they are caring for. By 'appropriate' we do not only mean that the services are of the right type (e.g. care at home during the day) but also that the carer can be sure that the service will be of sufficient quality. Many carers feel guilty about needing help and respite even where available services are of high quality and so many are unlikely to use respite services unless they have some confidence that they will be of high quality. One view from carers that was expressed to us on more than one occasion was that an early poor experience with a respite care service had deterred carers from ever considering the use of respite care again. Issues around the limited availability of information for carers were raised in most of the discussions we had with carers and are discussed in Section 3.5.1.

The Welsh Assembly Government has already recognised the need for carers to have access to appropriate information:

"*Research has highlighted the need for Carers to have the right information at the right time to support them in their caring role. In particular, information for carers needs to be easily accessible, relevant and factually correct. The kind of information carers may need is likely to vary and may include prognosis and care planning for the person cared for, medicines management, safe lifting and handling, rights, including the right to a carers assessment, what social services or NHS support could be available, what financial support could be available, employment provisions, including flexible working and support groups*."

(Explanatory Memorandum to the Proposed Carers Strategies (Wales) Measure, September 2010).

As this research has been about respite care we have focussed on the “*what social services or NHS support could be available*” aspect of the above list of information requirements. From discussing this issue with carers and other stakeholders we believe that carers need access to better information about the full range of respite and related services that are available to them, whether or not they are provided or funded by social services or the NHS.

Other work is already underway in order to improve access to information more generally, for services users, carers and professionals. The ‘Setting the Direction’ strategy for primary and community services delivery suggested the development of ‘communications hubs’ designed to provide a single point of access for information about individualised care across the health and social care system. Work on developing this approach is currently under way. The Gwent Frailty Programme, for example, has set out it’s approach to developing a single point of access.[17]

4.4.1 The Assembly Measure

The Carers Strategies (Wales) Measure 2010 was approved by the National Assembly for Wales on 21 September 2010 and received royal approval on 10 November 2010.

The overall aim of the Measure had been described as follows:

“The overall intention of the proposed Measure is to improve the lives of carers in the following key areas:

• to ensure that carers have the right information at the right time to support them in their caring role. The Carers’ Strategy Implementation Plan in Wales 2000 highlighted a need for the provision of easily accessible, relevant and factually correct information for carers, as well as acknowledging the need for a longer term view of the information needs of carers. The kind of information carers may need from time to time would include information about financial benefits, employment provisions including flexible working, rights to a needs assessment, social services functions available to them, care planning for the person cared for, medicines management, safe handling and lifting and other matters related to the care of the person cared for.

• to ensure that statutory agencies properly engage with carers as partners in the provision of care involving them at all levels in the assessment, delivery and evaluation of care arrangements.”

(Explanatory Memorandum to the Proposed Carers Strategies (Wales) Measure, September 2010).

The Measure gives powers to Welsh Assembly Government Ministers to make regulations that:

- “*place a duty on relevant authorities to prepare and publish a strategy setting out how they will work together to provide appropriate information and advice to carers and to ensure carers are consulted about what services are to be provided to or for a carer or the person cared for;*
- *place a duty on the relevant authorities responsible for the strategy to implement the strategy;*
- *place a duty on the relevant authorities to provide the information and advice to carers in pursuance of the strategy without charge;*

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[17] See Holmes (2010).

- *require each responsible authority to make a copy of the strategy available for inspection at all reasonable hours and free of charge;*
- *empower Welsh Ministers, for each strategy, to designate an NHS organisation as the lead authority; and*
- *place a duty on the lead authority to submit a strategy in draft to Welsh Ministers who will need to satisfy themselves that the draft strategy complies with the requirements by or under the proposed Measure.*"

(Explanatory Memorandum to the Proposed Carers Strategies (Wales) Measure, September 2010).

4.4.2 Recommendation 3

The Welsh Assembly Government has already recognised the need to improve information flows for carers - this is reflected in the steps taken to introduce an Assembly Measure. Under the proposed Measure, the detail of any requirements relating to information for carers would be set out in future regulations.

We set out here some suggestions, based on our research, for issues to be considered when those regulations are being drawn up or, if more appropriate, where local authorities, local health boards and others are drawing up their own policies and strategies for carers:

i. **Using varied means of providing information**. Many of the stakeholders we spoke to emphasised the need to make information about respite services available to carers and care recipients through a wide variety of routes including social services, schools, GPs, health visitors, paediatricians, on discharge from hospitals, in libraries, by DVD, on the internet. Information for young carers may need to be presented and provided differently to information for adult carers. We support these ideas.

   Carers can lead busy, tiring and stressful lives. When they meet social workers for the first time they may need to take in a lot of new information. In these circumstances it is easy for carers to forget some of the things they are told, e.g. that they are entitled to direct payments and to separate carers' assessments. We suggest that, where it does not happen already, it would be helpful if carers were told important information of this nature both orally when they meet social workers for the first few times and also that this be supported by written information that they can refer to later.

ii. **The need for comprehensive information**. In our view, there is a danger that one outcome of the process following implementation of the Measure, and other processes already under way, could be that information for carers may continue to be restricted to information on local/regional services and possibly to services that are publicly provided or funded. This means that carers of people with relatively specialist needs, or who are not eligible for publicly funded services, may still have inadequate access to information on all of the services that are relevant to them. We recommend that WAG consider, in consultation with services providers and carers and their representatives, whether there is scope to make better use of existing information resources to develop an accessible all Wales source of information about all available respite services, whether access to those services is publicly funded or not. It is likely that the main interface for this information would be a website, perhaps supported by a telephone line. This could be directly useful for those carers who are actively researching support options and also useful for health and social care professionals who are seeking to provide support to carers. We envisage that it would provide generic information about carer's rights and carers' assessments; and specific information about providers of respite services of all types together with contact information. It would enable carers to see what specialised provision was available both inside and outside their area, and should include facilities outside Wales that can be accessed by carers and care recipients living in Wales. Careful consideration would need to be given to how this resource could be integrated with, or coordinated with, the work that is ongoing to develop regional communications hubs for a wider group of stakeholders and also with the existing information and directory services provided by third sector organisations that support carers.

iii. **Developing strategies under the Measure**. The Measure allows the Welsh Assembly Government to place a duty on public authorities to prepare strategies for providing information to carers either singly or jointly ("two or more relevant authorities"). In developing policy in this area we recommend that WAG introduce a general presumption that strategies will be developed jointly between individual local authorities (social services and education functions) and the local health boards unless there are strong reasons why this should not be the case. There may be a case for developing regional strategies jointly between each health board and all of the local authorities in that health board's region.

We believe that joint working in this way will make it more likely that carers will be able to access better and more comprehensive information more easily. Many stakeholders that we spoke to felt that the NHS was the most natural source of information about respite care for them because they all have regular contact with the NHS either through the care recipient, or in their own right and contact with the NHS did not have the same stigma as contact with social services. Many stakeholders working with children (as young carers or as care recipients) also emphasised the importance of using schools as a conduit for information.

iv. **Information about respite services available at short notice**. A particular problem for carers is access to respite care at short notice so that the carer can deal with an unplanned event. Since many respite services are planned a long time in advance, 'short notice' can mean relatively long periods such as a few weeks or even months. Carers felt that this type of service was particularly difficult to access, either because they did not exist, or it was hard to find out about them, especially at short notice. More than one stakeholder suggested to us that an online and/or telephone booking system for respite care, not unlike a hotel booking system, could prove a very useful tool for carers and might enable more efficient use of existing provision. In order for this to work it would need a network of respite care facilities/services across Wales that were willing to be a part of such a system and to make capacity available for respite services available at short notice. One possible starting point for investigating the feasibility for such a services could be publicly and privately run residential care homes. Regulatory requirements for the preparation of service delivery plans for service users may make this kind of short notice service more difficult to operate.[18] Consideration will need to be given to whether the requirements of the regulations can be met whilst providing this type of service, or whether the regulations need to be amended to enable provision of such a service. One option under the current

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– [18] See, for example, Section 14 of the Domiciliary Care Agencies (Wales) Regulations 2004.

system may be to have a longer term plan agreed with one or more providers and then, consistent with that plan, to use their services at short notice as required.

4.5 Data collection

As noted in section 2, the main publicly available source of existing data on respite services in Wales is the data collected from local authorities by Data Unit Wales. This data on respite services includes information on the numbers of adults and children receiving respite services, disaggregated by local authority, by age band of the care recipient (for the adults) and by health condition of the care recipient. These data are limited to respite services that include at least one overnight stay and so have a much narrower focus then this research.

In our discussions with staff involved with carers' services both at the Welsh Assembly Government and in local authorities, our impression was that this data on respite services is of little use for policy development purposes at either level. Neither was it very useful for the purposes of this research. The main reason for that is its very limited scope – i.e. it is restricted to respite services that involve an overnight stay and so it does not cover a very significant proportion of respite services. Data is also collected for Data Unit Wales on other services that include an element of respite, e.g. day centre services, but these are not recorded as respite nor are they recorded as a service to the carer as well as the care recipient.

This data is collected by Data Unit Wales as a part of the performance management data that it collects from local authorities. We make no comment on whether or not it is useful for performance management purposes – that is outside the scope of our investigation.

4.5.1 Recording a service as benefiting the carer or the care recipient

Most respite care services have a dual aspect because the service is given directly to the care recipient, but the break is also beneficial to the carer. This is not adequately captured in the current system of data recording at a national level in Wales – the main focus is on recording services as a benefit to the care recipient only. This problem could be alleviated by revising the system of recording and collecting service use data.

In practice many local authorities and local health boards do collect better information for their own purposes and are able to allocate a much wider range of services to carers in their data collection systems. That is why we were able to collect better data on respite services in our one off data collection for the purposes of this research.

4.5.2 The scope of the respite care definition

The working definition of respite most commonly used in the data collected by Data Unit Wales from local authorities specifies it as being overnight care for the care recipient. The most common distinction following this definition is then whether the respite service is provided in the client's home or in a residential setting. In practice, there may be other places, which do not fall into either of these categories, such as someone else's home. In addition, much of the respite care actually provided whether in the home or elsewhere, does not involve an overnight stay.

For carers of children, only those looking after children “in need” as defined in Part 3 of the Children Act 1989, will be eligible to receive short break care. The definition of “in need” is that the child’s health or development is unlikely to be achieved or maintained to a reasonable standard (or will be impaired or further impaired) without the provision of services from the local authority, or that the child is disabled.[19]

The definitions of respite care used in the PM2 form (for looked after adults) and in the SSDA903 form (for looked after children) are provided in Box 1. These forms are the basis of the respite care data collected by Data Unit Wales from the local authorities.

Box1: Respite definitions

PM2: Adult Services 2008-09 Guidance Notes for completion and submission (Tables Ab, Ac and Ad)

To be consistent with the Audit Commission the period of care should cover at least one night but should not exceed 3 months. If a client receives respite for more than 3 months, include them in this figure but draw attention to it and specify the number of clients involved in the comments box.

Overnight respite care – client’s home - This refers to overnight care provided in a client’s own home.

Overnight respite care – not client’s home - This refers to overnight care somewhere other than the client’s own home. Normally this will be in a residential unit.

For a client to be included as receiving respite care, the service must be specified in the client’s care plan.

Guidance Notes for the completion of SSDA 903 records 2008/09 (pages 10-11)

1.6.1 Respite Care is the term used to describe children who are subject to short-term break agreements. These children normally live at home, but are accommodated by a local authority in a pattern of short periods of care in order to give their parents (or guardians) some “respite” from the normal duties of looking after a child. A typical example would be a physically disabled child, who normally lives at home with its parents, but who is accommodated by a local council every weekend.

1.6.2 The breaks (or short term placements) must form part of a regular programme of support agreed between social services and the child’s parents/guardians. Each break must include at least one night away from home, but cannot exceed four weeks (28 days) of continuous care (reg. 13 of the Arrangement for Placement of Children (General) Regulations, 1991 and Reg 37 of the

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[19] The full text is provided in Section 17, subsections (10) and (11): http://www.opsi.gov.uk/acts/acts1989/ukpga_19890041_en_4#pt3.

Fostering Services Regulations 2002). Up to 120 days of accommodation away from home may take place under a single agreement in any twelve-month period.

1.6.3 These children form a special group, and in order that they can be readily identified, special legal status codes (V1) are used (see Part 2 for a full definition). Strictly speaking these children are moving in and out of care. Under the terms of the Children Act, they are only actually being looked after for those days (and nights) when they are being accommodated and are not looked after when they are back home with their parents (or guardians). The decision to treat these children as a special group is therefore a concession on the part of the Department, introduced to ease the burden of administration involved with a child who is endlessly starting and ceasing to be looked after.

1.6.4 Respite children should never be confused with other children (who are not subject to an agreement) but who nevertheless start and cease to be looked after several times during the year for a variety of reasons. Children receiving short term (or respite care) exhibit a number of common characteristics, which are set out below. If the circumstances of a child are such that he/she cannot meet all of these conditions, it should not be treated as being a respite case, but as separate periods of being looked after under legal status V2.

- Respite children normally live at home, and over the medium to long term, spend more time with their parents (or guardians), than being accommodated by the local authority.

- There is a formal agreement in place which clearly sets out the times (or circumstances) when the child is to be accommodated, and the placement (either a specific foster carer, or a named residential establishment). There must be series of breaks, i.e. at least two. A “one-off” spell of respite for a child’s parents/guardians is not sufficient for a child to be classified within this group.

- The legal status of these children is always Section 20 of the Children’s Act. (A child under any other status or order cannot be the subject of a “respite” agreement).

- There are strict limits on the duration of each break, and the total number of days care that is allowed under these arrangements in any one year, as set out in paragraph 1.6.2 above.

4.5.3 Discussion

In our view a common understanding of the range of respite services that is currently provided and the way in which those services develop over time is an important input for policy development. This is the case not only for the purposes of the Welsh Assembly Government, but also the local authorities and the local health boards. It may be particularly important as local authorities start to work more closely with each other to coordinate services and as they start to work more closely with the local health boards for the same purpose.

There will be costs to developing this common understanding and they need to be considered alongside the benefits. The costs will include the time inputs from staff at a wide rage of organisations needed to reach agreement on a common approach across Wales and the costs of making changes to data collection systems in order to start collecting data under revised definitions of respite care. There could be some offsetting savings if it were determined that the existing collection of respite care data by Data Unit Wales were no longer required, and to the extent that some local authorities and some local health boards are collecting this data already, not all of the costs will be additional.

4.5.4 Recommendation 4

We recommend that the Welsh Assembly Government work with the local authorities and the NHS to:

iii. consider whether there is sufficient value, given the costs, in collecting a common set of data on respite care services for the purposes of policy development; and

iv. if so, to develop a common definition of respite care for data collection purposes and to agree a common approach to linking a respite service with the carer, as well as the care recipient.

4.6 Professional standards and training for staff who provide respite care

The carers we spoke to emphasised the importance to them of high quality respite services. A number of stakeholders that we spoke to referred to the need for more training for care staff involved in the provision of respite care. This was in a number of contexts, including the need for more understanding of the needs of care recipients with less common conditions; the need to be more sensitive to cultural variations; and the need to be more sensitive to the needs of carers, as opposed to care recipients.

Formal carers who care for service users during periods of respite generally have received significant levels of care training, whether they are local authority staff, local health board staff or staff employed by other provider organisations. Whilst we would expect that training courses that lead to care-related qualifications refer to respite care we understand that there may not be any modules that relate specifically to the needs of carers, including respite care. A small number of stakeholders suggested the need to introduce an all Wales standard for respite care quality. One stakeholder suggested that this should be a national minimum standard and that a training module should be developed for care staff in relation to that new national minimum standard for respite care.

The Care Standards Act 2000 provides that a national minimum standard may be introduced in respect of the activities undertaken by “establishments and agencies” as defined under the Act. These include care homes, nursing agencies and domiciliary care agencies, but may not include all providers of respite care services.

4.6.1 Recommendation 5

Given the importance to carers of quality of care for care recipients and the ongoing changes in approach to service provision that we consider are necessary in respect of providing more flexibility and choice in services to carers then we recommend that WAG consider the development of best practice standards for quality assurance purposes in relation to respite care; and an accompanying training module for social and health care staff who may interact with carers. We envisage that the best practice standards would be aimed at practitioners and providers and adherence with the best practice standards would be monitored by commissioners. We also suggest that such an approach be considered in consultation with key stakeholders including carers, care recipients, service providers and training providers.

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Annex 1 Respite services funded by the local health boards

A1.1 Betsi Cadwaladr University Health Board (BCU-HB)

A1.1.1 Overview

BCU-HB covers the same geographical area as the six counties of Ynys Môn, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham. Services are managed separately in each of these areas.

In many cases respite provision is not recorded separately in a way that is easily accessible – it is usually provided as a part of a wider package of care.

The information on respite services provided by BCU-HB is presented below by locality. BCU-HB were not able to provide us with full information for all localities. In general there are no allocated respite beds in hospitals. Hospital beds may from time to time be used for respite services in an emergency. In general, requests for respite are not turned down if they meet the criteria for either Continuing Health Care or NHS funded registered nursing care.

A1.1.2 Ynys Môn

Children's services

Continuing Health Care

BCU-HB fund Continuing Health Care or contribute to jointly funded packages for 9 children where the services include a respite element. Most of these packages are fully funded by BCU-HB. The number of hours per month of respite care for each package varies considerably and lies in the range 14 to 94 hours.

Total spend on these packages (not just the respite elements) is approximately £500,000 per year. Most of these children are the ones that have respite away from home at the Tŷ Gobaith hospice. Nearly all of the children with complex health needs are eligible to go to the hospice.

The information above does not include any out of county placement packages. Some of these may include elements of respite.

Tŷ Gobaith

BCU-HB funds residential respite services for children at Tŷ Gobaith (a four bed hospice in the Conwy valley). Tŷ Gobaith also take siblings and other family members to stay and work with either at the hospice or in their homes.

Details of the respite services provided to Ynys Môn families are set out in the table below.

Table 5: Ynys Môn families in receipt of Tŷ Gobaith services funded by BCU-HB 2009-10

	No. of nights	Nursing outreach	Counselling hours	Sibling support	Social work
Family 1	19	0	21.5	0	3.3
Family 2	33	9.25	0	0	3.3
Family 3	30	34.25	0	0	0
Family 4	24	35	0	0	0
Family 5	30	51.25	2.15	0	3.25

Note: Some families do not wish to take up the full number of nights available to them. In addition one family receive 13 nights respite at Hope House in Oswestry.

Source: BCU-HB

BCU-HB policy in respect of planning and booking placements at Tŷ Gobaith are set out below.

"All families are offered to book in advance the minimum allowance covering the 12 months from January to end December each year. We calculate each summer an average bed night we can offer each family for the following 12 months keeping a quarter of our bed space free for new families, terminal care or emergencies within the family. After allocating the minimum bed space to each family and as the year progresses if we have a bed available we offer it as extra to families that have requested to be on the cancellation list, we would also know if one particular family is struggling e.g. Mum going into hospital or child suddenly deteriorating so that we can prioritise the available bed space to need.

When arranging the planned bookings we look at each individual child/young person and either grade them into band A, B C or Terminal care; band A are offered less the child/young person is usually stable or in the early stage of illness, band B is offered to a child/young person that is relatively stable but with high nursing needs or exceptional personal circumstances, band C are children/young people who are very unstable or deteriorating clinical condition. Families are offered the minimum to arrange bookings which include a mix of weekends and mid week (school term), we also try and share holiday periods fairly. Some families chose not to have as much as they could because they only want to come on weekends and or school holidays."

In addition BCU-HB are aware of three further families eligible for respite care. One family has stated that respite is not what they need at the moment but keep in touch; one family has been accepted but the family do not want to use us yet (early on in child's illness trajectory); and one child is in tertiary care.

A further six families are provide with bereavement support.

Adult services

In 2009/10 two patients received respite services. The total cost of these services in that year was £8,922.

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A1.1.3 Gwynedd

Children's services

Continuing Health Care

BCU-HB fund Continuing Health Care or contribute to jointly funded packages for 13 children where the services include a respite element. Most of these packages are jointly funded with the local authority. The number of hours per month of respite care for each package varies considerably and lies in the range 7 to 34 hours.

Total spend on these packages (not just the respite elements) is approximately £250,000 per year. Most of these children are the ones that have respite away from home at the Tŷ Gobaith hospice. Nearly all of the children with complex health needs are eligible to go to the hospice.

The information above does not include any out of county placement packages. Some of these may include elements of respite.

Tŷ Gobaith

BCU-HB funds residential respite services for children at Tŷ Gobaith (a four bed hospice in the Conwy valley). Tŷ Gobaith also take siblings and other family members to stay and work with either at the hospice or in their homes.

Details of the respite services provided to Gwynedd families are set out in the table below.

Table 6: Gwynedd families in receipt of Tŷ Gobaith services funded by BCU-HB 2009-10

	No. of nights	Nursing outreach	Counselling hours	Sibling support	Social work
Family 1	31	5.5	0	7	0
Family 2	51	0	0	0	0
Family 3	39	0	0	0	0
Family 4	7	2.15	0	2.15	13.15
Family 5	46	37	2.5	0	2.3
Family 6	50	42	3.8	20	12
Family 7	10	0	0	0	0
Family 8	6	32	0	0	0
Family 9	36	0	2	0	3.5

Note: Some families do not wish to take up the full number of nights available to them. A further family is now eligible for services but has not taken them up yet.

Source: BCU-HB

BCU-HB policy in respect of planning and booking placements at Tŷ Gobaith is set out in the section on Ynys Môn above.

A further nine families are provide with bereavement support.

Adult services

BCU-HB were not able to provide us with information on the adult respite services that they fund (if any) in Gwynedd.

A1.1.4 Conwy

In the Conwy area BCU-HB and the local authority work together with the aim of maintaining independence for service users. This means that support has focussed on supporting individuals in their own homes where this is appropriate.

'Pure' respite services

BCU-HB provided us with information about a number of services that were 'pure' respite services, i.e. were they were able to separate out respite from other services elements:

- One respite bed commissioned by the local authority in private nursing home and shared with BCU-HB on an as and when needed agreement. The cost is £537.39/week.
- Alzheimer's respite at home using trained home sitters. The cost is £10,000 per year.
- A respite flat in an extra care housing facility costing £26,000 per year. Additional community nursing costs are also paid.
- Bespoke respite packages for individual patients, both children and adults. Currently totaling £37,152 per year for 8 individuals.

Mixed services that include a respite element

BCU-HB provided information about a number of services that were not 'pure' respite services but which included a respite element. They were not able to easily separate out data for the respite elements of these services.

- Spot purchasing through intermediate care service. This is not all respite-related but can be accessed for crisis respite and reassessment plus intermediate care service input. Total budget - £26,000 per year.
- Comprehensive continuing care packages for both adults and children can include an element of respite but these are recorded under the CHC criteria and therefore the information regarding the respite element isn't easily retrievable and would need manual extraction.
- The Trio scheme for EMH patients is delivered by the local authority and funded by BCU-HB at £104,000 (funding includes home adaptation budget of £20,000). The scheme supports approx 12 patients in their own home. EMH specialist home support workers are in place and are part funded by health.

Hospice Provision

In the Conwy area BCU-HB contributes to three hospices, each of which have a respite element including the option of day care or in-patient care.

- St David’s Hospice (cost - £ 132,210)
- St Kentigens (cost - £ 40, 956)
- Ty Gobaith (children) (cost - £7, 303)

Palliative care

Marie curie services are also commissioned for palliative care and terminally ill patients in Conwy. Spend is £68,000 providing approximately 430 visits/ year and 5,150 hours of care. Inclusive within this is respite for families through the night sitting service. There is also a rapid response service out of hours provided by Marie Curie.

A1.1.5 Denbighshire

BCU-HB were not able to provide us with information on the respite services that they fund (if any) in Denbighshire.

A1.1.6 Flintshire

In 2009-10 BCU-HB spent £62,235 on respite services in Flintshire. This provided respite care in 15 cases as indicated in the table below.

Table 7: Summary of BCU-HB respite provision in Flintshire 2009-10

	Expenditure	No. of cases
Joint funding packages	£26,602	2
Agency	£9,003	1
Nursing home	£26,630	12

Source: BCU-HB

A1.1.7 Wrexham

In 2009-10 BCU-HB has recorded expenditure of £59,718 on respite services in the Wrexham area. This provided respite care in 13 cases as indicated in the table below.

Table 8: Summary of BCU-HB respite provision in Wrexham 2009-10

	Expenditure	No. of cases
Learning disabilities	£29,092	2
Children	£16,581	1
Nursing care	£47,863	3
No category recorded	£13,566	7

Source: BCU-HB

BCU-HB does not directly provide and respite services in Wrexham. All respite services funded by BCU-HB in Wrexham are commissioned. Commissioning is undertaken on a case by case basis under continuing health care, either in the patient's own home, in a care home or at a specialist placement. A mix of service types is funded, including:

- residential & nursing home placements in the independent sector;
- domiciliary agency services;
- foster care placements for children;
- Trio placements for elderly mental health patients.

Some patients also receive respite jointly funded with the local authority under NHS funded nursing care.

A1.2 Powys Teaching Health Board (PT-HB)

PT-HB covers the same geographical area as the county of Powys.

PT-HB were able to provide us with some information about respite services provided for adults through continuing healthcare and on services provided for children. They were unable to provide us with comprehensive information on adult respite services that they commission from other organisations or of respite beds available in hospitals.

Four adult patients in the Powys region are in receipt of respite services through continuing healthcare packages. One of these is a patient with Alzheimer's who receives respite in a nursing home at an annual cost of £3,526 in 2009. The other three patients all have neurological conditions and receive respite care at home at a total annual cost of £26,089 for all three packages.

PT-HB also has a contract with Crossroads covering both adult and children's services (£65,000 in total). The contract covers the provision of respite services to children with learning disabilities, autistic spectrum disorder and physical problems. In addition, twelve families are provided with access to a children's hospice in Oswestry. These children have "life-limiting illnesses" including developmental delay; end of life; and physical illnesses including cancer. PT-HB contributes £6,000 per annum towards the cost of this service. A community paediatric service also provides domiciliary care but this service is not generally regarded as a respite service.

A1.3 Hywel Dda Health Board (HDd-HB)

A1.3.1 Overview

HDd-HB covers the same geographical area as the three counties of Ceredigion, Carmarthenshire and Pembrokeshire.

A1.3.2 Children's services

HDd-HB do not have central records of respite services provided for children. Any respite service that does exist would be reflected in the package of care offered to each child but would not be separately recorded as respite.

A1.3.3 Adult services - Carmarthenshire

Through Continuing Health Care, HDd-HB funds six clients with respite packages plus three other care packages that include an element of respite. In addition there is one respite bed in Amman Community Hospital and there are three respite beds in Mynydd Mawr Community Hospital.

A1.3.4 Adult services – Ceredigion

In Ceredigion, HDd-HB funds respite services in private nursing homes and also contracts with other organisations to provide respite services. There are no beds in community hospitals that are dedicated to respite care, though from time to time beds may be used for respite purposes in an emergency.

HDd-HB funds respite places in private nursing homes for three patients, one in the 18-64 age band and two in the 65-75 age band. The younger patient has an annual allowance for eight weeks respite in the nursing home and the two older patients have annual allowances of 13 weeks each. HDd-HB's total spend on these services is about £24,000.

In Ceredigion, HDd-HB also has a contract with Crossroads to provide respite care services in patients' homes and through community support and with Beacon of Hope to provide palliative care services which include respite for carers. HDd-HB's expenditure on these services is about £45,000 per annum. HDd-HB also purchases services from the Stroke Association, British Red Cross Home from Hospital Service and Epilepsy Wales which are wider packages that include support to carers and may include some respite.

A1.3.5 Adult services - Pembrokeshire

In Pembrokeshire, HDd-HB funds similar services to those funded in Ceredigion.

HDd-HB funds respite places in private nursing homes for fifteen patients, spending about £75,000 in total. Three of these patients are in the 18-64 age band and the remainder are aged 65 or over. Their annual respite care allowance in the nursing home ranges from 45 days to 74 days, with most receiving either 45 days or eight weeks.

In Pembrokeshire, HDd-HB also has a contract with Crossroads to provide support and respite care services for carers of people with physical or sensory disabilities and a contract with the Paul Sartori Foundation to deliver palliative care services in the home. HDd-HB's expenditure on these services is about £130,000 per annum. HDd-HB also purchases services from the Alzheimer Society, Age Concern and All Pembrokeshire CRUSE which are wider packages that include support to carers and may include some respite.

A1.4 Abertawe Bro Morgannwg University Health Board (ABMU-HB)

ABMU-HB covers the same geographical area as the three counties of Neath Port Talbot, Swansea and Bridgend.

ABMU-HB funds four respite places at a private residential care home in Aberavon at a cost of £113,208.16 in 2009-10. This service provides 24 hour residential care for patients in the Neath Port Talbot area. Normally a maximum of 7 days respite is provided for each patient in each six week period. In addition there is scope for a two week period of respite once a year.

ABMU-HB did not provide us with information about additional respite services (if any) that they fund.

A1.5 Cwm Tâf Health Board (CT-HB)

CT-HB covers the same geographical area as the two counties of Merthyr Tydfil and Rhondda Cynon Tâf.

Following the reorganisation of the NHS in Wales and the development of the locality model, CT-HB are examining new and innovative ways of providing services such as respite care in the future.

A1.5.1 Children's services

CT-HB directly provide respite services to approximately 12 children within their own homes and they also fund respite services for 30 children via the independent sector.

The type of provision is determined by assessed need on an individual basis. This varies from short 2-3 hrs sessions within the family home to longer evening, nights and or weekend cover in their own home or specialist provision such as hospices or specialist schools.

Community-based respite is provided by the CT-HB using the specialist community children's team.

A1.5.2 Adult services

Currently CT-HB do not have designated respite beds in hospitals but provide Continuing Health Care (CHC) medical respite within the community hospital settings on an individual basis.

In addition, community respite is provided to approximately 28 patients within their own home, where the sessions vary from short 2-4 hourly sessions to evenings, nights or weekends, determined by a multi-disciplinary needs based assessment. Community respite within patients' own homes is funded through the CHC route and provided either by in- house community services or commissioned through nursing or domiciliary agencies.

Specialists placements are also provided , again based on assessed need, mainly in the independent sector. The uptake of this service compared to in-house community packages is relatively low. The adults in receipt of this service consist of a mixed age group from the elderly , to the younger disabled patients.

Mental health services

CT-HB mental health services provide a small number of hospital respite beds across the CT-HB area providing either weekly blocks of respite or individual days/ 24 hrs sessions . The aim is to provide services to a broad range of individuals so that they can remain in the community for as along as possible without needing access to either long term care or CHC. In addition, CT-HB also fund respite services provided by the independent sector in community or specialist settings. This is determined assessed need and is funded by CHC funds.

A1.6 Cardiff & Vale University Health Board (CVU-HB)

A1.6.1 Overview

CVU-HB covers the same geographical area as the two counties of Cardiff and Vale of Glamorgan.

We are able to provide below a description of the main respite services provided directly by CVU-HB and the services that they commission from others. CVU-HB were unable to provide us with detailed data on volumes and costs for all respite services as these are not collected centrally in this way.

A1.6.2 Children's services

Children's community nursing service

CVU-HB operates a children's community nursing service that provides respite services and health care for children with severe physical disabilities and complex needs. The respite services are mainly provided in the children's own homes and involve overnight or day 'sitting' services. In addition a Saturday club is provided at St David's hospital in Cardiff.

Continuing healthcare

More detailed information is available for additional services funded by NHS Continuing Healthcare – see Figure below.

Table 9: Children's respite services funded by Continuing Healthcare at CVU-HB

	Cardiff		**Vale of Glamorgan**	
	Number	Cost (£)	Number	Cost (£)
Learning disabilities	1	13,992	-	-
Other	9	71,736	2	30,338
Total	**10**	**85,728**	**2**	**30,338**

Note: NHS provision has been excluded
Source: CVU-HB

Commissioned services

CVU-HB also currently commissions children's respite services from two organisations as follows.

- Action for Children(NCH). This organisation provides respite service for children in Cardiff who in addition to a learning disability have associated complex health needs and/or challenging behaviour the contribution funds psychology support to this service. (Numbers of children not quantified). Annual CVU-HB contribution - £33,000.
- Ty Hafan. This organisation provides residential respite services for children with a restricted life expectancy. The CVU-HB provide a contribution to this service of £140,459 per annum (numbers of children is not quantified).

Services jointly funded with local authorities

A special school for severely disabled children - Ty Gwyn in Cardiff - is due to open in 2010. The school will cater for 150 pupils and will also include a separate residential respite unit, that has eight bedrooms.[20] This will provide residential respite during the week.

CVU-HB also funds residential weekend respite services for children with complex physical needs jointly with local authorities at Craig y Parc residential school in Cardiff.[21]

Again, jointly with LAs, CVU-HB funds services provided by Barnardos for children with challenging behaviour and those on the Autistic spectrum. Specialised residential provision is provided at Ty Orbis and Ty Coryton.

– [20] See http://www.cardiff.gov.uk/content.asp?nav=2874,5852&parent_directory_id=2865&id=9897&Language=CYM . Downloaded on 9 August 2010.

– [21] See http://www.scope.org.uk/services/education-and-learning/schools/craig-y-parc. Downloaded on 9 August 2010.

- Ty Coryton in Cardiff is a residential school for 50 residential and day pupils with autism.
- Ty Orbis in Brecon is a 52-week residential school for 8 pupils with autism.[22]

A1.6.3 Adult services

Community hospitals

For the elderly living at home, CVU-HB provides a small number of respite beds in community hospitals such as Rookwood Hospital in Cardiff.

Continuing healthcare

In addition there is some funding of beds in independent sector care homes through Continuing Care.

Table 10: Adult's respite services funded by Continuing Healthcare at CVU-HB

	Cardiff		Vale of Glamorgan	
	Number	Cost (£)	Number	Cost (£)
Learning disabilities	6	161,672	4	64,775
Other	7	68,935	3	56,412
Total	**13**	**230,607**	**7**	**121,187**

Note: An Adult case included within Cardiff relates to respite 3 nights per week at a cost of £121,914 per annum
NHS provision has been excluded
Source: CVU-HB

Commissioned services

For younger adults with specialist needs, CVU-HB commissions residential services from the independent sector. There is limited local provision of appropriate services and so there is often a need to go out of the CVU-HB area.

For adults with learning disabilities and challenging behaviour CVU-HB commissions specialist residential provision.

In relation to palliative care, CVU-HB funds one hospice that provides an element of respite for those patients living at home. They also fund 'sitting' services at night.

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[22] See http://www.walesonline.co.uk/news/education-news/tm_headline=24-7-school-a-first-for-wales&method=full&objectid=18690237&siteid=50082-name_page.html. Downloaded on 9 August 2010.

A1.7 Aneurin Bevan Health Board (AB-HB)

A1.7.1 Overview

AB-HB covers the same geographical area as the five counties of Newport, Monmouthshire, Blaenau Gwent, Torfaen and Caerphilly.

Respite provision funded by AB-HB is tailored to individual need and is offered at home and at placement. Further work is currently underway to develop an age appropriate respite facility for adults with complex health and social care needs under the age of sixty five years old within Gwent as respite placements are very limited for this age group.

The main source of information for AB-HB has been their complex care database although the information regarding children's respite services has been provided directly from the relevant department.

A1.7.2 Children's services

Much of the respite care provided to children is at home. One of the reasons for this is that there are very few locations where residential placements are available (only 2 in the AB-HB area). Details of numbers of placements and costs are provided in the table below.

Table 11: Children's respite services funded by AB-HB

Type of Placement	No of Children	Cost per month
Respite at home	44	£111,887
Respite at placement	4	£2,783
Total	48	£114,670

Note: Respite care at home is provided via the in-house community paediatric service in the patient's own home. The monthly cost per placement is the annual expenditure per placement divided by 12. Some placements may last for less than 12 months and so in those cases these figures will not reflect actual spend per month.

Source: Aneurin Bevan Health Board & LE Wales calculations

Expenditure on respite services for children is high (per placement) compared to expenditure on services for adults (see next section). There are a number of reasons for this. In general the community care packages that children receive have higher levels of hours and nursing input than do equivalent services for adults. Some children, for example, are provided with nursing support to attend school 5 days per week and also receive respite hours in addition to this. Manual handling requirements also mean that children's community care packages often require two members of staff to be in attendance. The children's needs are often high and they will often require specialised equipment such as a bed, chair, suction machine, feeding pump etc which are all costed within the care package. In addition some children are provided with residential placements outside the ABG-HB area – the cost of these placements is often very high, e.g. £3,000/week.

A1.7.3 Adult services

There is variation in the amount of respite provision across the five localities and feedback from the localities indicates that respite care is sourced mainly from external providers as opposed to having dedicated respite care beds in community hospitals.

The total number of respite cases is shown in the table below.

Table 12: Adult respite services funded by AB-HB 2009-10

Number of cases	121
Cost per annum	£367,135
Monthly cost per placement	£253

Note: The monthly cost per placement is the annual expenditure per placement divided by 12. Some placements may last for less than 12 months and so in those cases these figures will not reflect actual spend per month.
Source: Aneurin Bevan Health Board & LE Wales calculations

Breakdown by locality

Table 13: AB-HB adult respite services 2009-10 - breakdown by locality

	Blaenau Gwent	**Caerphilly**	**Monmouth**	**Newport**	**Torfaen**
No of cases	2	25	13	38	43
Cost per annum	£14,018	£50,505	£48,420	£105,894	£148,298

Note:
Source: Aneurin Bevan Health Board & LE Wales calculations

Breakdown by category of care

There are four main categories of adult care within the AB-HB complex care database - this is illustrated in the tables below. The majority of respite care (at placement) is provided within the independent care home sector and has been contracted on a case by case basis.

Table 14: AB-HB adult respite services 2009-10 - Adult physical disability

Type of Placement	No of Adults	Cost per annum
Respite at home	21	£69,991
Respite at placement	80	£227,121

Note:.

Source: Aneurin Bevan Health Board

Table 15: AB-HB adult respite services 2009-10 - Adult Learning Disability

Type of Placement	No of Adults	Cost per annum
Respite at home	7	£38,317
Respite at placement	3	£22,702

Note:

Source: Aneurin Bevan Health Board

Table 16: AB-HB adult respite services 2009-10 - Adult Mental Health

Type of Placement	No of Adults	Cost per annum
Respite at home	3	£1,840
Respite at placement	2	£5,108

Note:

Source: Aneurin Bevan Health Board

Table 17: AB-HB adult respite services 2009-10 - Adult Palliative care

Type of Placement	No of Adults	Cost per annum
Respite at home	3	£324
Respite at placement	2	£1,732

Note:
Source: Aneurin Bevan Health Board

Annex 2 Respite services funded by local authorities

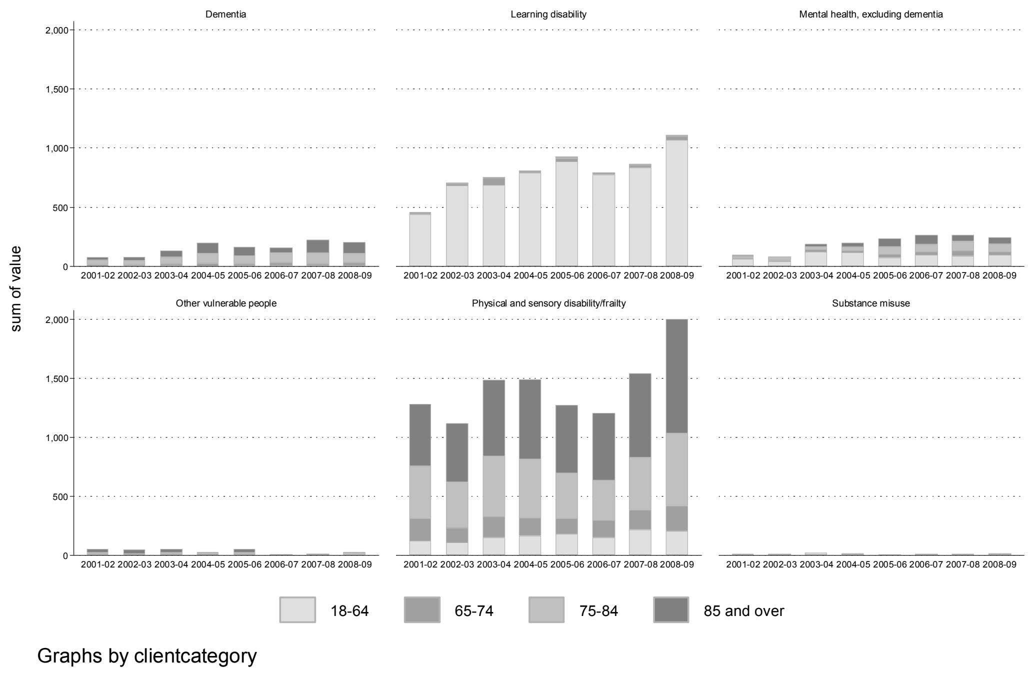
A2.1 Data collected by Data Unit Wales

Adults in receipt of respite care services

The data from Data Unit Wales on respite care services received by adult care recipients suggests that there are particular conditions that attract respite care, that there is some correlation between conditions and certain age groups, and that a small number of local authorities in Wales contain the vast majority of recipients of respite care services. The data are collected in PM2 returns, in Tables Ab, Ac and Ad. Similar information on the volume of day and domiciliary adult services, containing more detail, used to be collected in the AS3 return, but this has not been collected since 2005-06.

There are two groups of looked after adults that stand out as being the most numerous: those with physical and sensory disability (mostly aged over 65) and those with learning disabilities (almost all aged 18-64). Some caution should be raised by the slightly subjective nature of the classification system, and the potential for overlap of conditions, but this does highlight that mental health needs (due to dementia or other reasons) contribute a relatively small proportion of the total number of looked after adults.

Figure 10:No. of adults receiving community respite care services at 31 March 2001/2-2008/9, by need



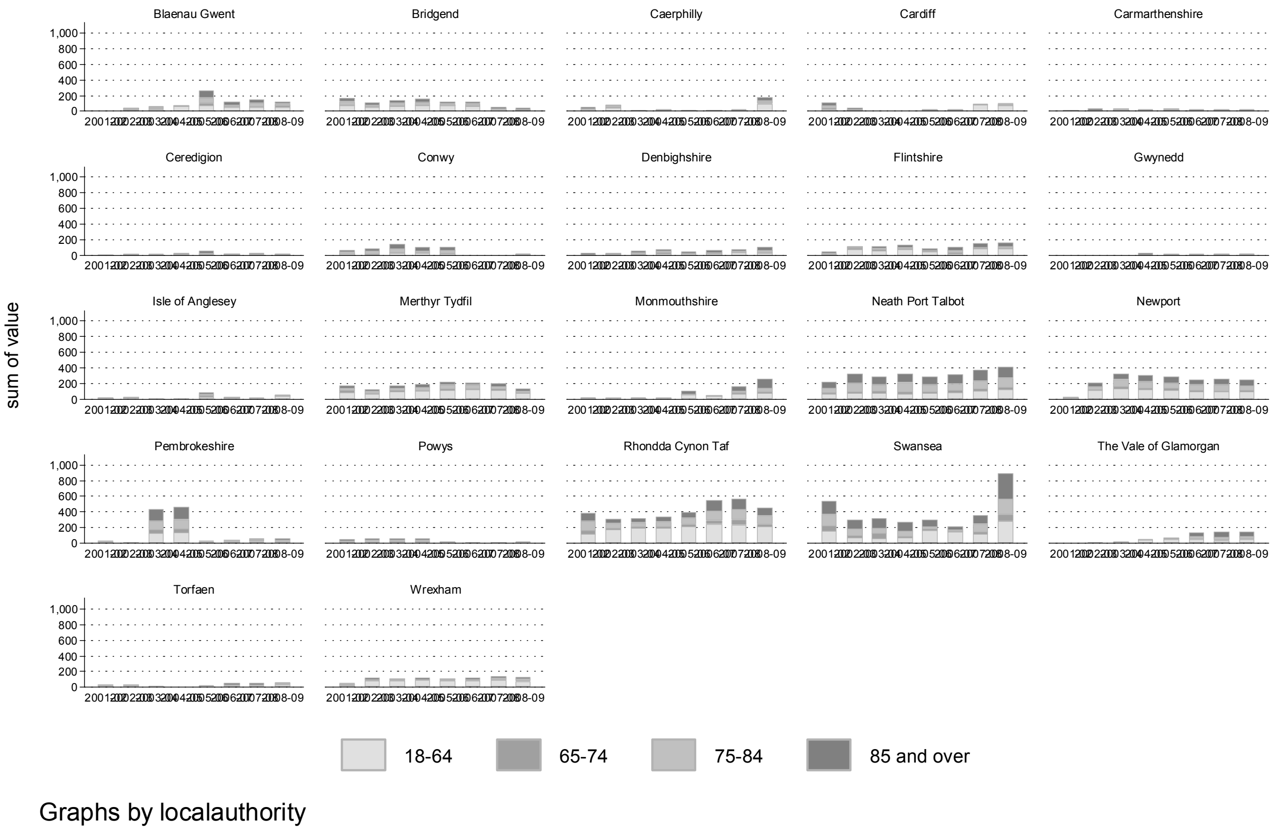
Note:

Source: LE Wales calculations on data from PM2 Table Ab, Data Unit Wales

There are three local authorities in which there is a stable high concentration in the number of looked after adults receiving services: Neath Port Talbot, Swansea and Rhondda Cynon Taf. There are four more local authorities in a stable second tier of concentration: Newport, Merthyr Tydfil, Flintshire. Brigend and Wrexham have a low (fairly) stable level of concentration.

Beyond these nine aforementioned, several local authorities appear to have experienced (sometimes sudden) recent increases in the number of looked after adults receiving respite care services. These include Blaenau Gwent, Monmouthshire, Denbighshire, the Vale of Glamorgan, Caerphilly and Cardiff. These changes may be caused by increases in demand or could be related to an expansion of provision or more penetrating marketing of respite care services; it is impossible to tell from this data alone.

Figure 11:No. of adults receiving community respite care services at 31 March 2001/2-20008/9, by LA



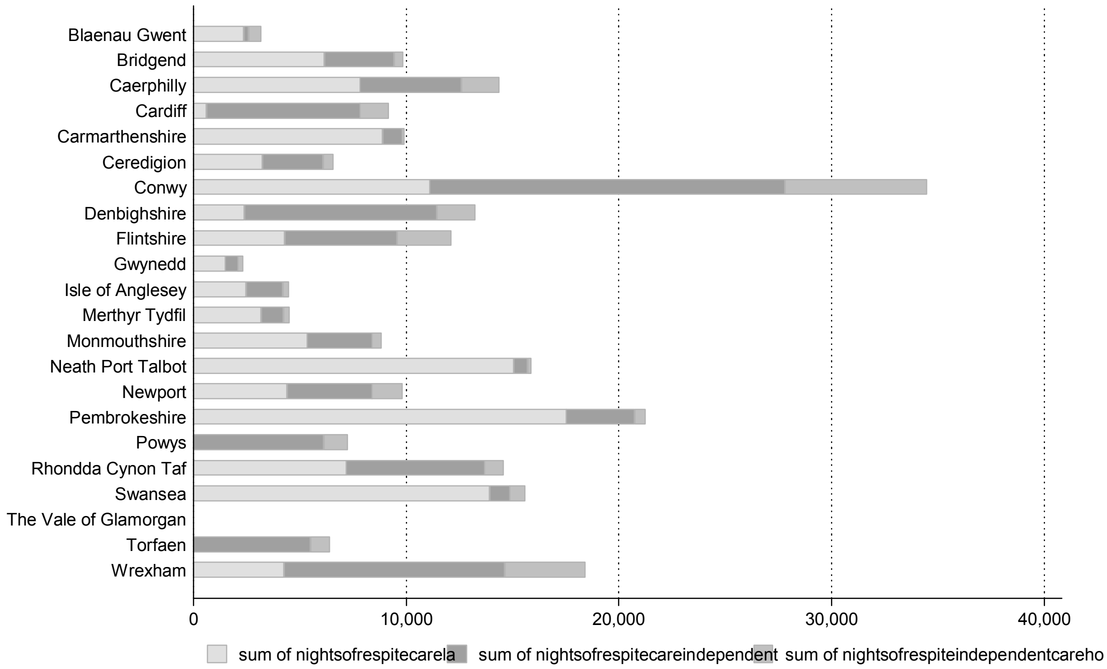
Source: *LE Wales calculations on data from PM2 Table Ab, Data Unit Wales*

We also have information on the number of nights of respite care and the number of hours of homecare received by adults in Wales. The data are available by local authority and distinguish whether the provision is directly from the local authority or from the independent sector, and are available for the years 2001-02 to 2008-09 (there are no data on respite care for the Vale of Glamorgan since 2005-06).

Across Wales in 2008-09, there were 242,000 nights of respite care provided with about half being provided directly by local authorities (122,000 by local authorities, 94,000 by the independent sector and 26,000 in independent care homes). On top of this there were 11.8 million hours of home care provided, with the independent sector providing a little over half of the provision (5.2 million by local authorities and 6.6 million by the independent sector).

Across local authorities, the amount of respite care provided was most commonly under 10,000 nights (12 local authorities). At the top end, the most nights were provided in Conwy (35,000), followed by Pembrokeshire (21,000).

Figure 12:No. of nights of respite care services received in 2008/9, by LA



Note:

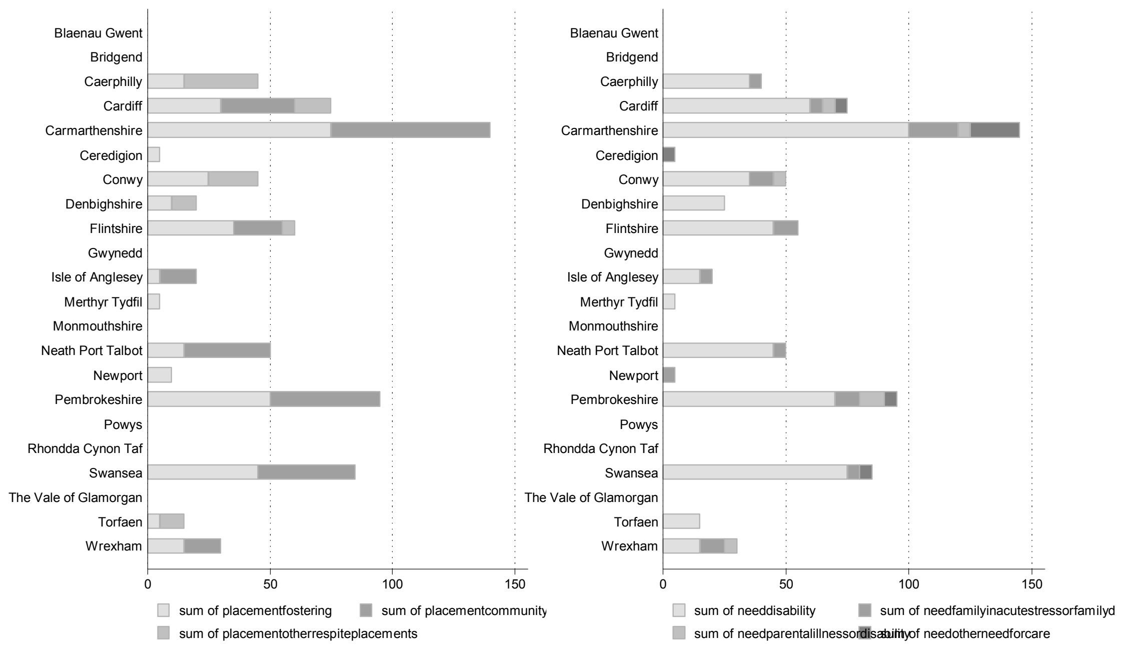
Source: LE Wales calculations on data from PM2 Table Ac, Data Unit Wales

Children in receipt of respite care (short break) services

There were 705 reported short-break (respite) placements for looked after children across Wales in 2008-09. A third of local authorities (seven) did not report any short term break placements, but does not necessarily imply that no short break placements occurred.

About a half of short break placements across Wales were with short break foster carers, with a further 40% being placed in community homes. Three-quarters of short break placements related to children with disability, with about an eighth (13%) being due to the family being in acute stress or family dysfunction, and the remaining eighth being split evenly between parental illness or disability and other reasons. The patterns observed for Wales are approximately the same as those observed at local authority level for most authorities.

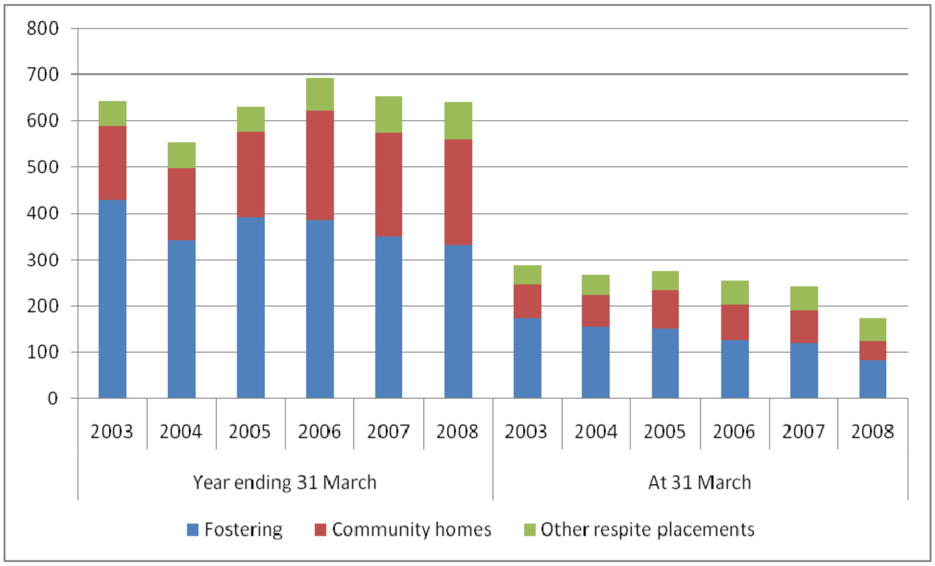
Figure 13:No. of short break placements, by type and by need, for looked after children in 2008/9, by LA



Note:

Source: LE Wales calculations on data from SSDA 903, Data Unit Wales

Figure 14:No. of short break placements, by type, for looked after children 2002/3 - 2008/9



Note:

Source: LE Wales calculations on data from WAG (2008) SSDA 903, Data Unit Wales

A2.2 Data collected by LE Wales

A2.2.1 North Wales

Overview

This section includes data from the six local authorities of Ynys Môn, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham. This is the same geographical area as that covered by Betsi Cadwaladr University Health Board.

Ynys Môn (Anglesey)

There were 130 adult service users who received overnight residential care in Ynys Môn in 2009/10, of which 39 had learning disabilities and the remainder were not recorded. As well as this, 154 services users received some form of flexible support, which comprises check visits, day care, home care, meals-on-wheels, overnight residential care, or a sitting service or domiciliary care.

There were 3,578 sessions of overnight residential care provided at a cost of £58 per session (night), and averaging approximately £1,599 per service user per year. The average cost per service user per year of flexible services is not so straightforward to calculate, but the data show that it varies by type of need: about £1,500 for learning disability, about £1,100 for physical disability, about £750 for mental health or EMI and about £700 for older people in general.

Ynys Môn also provided carer support, in addition to the flexible support care and overnight residential care. This support varies as per need per quarter, and has included a Carers Outreach Service (about 85 users), Disability Advisor and Telecare (35), regular pre-emptive respite support (121), carer assessment. (about 100), sitting services at home (about 40), regular day care (about 10), and financial support and advice (about 15).

Table 18: Number of adults receiving LA-funded respite services during 2009/10 in Ynys Môn

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other*	Total
Overnight Residential		39				91	130
Total flexible support	3	3	45	12	0	91	154
Check visits			4				4
Day care			16	3		28	47
Home Care			3	2		10	15
Meals-on-wheels			1				1
Overnight support at home						2	2
Sitting service/ domiciliary	3	3	21	7		51	85

Note: * This group includes 'older people' and 'adults with physical/sensory disabilities'.
Source: Ynys Môn Adult Social Services

Ynys Môn provided overnight residential short breaks for 16 disabled children as well as group activities (after-school club, summer activities programme, Saturday club) in 2009/10. The short breaks were approximately 750 sessions throughout the year, with a maximum of two children at a time. The afterschool club, which ran throughout the year including a weekend daytime capability, has four staff and costs £50,000. The summer activities programme ran for 24 sessions and was accessed by 62 children. The Saturday club ran for 12 sessions and was accessed by 58 children.

Gwynedd

There were about 224 adult carers who benefited from LA-provided overnight residential respite care in Gwynedd in 2009/10. The majority of service users were over 75 years old and suffering from physical or sensory disability or frailty.

Gwynedd also contracted out domiciliary services to Crossroads Care, which provided 6,648 hours of services to 67 carers at a total cost of £64,070 (approximately £10 per hour).

Table 19: Number of adults receiving overnight residential respite care during 2009/10 in Gwynedd

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
All ages	184	2	5	24	0	9	224
18-64 yo	4	1	1	0	0	1	7
65-74 yo	17	0	2	1	0	0	20
75-84 yo	55	1	0	7	0	3	66
85+ yo	108	0	2	16	0	5	131

Note:
Source: Gwynedd Adult Social Services

The LA funded provision of contracted services by Barnardo's and Short Break carers, as well as providing a support service (for replacement care or outreach). Barnardo's Amser Ni provided 46 weekend breaks, whilst Barnardo's support service provided 150 sessions, at a total cost of £60,000.

Two short break carers provided (weekly) short breaks for four service users, receiving a weekly fee of £200, plus a boarding allowance for each placement (total cost, assuming 52 weeks is approximately £10,400 per short break carer, or £5,200 per service user). The support service has 78 staff, with an approximate hourly cost of £10.

Gwynedd also responded to the qualitative questions we asked as follows.

1. What's your perception of how carers feel about the respite services available to them?

Adults services

Carers value respite but would like a service that offers flexibility and is able to respond to changes of circumstances. At the moment carers have to plan their activities largely around the time they are 'allocated' respite e.g. every Tuesday - carers would like more of the freedom allowed to non-carers particularly when the unexpected happens e.g. a funeral to which they would like to go. In other words they would like the respite required when required.

Children's services

Overnight short breaks away from home.

For disabled children those carers / parents that receive a service appreciate it but would value more than they currently receive. For others who have been on a waiting list for a long time without receiving a service it is very frustrating.

Short breaks in the home / overnight or daytime sessions.

Support services provide services which are either to aid the development and the pleasure of the child / young person or to provide respite for parents. On the whole we feel that parents appreciate this service but also can be frustrated again at times when the service is unable to be provided due to illness etc.

2. How important are respite services relative to other services provided to carers and care-recipients?

Adults services

Respite services is possibly the most valued service for carers, but that might depend on the nature of the respite offered.

Children's services

Respite services are one of the most valued services for parents / carers but this can vary from a couple of hours to a weekend break.

3. What is most difficult about matching carers with appropriate respite services?

Adults services

Lack of resources both in terms of finance and staff. There is also a lack of overnight respite available in Meirionnydd (a heavily Welsh speaking area) with the result that carers and cared-for have turned down offers of residential respite care because of the lack of Welsh speakers in the care homes.

Children's services

The difficulty within the service is mostly due to recruitment in the first place for overnight carers. Otherwise there are issues about service being available in child's area especially in areas such as Meirionnydd, their own language, etc.

Conwy

Conwy was unable to provide data for this report, though we did receive answers to the qualitative questions we asked. In addition, data for some respite services for adults and for looked after children provided by Conwy are included in our analysis of the data collected by Data Unit Wales.

1. What's your perception of how carers feel about the respite services available to them?

Conwy County Borough Council provides varied and extensive respite services for Carers of older people/physically disabled and sensory impaired. These include respite beds in nursing homes which can be pre-booked, sitting services – to include one off services or regular hours weekly, day care for the cared for, PSS Trio Scheme – at home day care, befriending services via Alzheimer's society etc. These are services that Carers request on a regular basis and is therefore deemed to be an exceptional service that the authority provide for Carers.

2. **How important are respite services relative to other services provided to carers and care-recipients?**

Respite services for Carers are paramount to ensuring that Carers have a much needed break and enables most Carers to continue with their caring role. Respite is such a broad spectrum of services which supports both the Carers and the cared for. As an authority we provide a flexible respite service for Carers.

Other services provided for Carers are also important for the Carers physical and mental well being which include emotional support, advocacy, providing advice and information & signposting, all playing an essential part in supporting the Carer.

Respite services are integral for Carers to ensure that they have a break but it is also important to combine the respite services with other services offered to Carers and the cared for to ensure that all levels of care are taken into consideration thus preventing a crisis occurring.

3. **What is most difficult about matching carers with appropriate respite services?**

One of the most difficult factors in matching appropriate services that assist carers is that every carer is an individual in their own right and have their own personal needs. As an authority we have taken this into consideration by providing flexible respite services allowing Carers to be imaginative and creative with their request for respite that matches their individual needs ensuring that “Carers will be able to have a life of their own alongside their caring role” in accordance with the National Carers Strategy.

Denbighshire

There were about 270 adult service users who received a respite service in 2009/10 in Denbighshire. Most received overnight residential care (270), but some would have also made use of homecare or day care, though there is no data recording the number of service users accessing these services for respite purposes. In addition to this, service users also accessed unplanned provision of domestic/sitting services, adult placements, contracted short breaks (Crossroads Care, MS Support Centre, MIND) and Direct Payments (as one-off grants available for holiday breaks).

Table 20: Number of adults receiving LA-funded respite care during 2009/10 in Denbighshire

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
Overnight residential care							
All ages	193	44	25	(inc. in 1st column – physical disability)	3	5	270
18-64 yo	14	42	4		3		63
65-74 yo	32	1	1			1	35
75-84 yo	58		13			2	73
85+ yo	89	1	7			2	99
Homecare (proportion attributable as carer respite unrecorded)							
Day Care (proportion attributable as carer respite unrecorded)							
Other services directed at carers							
Domestic/ Sitting services							113*
Adult placement							21* (21 service users)
Additional contracted short breaks							90* (80 service users)
Direct payments (one-off Grant for Holiday Break)							29*

Note: * number of carers

Source: Denbighshire Adult Social Services

About 26 disabled children received services that provided short breaks for their families. Almost all children received services from Barnardo's 'My Time' sitting service and Direct Payments, and about half used each of Family link (137 sessions) and overnight residential care (285 sessions). The cost per service user of short breaks was about £3,834 (£1,624 for Barnardo's, £513 for Direct Payments, £844 for Family link [£92 per session] and £2,854 for overnight residential care [£110 per session]).

Table 21: Number of children receiving short breaks services during 2009/10 in Denbighshire

Service	Total sessions	Total capacity	Total service users	Total cost (£)	Cost per session (£)	Cost per place (£)	Cost per service user (£)
All services			26				£3,834
Barnardo's Sitting Service 'My Time'		6	27	£43,835		£7,306	£1,624
Fostered Short Break Services	137		15	£12,656	£92		£844
Direct payments			23	£11,800			£513
Overnight residential	285		11	£31,399	£110		£2,854

Note:

Source: Denbighshire Children's Social Services

We also received responses to the qualitative questions we posed.

1. **What is your perception of how Carers feel about the respite services available to them?**

Many Carers are very positive about the level of respite they receive – some receive rolling respite that allows Carers to have a break on a regular basis, say every 6 – 8 weeks. It can, however, be challenging to provide respite that is flexible enough to meet the needs of the service user and Carer, particularly in regards to emergency respite, and 'one off' episodes of respite, eg if the Carer needs to attend hospital appointments, or a weekend family event such as a wedding.

2. **How important are respite services relative to other services provided to Carers and care-recipients?**

Respite is always regarded as a high priority by Carers although Carers also have high regard for other services that also provide 'breaks' for Carers such as emotional support, support groups, training and holistic therapies. Respite can mean different things to different carers, and can range from a 2 week break to a couple of hours away from the caring role. Carers also want quality respite for the person cared for, and can be reluctant to request respite if they don't feel that the level and quality of care will equal that which they provide themselves, both in terms of personal care and social stimulus.

3. **What is most difficult about matching Carers with appropriate respite services?**

Maintaining flexibility as outlined above.

Flintshire

Flintshire contracts out all of its provision of respite services, with North East Wales Carers Information Service (NEWCIS) being in charge of administrating overall provision and contracts.

According to NEWCIS data presented in the Flintshire Social Services Annual Report for 2009/10, Flintshire supported 1,891 carers, which was 37% higher than the previous year. Some service level agreements cover both carers of adults and of children, or both adult and young carers. The data provided in the table below describe the provision for 2008/09.

Table 22: LA-funded respite and short break services during 2008/09 in Flintshire

Service	Total hours	Total sessions	Total service users	Total carers	Total cost
Alzheimer's Society total SLA	9152	1144		160	£77,780
Weekend respite day care	*7488*	*936*	*87*	*87*	*£34,263*
Emergency respite day care	*1664*	*208*	*14*	*14*	*£11,502*
Advocacy service			*69*	*69*	*£32,015*
British Red Cross Emergency Card Service				311	£7,487
Crossroads At Home Respite Care	2702		52	51	£50,282
Parent Carer Children Service	*1383*		*25*	*24*	*n/a*
Adult Carer Dementia Service	*1319*		*27*	*27*	*n/a*
Crossroads Emergency Respite	614		13	13	£11,525
Crossroads Top up for parent carers respite breaks	234		1	1	£3,928
Hafal respite breaks MENTAL HEALTH			89	89	£20,883
Hafal Crisis Family Liaison post			47	47	£35,107
Hafal Crisis Family Liaison post support breaks				35	£7,857
Multiple Sclerosis Centre - various services	4500		30	60	£12,035
Admiral Nurses - variety of services DEMENTIA			97	97	£47,440
NEWCIS Short break grants			186	195	£48,000
Adult			*138*		
Child			*48*		
NEWCIS holistic service (drop in, community hospital)		90		764	£6,662
NEWCIS training courses		30		121	£4,190
NEWCIS counselling				158	£4,000
Daffodils short break activities (for 0-25 yo)		1304	276	570 (414 adult; 156 young)	£9,160
NCH – Cornel Clyd short breaks (weekend and after school)	2940	120	5		£24,836
Barnardo's Young Carers Weekly Support				195 (129 caring for an adult; 66 for a child)	£31,426
Barnardo's Young Carers Additional				42	£9,376

Table 22: LA-funded respite and short break services during 2008/09 in Flintshire

Support for Young Carers caring for adults with mental illness					

Note:

Source: Flintshire Adult and Children's Social Services

Wrexham

Adult services

In Wrexham, 348 adult service users received overnight residential respite care in 2009/10. Overnight residential respite provision was a mix of direct provision by the LA and contracted provision by independent providers. In addition to this, the Carers Respite Service provides emergency and planned respite care for older people with mental health problems and Crossroads provide at-home respite services.

The cost of LA-provided adult residential respite ranged between £200 and £390 per session and was about £10,000 per service user. The cost per service user of the Carers Respite Service was on average £2,353 and of Crossroads' at-home respite was £1,750.

Table 23: LA-funded Adult respite services during 2009/10 in Wrexham

Service	Total hours	Total sessions	Total service users	Total cost (inc recharges)
LA Homes respite (overnight, residential)	*n/a*	*5,890*	*146*	*£1,026,840*
Nant Silyn	*n/a*	*3,945*	*90*	*£441,840*
TOTAL: GATE, Heol y Gelli, Oak Drive	*n/a*	*1,945*	*56*	*£585,000*
GATE	*n/a*	*839*	*23*	*£295,000*
Heol y Gelli	*n/a*	*758*	*20*	*£155,000*
Oak Drive	*n/a*	*348*	*13*	*£135,000*
Independent homes	*n/a*	*11,304*	*175*	*OP £62,800* *LD £462,500* *MH £35,600* *PSNI £ 60,200* *£621,100*
Independent homes, with nursing	*n/a*	*3,180*	*27*	*OP £282,600* *LD £153,300* *MH £20,500* *PD £88,000* *£544,400*
Carers Respite Service (emergency and planned respite for Carers of older people who experience mental health problems)	*4229 pa*	*n/a*	*34*	*£80,000*
Crossroads home based respite	*8700 pa*	*n/a*	*80*	*£140,000*
Total Respite (Adult Social Care Services – as defined above)	*12,929*	*20,374*	*462*	*£2,412,340*

Note:

Source: Wrexham Adult Social Services

Children's services

A number of short break services are available to disabled children and young people and their families as well as to young carers, including provision for overnight breaks, direct payment packages and evening and weekend activities.

Table 24: LA-funded respite/ short break provision for children & young people during June 2010 in Wrexham

Service	Foster provision	Children's respite centre	Total (children, young people, families, young carers)
Overnight short breaks for children and young people with disabilities*	2	19	21
Direct payment packages for children and young people with disabilities			24
Group evening and weekend activities for children and young people with disabilities			101
Family daybreak scheme providing leisure and socialization for 5-16yr olds			150
Access to play schemes during school holidays			40
Group activities, socialisation and holidays for young carers*			80

Note:

Source: Wrexham Children's Social Services

A2.2.2 Powys

Overview

The local authority area of Powys covers the same geographical area as the Powys Teaching Health Board.

Powys

A total of 218 adult service users received 93,900 hours of overnight residential respite care in Powys in 2009/10. All of the respite service provision was contracted out to independent providers (Crossroads, Hafal, Powys Carers Service and Alzheimer's Society). Three-fifths of these service users were people over 75 years old.

Crossroads provided respite to 210 adults, amounting to 20,286 hours, at an hourly cost of £22 (approximately £2,079 per service user). Hafal provided a variety of services to 235 care recipients and 482 carers, totalling 2,160 hours at a cost of approximately £16 per hour (48 weeks of delivery at 45 hours per week).

Table 25: Number of adults receiving LA-funded respite care during 2009/10 in Powys

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
All ages	151	54	13	0	0	0	218
18-64 yo	10	50	0	0	0	0	60
65-74 yo	21	3	2	0	0	0	26
75-84 yo	44	1	7	0	0	0	52
85+ yo	76	0	4	0	0	0	80

Note: Some of those adults classed here as “mental health” could be considered as EMI.
Source: Powys Adult Social Services

Powys supported about 300 young carers through its service provision in 2009/10. There were four services: two carers groups and two activity streams.

Powys Young Carers peer support groups helped 84 young carers over 234 sessions with about half of that being specifically for respite purposes. Small Steps: Young Adult Carers Group (15-25) helped 17 young carers over 38 sessions (114 hours). Small-scale activities were organised for 300 young carers and large-scale activities (over four sessions) were arranged for 200 young carers.

Services for families of disabled children are recorded into North and South Powys areas. Each area provided four services: family based short breaks, respite at two facilities (Bannau and Camlas) and a family aide. The bulk of provision was attributable to respite at Camlas for South Powys families.

Table 26: Short breaks provision for disabled children during 2009/10 in Powys

Service	Total hours	Total sessions	Total service users
North Powys Family Based Short Breaks	1,440	120	5
North Powys Bannau Respite	384	32	2
North Powys Camlas Respite		140	5
North Powys Family Aide	5,235	52	18
South Powys Family Based Short breaks	2,232	186	6
South Powys Bannau Respite		56	5
South Powys Camlas Respite		550	20
South Powys Family Aide	4,320		33

Note:
Source: Powys County Council

A2.2.3 South West Wales

Overview

This section covers the three local authorities of Ceredigion, Carmarthenshire and Pembrokeshire. This is the same geographical area as that covered by Hywel Dda Health Board.

Ceredigion

Ceredigion provides overnight residential respite care directly and via independent contractors.

Ceredigion have about 484 adult carers. There are 221 service users who benefited from LA-provided overnight residential respite care in Ceredigion in 2009/10 all of which will have had an adult carer. These services were provided to 221 service-users, of which 174 were over 65 years old and 23 were under 18 years old. The total cost for this service was £197,750, which corresponds to 3,368 sessions of about 12 hours each (£59 per session). In addition to these, 33 young carers accessed services from Ceredigion.

Ceredigion's contracted independent providers of overnight residential respite services provided 2,770 sessions at a cost of £149,580 (£54 per session) and 491 sessions where service-users received nursing care at a cost of £37,500 (£76 per session).

Ceredigion contracts out a variety of services to several providers (Crossroads, Hafal, British Red Cross, SSD CAT@H, Tim Plant Anabl, Dash and Young Carers). The service level agreements governing these include respite services but do not itemise the cost attributable to respite services separately. Nevertheless, 698 carers, who are supported by third party organisations, benefited from these services, which include cover for day and evening activities (employment or leisure), training, carers' emergency card and telecare equipment, short breaks (days or weekends) for adult carers and young carers.

In addition to this, the LA provides homecare (domiciliary care), directly or via independent providers, and day centres. The proportion of such services attributable as respite services cannot be determined, but the average cost per service user of domiciliary care each year is £5,402 (with approximate hourly rates of £37 for LA provision which includes employee pay, travel and all indirect overheads) and £17 for independent provision which relates specifically to the hourly charge paid to the independent provider excluding similar indirect overheads).

Lastly, 46 service users accessed supported accommodation and 6 were given adult placements in 2009/10.

Table 27: Number of people receiving LA-funded respite care during 2009/10 in Ceredigion

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
Number of service users of LA-provided overnight residential respite							
All ages	60	41	4	2	0	116	221
18-64	5	41	0	0	0	1	47
65+ yo	55	0	4	2	0	115	174
Number of carers who accessed services							
Total number of adult carers							484
Young carers							33
Contracted carer services							698
Number of service users receiving other services							
Contracted care homes*							(3,261 sessions)
Supported accommodation							46
Adult placements							6

Note: * The duration of one session is 12 hours.

Source: Ceredigion Adult and Children's Social Services

Ceredigion also responded to our qualitative questions as follows.

1. What's your perception of how carers feel about the respite services available to them?

Staff feedback small sample

perception:

- always the same people using respite - never any new people.
- numbers using respite has declined considerably
- nursing homes have seen a high number of cancellations due to the costing/means testing

- meeting the needs:
- the criteria is very strict and it seems Dementia patients are a priority - socialisation is not seen as a priority and elderly people who are lonely, without carers are not getting to use the day centre - this isolation leads to depression and anxiety

2. How important are respite services relative to other services provided to carers and care-recipients?

Staff feedback small sample

- for some people it is critical to sustaining role and or family life, working life
- vital to enable carers to go shopping, visit the hairdressers, doctors appointments etc
- vital to enable carers to take a proper break/holiday
- there are huge waiting lists for sitting services

3. What is most difficult about matching carers with appropriate respite services?

Staff feedback small sample

- location - too far away
- transport
- flexibility and amount of time ie daily in part, weekly, monthly, to set periods in year, to meet work demands
- short notice need
- emergency need
- nights only need
- shortage of availability for Dementia care
- waiting lists
- time of day does not always suit peoples needs or work patterns
- cost

Carmarthenshire

There were between 375 and 600 adult service users who received a respite service in 2009/10. The two most accessed services were overnight residential care and day care. The number of service users who accessed residential respite was 375: 340 service users in LA services, 17 in private services and 18 in voluntary organisations. Data on day care is not specific to respite, but Carmarthenshire suggest that about half of their 1,200 service users do so in the context of respite.

About two-thirds (266) of the 375 overnight residential respite service users were over 75 years old. The 145 service users (evenly split between four age groups: 18-35, 40-49, 50-64 and over 65) of HAFAL support services include or were linked to 93 carers. Carers were more concentrated in older age groups (8 of 18-35 years old, 47 of 40-64 years old and 38 over 65 years old).

In all, 6,401 sessions of support services were provided by 11 full-time equivalent staff across several locations comprising one-to-one or group sessions, information, day activities and (in one town) 24-hour supported accommodation for seven users.

Crossroad Care Sir Gar also provides domiciliary and group-based services (such as day care), amounting to almost 76,000 hours (51,521 for domiciliary, 24,212 for group-based).

Table 28: Number of adults receiving LA-funded respite care during 2009/10 in Carmarthenshire

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
Overnight residential	298	69	8				375
Day care*	402.5	163	30		2	1.5	599
HAFAL support services							145
Crossroads Sir Gar							(75,733 hours)

Note: * Day care data on respite are estimates, based on 50% of all day care service users

Source: Carmarthenshire Adult Social Services

Carmarthenshire provided 1,578 overnight residential short breaks (24-hour sessions) for up to eight disabled children at a time in two sites (three in Blaenau and five in Llys Caradog) and via a service level agreement with Barnardo's. Barnardo's provided 2386.5 day sessions and 222 overnight sessions (including 125.5 uncontracted overnight sessions) in 2009/10, with each session being on average six hours in duration.

Carmarthenshire also provided responses to our qualitative questions.

1. What's your perception of how carers feel about the respite services available to them?

Carers who are offered and accept respite are (according to experience and consultation over the years) mixed in their perceptions. Some are very happy with what's offered. Others are less happy - for the sake of the service user - but accept it as it's all that's offered and they must have a break and there are others who refuse it because their perception and often their experience is so disappointing that they refuse to place their relatives in such circumstances again. In particular the quality of respite care for Dementia sufferers is not well received. Carers have accepted a break whilst their relative is placed in a standard older people's residential home and when they return they find their relative has deteriorated to such an extent that they refuse to place them again. This inevitably leads to carer breakdown. In recent times a specialist dementia care charity have developed a dedicated respite care home with just seven beds. This will provide 3 permanent beds to begin with until an adequate throughput of clients make 100% respite viable.

Carers of people with Physical or Sensory Impairment are not well provided for with only one specialist provider in the county - many have to access out of county provision. This is being addressed in a new PDSI strategy.

Continuing Health Care recipients usually benefit from structured respite but this is mostly provided from within Health's Community Hospitals and governed by GP's and Consultants. Otherwise it is provided in Private Nursing Homes who usually only offer it when they have a vacant bed - LHB's don't commission a number of beds for the year in the private sector so it is understandable that providers only want permanent beds (kept full if possible)

2. How important are respite services relative to other services provided to carers and care recipients?

Respite was the second highest support requested by carers during extensive consultations - Information was highest.

Carers often accept the caring role without understanding what they are taking on. Often, they will refuse (and often they may not get offered) a carers assessment because they feel it isn't necessary. It is vital that these carers are reviewed at least 6 monthly or they slip through the net and require greater support and intervention further down the line.

Respite is often seen by Health as a Social Care responsibility and will advise carers to contact the Department. However, many carers shy away from social services due to stigma and a sense of pride that averts them from seeking help as it's perceived as failure on their part. To address this there is a need for respite care and other carer support to be marketed to both carers, as a means of sustaining their role and well being and to managers as a vital business case.

3. What is most difficult about matching carers with appropriate respite services

As alluded to above, carers are often put off respite because the provision available is unsuitable: in residential homes where they are unfamiliar with their surroundings and the carers or it's too far away that it makes visiting impossible. Also, poor matching of service users to providers means that SU's are often placed where there is availability rather than appropriate facilities and standards. Certain categories of disability make respite difficult to provide for: Mental Health, Learning disability and Dementia are examples.

A model for dementia care is developing in Carmarthenshire whereby day care and residential respite care are linked. Within two of our three localities we provide both services from the same provider, one is in-house provision, the other is a commissioned charity. What this model offers is:

- Dedicated respite provision in a specialist respite care unit with a maximum of seven or eight units

- A core of staff who work across both day and respite services, thereby affording much needed continuity of care that recognises or identifies deterioration or changes at the soonest opportunity that often avoids hospital admissions
- Carers can familiarise themselves with staff and management and benefit from a therapeutic relationship
- Service users are less confused and more amenable, causing fewer management problems
- These services are based within communities of fewer than 55,000 population
- The charity provision is a small home converted from a house in a street that makes it less conspicuous or obvious and lends itself to community ownership

The most difficult thing within adult services is that respite is provided within residential settings that are home to 50 or 100 other people.

Good quality respite depends on the carer being satisfied that the quality of care for the cared for person and the experience they have is of a high standard. If this is achieved the quality of the break for the carer is greatly enhanced. Warehousing people whilst carers have a break is a non-starter.

Within Learning Disabilities respite provision is provided from a mixed market. Adult Placement scheme is growing with greater numbers using and enjoying this service. It is hoped to generate respite AP schemes for mental health and older people in the future.

Direct Payments for service users are relatively well advanced on a Wales basis with only a handful of carers receiving DP's.

A Carers Flexible Support Grant is available across all services that is predominantly used by carers to access a break - to pay for respite for the service user or to pay for accommodation and fares for them to go away. On average, grants of £200 are made and this equates to (roughly) 225 grants or one-off Direct Payments from a pot of £45,000 (some carers will want something practical like a washing machine, mobile phone or lifting aids).

Pembrokeshire

Pembrokeshire were not able to provide us with data on adult respite services but were able to provide records for 134 disabled children who received a respite or short break service in March 10. This does not represent the total number of disabled children receiving a service in that month as data were not available for all respite/short break services for children and young people.

Services are varied, and mostly contracted out, with the notable exception being Holly House, a residential care centre for disabled children (including those with ASD). Contracted services include overnight care, befriending, activity days or centres, short breaks during the day, evenings or weekends, sitting services, Family Link, services for young carers and emergency card schemes.

Table 29: LA-funded respite and short break services during March 2010 in Pembrokeshire

Service	Carer group	Total hours	Total sessions	Total service users	Total cost
Holly House	Children			65	
Fostering (LA/agency)	Children			10	
Barnardo's Family Link fostering	Children			22	
Barnardo's sitting & supported activity	Children			20	
Barnardo's V Linx Service	Children				
Tots to Teens after school club	Children				
Holly House summer programme	Children				
Specialist Summer School	Children				
Holiday Play scheme	Children				
Direct payments	Children			37	

Note:

Source: Pembrokeshire Adult and Children's Social Services

A2.2.4 Western Glamorgan

Overview

This section covers the three local authorities of Neath Port Talbot, Swansea and Bridgend. This is the same geographical area as that covered by Abertawe Bro Morgannwg University Health Board.

Neath Port Talbot

There were 570 adult service users who received overnight residential respite care in 2009/10. The total care provided to adults was 15,063 nights, split across LA direct provision (13,818 nights with a daily capacity of 53 beds) and contracted provision (1,245 nights, including 22 nights of nursing care). There is capacity for emergency as well as planned overnight respite. Additionally, there are sitting services provided by the Alzheimer's Society and SNPT Crossroads, adult family placements and a Glamorgan holiday home (for older people).

Contracted provision of overnight residential care came from independent care and nursing homes. A small number of clients used Swansea Council respite services.

Table 30: Number of adults receiving LA-funded respite care during 2009/10 in Neath Port Talbot

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
All ages	435	100	35				570
18-64 yo	70	93	27				190
65-74 yo	34	3	5				42
75-84 yo	124	4	3				131
85+ yo	207						207

Note:
Source: Neath Port Talbot Adult Social Services (PM2 Table 2b)

Short breaks for carers of disabled children were provided for 42 disabled children in 2009/10. The short breaks were provided in a variety of ways: residential care (29), specialist residential care (1), relative carer (1), foster carer (2) and Family Link (9).

Neath Port Talbot also provided responses to our qualitative questions.

1. What's your perception of how carers feel about the respite services available to them?

Carers Perspective: At a recent Carers 'Have your Say' event held in December 2010, 70 carers used the qwisdom system to provide their views on a range of topics one of which was having a break from caring, this produced the following results:

I think having a regular break from caring as

75%	responded	Very important
15%		Important
8%		not that important
0%		Not at all important
0%		don't know

I have a regular break from caring

38%	responded	At least one a week
9%		At least once a month
7%		At least once every two months
7%		Once of twice a year
38%		Never

The reason I can't have a break is because the person I care for does not want to go to day services/ respite

41%	responded	yes
59%	responded	no

I would prefer to have a break from caring

29%	responded	during the day
11%		during the evening
14%		at the weekend
7%		Overnight
39%		don't mind

The Service Development Officer for Carers conducts a 6 monthly audit of completed Carers Assessments (Adult). In the 62 completed forms viewed in January 2010, respite or a break from caring was noted in 22 cases for example, explore the respite options; a new offer of respite service to the client, an increase in respite service, respite provided by a sitting service e.g. Crossroads or where the offer of respite was declined by either the client or carer.

2. How important are respite services relative to other services provided to carers and care-recipients?

Please see Carers views above. Each carer will have his/her own views of how caring has effected their lives and which services or combination of services they (or the person they care for) will be the most appropriate for their circumstances.

3. What is most difficult about matching carers with appropriate respite services?

Getting the balance right where respite provides a positive experience for the client (therefore the client is keen/ happy to use the service) and a break from caring for the carer, when the carer wants/ needs the break.

Swansea

Swansea provided a wide range of respite services in 2009/10 including internal residential respite, flexible short term respite at home provided by external agencies, residential respite provided by the private sector and respite provided through a direct payment. It was not always possible to get information on numbers of users and carers for each service. This information has been included where possible.

Table 31: LA-funded respite services during 2009/10 in Swansea

Service	Total hours	Total sessions	Total service users	Total carers*	Total cost
Learning Disabilities – Figures for internally provided respite (does not include respite purchased from the independent sector on an individual basis)		5460			£868,808
Mental Health		108			£120,883
Older People			656		£680,879
Younger Adults with a Physical Disability (18-65)		93			£242,819)
Older People with Mental Ill Health		312	144	144	£142,900
Alzheimer's Society: Flexible support at home - Carers of older people with dementia	11,811			105	£169,100
Swansea Carers Centre: Flexible support at home - Carers of older people	6,055		47	49	£77,568
Swansea Carers Centre: Day Care - Carers of older people	8662		65	61	£56,358
SNPT Crossroads: Flexible support at home and or domiciliary care - Carers of adults	11,866		49	70	£187,725
SNPT Crossroads: Flexible support at home - Carers of adults with Parkinson's	4,590		3	3	£5,100
SNPT Crossroads: Flexible support at home - Carers of adults with a Physical Disability	554.5		6	6	£8,772
Hafal: Day care - Carers of adults with a mental health problem	5107		60	97	£72,012
Respite (contracted) Older people / Younger adults with a physical disability			183		£66,509
Respite (contracted) Learning Disability					£21,000
Direct Payments (for respite) – younger adults with disability			3		£1,084
Flexible Carers Support for outcomes of Carer's Assessment				45 (est)	£15,800
Flexible Carers Support for short term needs				8	£6,800

Note:

Source: Swansea Adult Social Services

Action for Children was contracted to provide overnight residential care and community short breaks to support parents of children/young people with significant disabilities. There is a high demand for this service. There is no current information available on the number of carers supported. The cost per hour of residential care was about £38 and of community short breaks was about £15. Families can also access direct payments, but there is no data to say what proportion of direct payments (taken by 75 families) was used for respite purposes.

Table 32: LA-funded short break services during 2009/10 in Swansea

Service	Total hours	Total sessions	Total service users	Total carers*	Total cost
Action for Children: Residential – Parent Carers of Children and Young People with significant disabilities	18,324	1,527			£699,111
Action for Children: Community Short Breaks – Parent Carers of Children and Young People with significant disabilities	11,500				£364,900
Direct Payment Packages (not solely respite)			75		

Note:

Source: Swansea Children's Social Services

Consultation with carers

Swansea also provided us with the following information on consultations with carers.

A number of consultations have taken place with Carers in Swansea. Respite has been a common theme that was highlighted. There have also been specific consultations with carers on respite. The general perception is that where respite has been provided it is greatly appreciated and well thought of whether it is through flexible short breaks or residential respite. Issues that have been raised include the inflexibility of residential provision, waiting lists and access to suitable provision.

Consultations include:

- Carers Rights day events including: Working Together With Carers – an event for all Carers, Working Together-Making a Difference – focusing on the needs of Parent Carers, A Celebration of the Carers Special Grant, Event for Carers of Adults with a Mental Health Problem, A Lifetime of Caring Event, Carers Health and Wellbeing
- Consultation event for the Health Social Care and Wellbeing Carers Needs Assessment
- Carers of older people as part of the review of respite provision in older people's services
- Carers of adults with a learning disability as part of a respite report in learning disability services
- An event to consult with parent carers of children with a learning disability as part of the Child Disability Team Review.

Below are a summary of the views of carers:

The view of carers of older people

- Most carers like to be able to book 'short breaks' well in advance, as this helps them to arrange holidays. This is only possible for 'in-house' services.
- Most carers like to access services that are 'on their doorstep', although they are prepared to travel if there is evidence the quality of placement is better.
- Most carers found that their first encounter with respite care services was both emotionally difficult and rather 'baffling' in terms of access to information. A number felt that the entrance lobbies to our current services could have a carers information stand.
- Whilst understanding that care recipients might prefer to stay at home when the carer is away, many carers prefer the traditional respite care home model as it gives them 'complete peace of mind.'
- Whilst initially hesitant about agreeing to the people they cared for being placed in a traditional care home, most carers said that the experience was positive for them and the people they cared for.
- Carers who were new to current service provision or were considering respite for the first time were more open to the possibility of exploring different options, and many did not want to consider a respite care home.
- Some carers do not like to be separated from their loved ones, and would prefer to take s short break together.

The views of older people who are recipients of care

- Most care recipients said that going into traditional respite care would not have been their first choice, but they were willing to do so, as they recognised the need for their carers to have a break.
- Most care recipients said that their experience of respite care homes was often better than expected and were full of praise for the staff who supported them.
- The majority of care recipients liked the idea of respite care in their own home and said this would be their preferred choice.
- Other care recipients said that they preferred the 'emotional and personal space' that was more possible in larger traditional respite care home settings. Even more private and independent people said they liked the idea of respite care in an extra care complex, where they had greater autonomy and their 'own front door'.

Minority Ethnic Carers

- There needs to be a variety of respite care options to support a **more** diverse range of people, than is currently provided. Any current lack of 'take up, may not be due to lack of need, but lack of suitability.

Learning Disabilities

- There is a need for better feedback to Carers on the respite stay.
- In general, the service provided is flexible and well thought of.

Parent Carers of Children with Disabilities

- There is insufficient respite provision and there are long waiting lists.
- The general perception is that the existing provision is well thought of but can be inflexible.

Younger Adults

- Feedback about the respite service is generally very good. Special requests for things to improve their stay have been limited to internet access in bedrooms, and CD and DVD players to be available.
- Anecdotal evidence (from Care Managers) is that the service is not popular, however, with younger disabled people between the ages of 18 and 40 approximately, because the facility has an older age profile and there are few activities (and few age appropriate activities) on offer.

Update 2010

- The respite review on older people's services has resulted in a greater choice in respite provision. Options now include residential respite, adult family placement, respite at home provision, a designated flat in an extra care complex and flexible day respite in day centre.
- BME carers are now provided with both support and a break one day a week in a day care setting.

Bridgend

There were 341 adult service users who received a respite service in 2009/10. There are four types of service available: overnight residential care directly by the LA or via an independent (local) provider, adult placement or domiciliary care.

Provision of overnight residential care (293 service users) is either directly by the LA (two-thirds) or via independent (local) providers (one-third). Overnight residential care for 18-64 year olds is almost all provided by the LA directly. Adult placements (27 service users) and domiciliary care (68 service users) were accessed almost exclusively by 18-64 year olds.

Table 33: Number of adults receiving LA-funded respite care during 2009/10 in Bridgend

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other*	Total
All ages	13	145	0	47	0	136	341
18-64 yo	12	134		12		37	195
65-74 yo	1	10		6		14	31
75-84 yo		1		11		31	43
85+ yo				18		54	72

Note: * This group is recorded as "Older People".
Source: Bridgend Adult Social Services

Bridgend operates a 'family link' service which provides short breaks for children who need care. This scheme allows the child/young person a break from their families. The break can be flexible depending on the needs of the child. It can be for a few hours a week or fortnight, to an overnight stay or even a whole weekend. The short break carers provide these short breaks on a regular basis. Other respite services are also provided. Details on numbers and costs for both types of service are shown below.

Table 34: Respite provision for children in Bridgend

Local Authority	Service	Session Duration (hours)	Total Sessions	Total hours	Total Staff / capacity	Total Service Users (cared for)	Total carers	TOTAL COST £
Bridgend	Family Link	6	989	-	-	24	18	£ 24,124.84
Bridgend	Respite	687	1093	19735	15	42	3	£ 483,989.54

Note:
Source: Bridgend Social Services

A2.2.5 Central Glamorgan

Overview

This section covers the two local authorities of Merthyr Tydfil and Rhondda Cynon Tâf. This is the same geographical area as that covered by Cwm Tâf Health Board.

Merthyr Tydfil

There were about 220 adult service users who received a respite service in 2009/10. There are three types of service available: overnight residential care (212 users of in-house services and 7 users of externally-provided services), night sitting (37), day sitting (65).

Overnight residential care was provided at Llysfaen respite centre and short term nursing and residential homes, where 4,638 sessions were provided at a total cost of £436,898 (approximately £2,000 per service user, or £94 per session). Day sitting and night sitting were contracted out for a total of 23,402 hours of service, and residential care was provided through a mix of direct LA provision (3,938 days) and contracted services (1,244 days). Total cost of related day services, grants and contracts for provision was approximately £1.8 million.

Merthyr Tydfil did not provide any data on respite services for children or young carers for this report , though data for some respite services provided by Merthyr Tydfil for looked after children are included in our analysis of the data collected by Data Unit Wales.

Rhondda Cynon Tâf

Adult Services

About 755 adults accessed services for respite care in Rhondda Cynon Tâf in 2009/10. This compares with over 900 being recorded as 'Carers under the Act' and 6,000 on the LA's Carers Support Project mailing list.

Table 35: Number of adults receiving LA-funded respite care during 2009/10 in Rhondda Cynon Tâf

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
All services	357	220	21	156	1	0	755
18-64 yo	27	214	13	5	1	0	260
65-74 yo	40	4	4	11	0	0	59
75-84 yo	128	0	4	66	0	0	198
85+ yo	162	2	0	74	0	0	238

Note:

Source: Rhondda Cynon Tâf Adult Social Services

Table 36: Number of nights of LA-funded respite care during 2009/10 in Rhondda Cynon Tâf

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
All services	5,447	4,151	73	5,097	1	366	15,135
18-64 yo	118	4,037	52	19	1	1	4,228
65-74 yo	403	55	7	188	0	365	1,018
75-84 yo	1,890	0	14	2,807	0	0	4,711
85+ yo	3,036	59	0	2,083	0	0	5,178

Note:

Source: Rhondda Cynon Tâf Adult Social Services

In addition to overnight residential respite care, Rhondda Cynon Tâf provides a range of contracted services, covering day care, sitting services (home care), adult placement, direct payments and other support and activities. Available data for these services is summarised in the table below.

Table 37: LA-funded contracted services during 2009/10 in Rhondda Cynon Tâf

Service	Total hours	Total sessions	Total service users	Total carers	Total cost
Adult placement (learning disability)			n/a		£13,094
Crossroads (mental health excl. dementia)			n/a		£41,391
Day centre (physical/learning disability, dementia)			1148	220	£4,801,920
Employment and training (learning disability)			*(part of 1,148)*		*£1,741,005*
Headway (physical disability)			*(part of 1,148)*		*£26,834*
Home care					n/a
Mental health grant (WAG) (mental health excl. dementia)					*£24,325*
Direct Payments (physical/learning disability, mental health excl. dementia)			37	35	£33,299
Emergency respite grant (WAG) (mental health excl. dementia)			69	69	£35,841
Glamorgan Holiday Home (physical disability)	45,696	272	221		£82,455
Carers Support Project (Events, Activities)		53	744		£14,831

Note:

Source: Rhondda Cynon Tâf Adult Social Services

Children's Services

There were about 115 families with disabled children supported by short break services in 2009/10. As well as overnight residential care, families accessed domiciliary care, direct payments and Family Link, as well as one-to-one support (via Family Support or '1 in 7' programmes).

Table 38: LA-funded short break services during 2009/10 in Rhondda Cynon Tâf

Service	Total hours	Total sessions	Total service users	Total carers*	Total cost
Respite (overnight, residential)		2,300	102		£968,553
Crossroads	9,254				£109,941
Domiciliary care (Extracare)			6		£16,567
Direct Payments			60		£171,666
Family link service (estimated use)		720	30		£65,097
One-to-one family support and '1 in 7'		2,298	112		

Note: * There are no data specifically on carers, but the ratio is at least 1:1 with service users and is likely to be higher.

Source: Rhondda Cynon Tâf Children's Social Services

A2.2.6 Southern Glamorgan

Overview

This section covers the two local authorities of Cardiff and Vale of Glamorgan. This is the same geographical area as covered by Cardiff & Vale University Health Board.

Cardiff

In Cardiff, 299 service users received overnight respite care during 2009/10 at a cost of £510,266, excluding the costs of the learning disabilities block contract. The latter represents about 18% of the number of sessions funded. A further 87 carers were benefiting from day sitting services and 36 carers were benefiting from night sitting services, on average during the year in 2009-10. The average day sitting provision was 3hrs per week.

Table 39: Number of overnight residential sessions of respite care during 2009/10 in Cardiff

	18-64	65-74	75-84	85+	Total
Contract type					
NURSING RESPITE	188	458	167	284	1,097
PART III RESPITE		168	250	330	748
RESIDENTIAL RESPITE	3,258	1,434	1,958	2,623	9,273
Group					
Physical Disability	826	1,075	1,644	2,334	5,879
Learning Disability	2,216				2,216
Mental Health	88	142			230
Mental Health (dementia)	11	843	731	903	2,488
Substance misuse	305				305
Total	3,446	2,060	2,375	3,237	11,118

Note: The total number of sessions includes 2010 nights covered by a learning disabilities block contract.
Source: Cardiff Adult Social Services

Cardiff was unable to provide data on children's services for this report, though data for some respite services for children provided by Cardiff are included in our analysis of the data collected by Data Unit Wales.

Cardiff also provided responses in respect of adult services to the qualitative questions that we had.

1. What's your perception of how carers feel about the respite services available to them?

On the whole, carers are satisfied with the quality of the respite services available, but not necessarily the amount of respite available to them.

The areas that need improving are flexibility in relation to booking respite in advance, so a carer can book a holiday or emergency respite.

2. How important are respite services relative to other services provided to carers and care-recipients?

From information gathered from carers assessments completed by our Carers Assessment Worker, information is the most requested service, but this is closely followed by respite. Very few carers want or ask for other services, even when prompted by social workers so I would say that although other services for some carers, especially those whose cared for person refuses to receive any form of respite, is important, it doesn't focus as highly as respite.

As we now have to consider the carers' wishes to return or remain in employment (and this fits in with the new carers officers based in Job Centres) and leisure activities, life-long learning etc, respite is becoming a more critical element of meeting carers' needs so that they can consider these areas.

3. What is most difficult about matching carers with appropriate respite services?

Resources to enable the development of specific respite services to meet the different needs of carers.

We have a large black and minority ethnic community in Cardiff with a large number of different communities all having different ethnic, cultural and religious needs. Finding respite services that fit in with these needs is difficult.

There is also the issue of age appropriate respite, especially for young people with physical disabilities.

The Vale of Glamorgan

Between 60 and 160 adults accessed respite services in 2009/10, with the likely figure being closer to 160. Respite services in the Vale of Glamorgan are specific to type of need, so it seems that there would be relatively little double counting.

The cost of overnight residential respite provided directly by the LA is about £400 per week, whilst the contracted services vary between £200 and £400 per week, depending on the care needs of the service user. The average annual cost per service user was about £2,300: care for services users with learning disability cost the most (£6,547) and for older people cost the least (£693).

Table 40: LA-funded respite services during 2009/10 in the Vale of Glamorgan

Service	Total hours (est)*	Total sessions	Total service users	Total carers	Total cost
Brocastle free respite bed	3672	153	10		£8,743
Bryneithin older people mental health	7824	326	28		£18,629
Carthref Porthceri	4272	178	11		£10,171
External learning disabilitiy	6456	269	7		£46,016
External older people nursing respite	2040	85	5		£12,143**
External physical and sensory impairment	1296	54	4		£7,714**
External older people	1560	65	3		£9,286**
Hospital team - external nursing respite	1344	56	4		£4,046
Learning disabilities internal	21912	913	54		£226,873
Older peoples mental health external nursing	3624	151	2		£11,740
OPT Residential RESPITE external	1560	65	3		£4,347
Physical and sensory impairment - external nursing costs	1056	44	2		£2,939
Southway older people (some dementia)	9312	388	32		£22,171

Note: * assuming one session is 24 hours; ** weekly cost is in the range £400 to £2000 depending on service and need.

Source: The Vale of Glamorgan Adult Social Services

We do not have data on short break services for young carers and disabled children.

A2.2.7 South East Wales

Overview

This section covers the five local authorities of Newport, Monmouthshire, Blaenau Gwent, Torfaen and Caerphilly. This is the same geographical area as covered by Aneurin Bevan Health Board.

Newport

There were at least 121 adult service users who received a respite service in 2009/10. Overnight residential respite services (5,820 nights) were provided by the LA directly or by contracted independent residential care homes. In addition to this, several services are funded by two grant schemes, and a further contract for overnight residential respite was in place with Crossroads.

The grant-funded services covered befriending, day breaks, night sitting, at-home respite care and support worker services. The same grant funding paid for services specific to disabled children.

Monmouthshire

There were between 260 and 380 carers who benefited from a respite service in 2009/10. The services most accessed were a befriending project by Alzheimer's Society (at least 257) and overnight residential care provided by Crossroad Care (120). There were several other services provided on a smaller scale, though not all elements of these can be classified as respite care.

Overnight residential care cost approximately £20 per hour, and support workers cost approximately £30 per hour.

Table 41: LA-funded adults' services for carers during 2009/10 in Monmouthshire

Service	Total hours	Total sessions	Total service users	Total carers	Total cost
Hafal Support Worker	450			15	£13,500
Support Worker	450				£12,485
Alzheimer's Society Dementia Cafe	450				£8,300
Alzheimer's Befriending Project	450			257	£19,172
Alzheimer's Befriending Project	2500				£30,587
Community Disability Team*	49712	52		11	£14,981
British Red Cross		300			£6,057
BiPolar Carers Trust: Carers Training		2		24	£2,200
Powys Sense: Carers Workshops		5			£7,335
Mental Healthcare Team (flexible respite for carers)					£7,500
Age Concern	1200			20	£26,426
Crossroads: respite care	2000			120	£34749
Carers Flexible Pot*					£17,176
Community Care Teams: Sitting service			3		£345
Community Care Teams: Personal care			1		£25
Community Care Teams: Sitting service			2		
Free leisure passes (25% discount)				24	

Note: * Community Disability Team provided high level support; Carers Flexible Pot (administered by Carers Project) provided one off support for carers including carers events).

Source: Monmouthshire Adults' Social Services

Short break support for carers of disabled children (between 81 and 195) and for young carers (10) was provided alongside other support services. Indicatively, the annual cost of each service per carer for "activities and support" was £180 for carers of disabled children and £566 for young carers in 2009/10.

Table 42: LA-funded short break services during 2009/10 in Monmouthshire					
Service	**Total hours**	**Total sessions**	**Total service users**	**Total carers**	**Total cost**
Children with Disabilities Team*				195	£13,421
Family Support Worker					£20,697
Young Carers Activities and Support				10	£5,660
Activities and support				81	£14,566

Note: * Children with Disabilities Team provided Carers Support Group, newsletters, unplanned crisis support, Direct Payments.
Source: Monmouthshire Children's Social Services

Blaenau Gwent

Blaenau Gwent was unable to provide data for this report, though data for some adult respite services provided by Blaenau Gwent are included in our analysis of the data collected by Data Unit Wales.

Torfaen

At least 360 adults received services that provided respite to their carers in 2009/10. There were four services: overnight residential respite, nursing respite, domiciliary care and day care.

Table 43: LA-funded respite and short break services during 2009/10 in Torfaen					
Service	**Total hours**	**Total sessions**	**Total service users**	**Total carers**	**Total cost**
Residential respite		4928			£379,708
Nursing respite		1051			£93,059
Domiciliary care (to Sep 2009)	4118		391		
Day care			217		
Short breaks for young carers				72	

Note:
Source: Torfaen Adult and Children's Social Services

Short breaks were provided for 72 young carers. Torfaen spent £245,963 on respite for children during 2009/10.

Caerphilly

There were 240 adult service users who received a respite service in 2009/10. There are five types of service available: overnight residential placement, overnight nursing general medical placement, day sitting, night sitting, and holiday home placement.

The annual cost per service user was £10,786 in LA direct services, which are provided at two residential homes (Montclaire and Ty Gwilym) specialised in services for learning difficulties. The annual cost per service user was £967 in independent services, which cover older people, learning disabilities and physical disabilities separately.

The majority of service users (208) accessed LA-funded independent services rather than direct LA provision (57). However, the amount spent is much more on LA direct services (£614,827) than on independent services (£201,115), split between older people (£145,292), learning disabilities (£32,169) and physical disabilities (23,654).

Table 44: Number of adults receiving LA-funded respite care during 2009/10 in Caerphilly

	Physical and Sensory Disability/ Frailty	Learning Disability	Mental Health	EMI/ Dementia	Substance Misuse	Other	Total
All services	112	82	5	39		2	240
18-64 yo							101
65-74 yo							27
75-84 yo							57
85+ yo							55

Note:

Source: Caerphilly Adult Social Services

There were 39 young people who received short break services in 2009/10, 15 of whom accessed fostering and 24 who accessed the Action for Children Resource Centre.

Annex 3 Projections of the demand for informal carers to 2030

In this part of the study, we estimate the demand for respite care over the next 20 years, so that we can predict what the cost of public provision might be in the future. To make our estimates, we use two different projections of the number of carers and care recipients at intense levels of informal care provision. We elaborate on this analysis by considering how the evolution of telecare services may affect the demand for intense informal care and subsequently, the demand for respite care.

A3.1 Data Sources

Our main source for the projections is Pickard (2008), which looks at the demand and supply of informal care for younger adults[23] and older people[24] in two separate papers. The author uses 2000/01 General Household Survey (GHS) data from the Office of National Statistics (ONS) on the provision for informal care, which has a sample size of 14,000 adults. With the following underlying assumptions, Pickard makes projections on the provision of care and the need for informal care for younger adults and older people.

Provision of care assumptions[25]

- There is a constant probability of providing care by age, gender, marital status and education
- The number of people by age and gender changes in line with Government Actuary's Department (GAD) 2006 based population projections
- The proportion of the population in private households, based on the 2001 Census remains constant by age and gender
- Marital status changes in line with GAD 2003-based marital status and cohabitation projections (ONS)
- The probability of providing care for more than 20 hours a week to an older parent by age, gender and marital status in England remains unchanged.[26]
- The probability of providing care for more than 20 hours a week to a younger adult by age, gender, marital status and educational qualifications in England remains unchanged, as reported in 2000/01 GHS.[27]

– [23] Informal Care for Younger Adults in England: Current Provision and Issues in Future Supply, England 2005-2041, Pickard 2008

– [24] Informal Care for Older People Provided by Their Adult Children: Projections of Supply and Demand to 2041 in England, Pickard 2008

– [25] Informal Care for Older People, Pickard 2008 and Informal Care for Younger Adults, Pickard 2008

– [26] Informal Care for Older People, Pickard 2008

– [27] Informal Care for Younger Adults, Pickard 2008

Need for care assumptions[28]

- Pickard uses the PSSRU long term care finance model (Wittenburg).
- The prevalence rates of physical and sensory impairments are assumed to remain constant in future years
- The prevalence rates of learning disabilities are assumed to rise slightly, in line with projections by Emerson and Hatton (2004).[29]
- The prevalence rates of disability are assumed to remain constant in future years[30]
- Assumption that the proportion of younger adults receiving informal care remains constant in future years by age, gender, severity of disability and household composition.[31]
- Assumption that the proportion of disabled older people receiving informal care remains constant in future years by age, gender and marital status.[32]

Under these assumptions, Pickard produces projections of the provision of and need for intense informal care in England. It is important to note that the projections relate to the provision of 'intense care' only, that is, 20 hours a week or more of care. As well as estimating the supply and demand of informal care, Pickard also calculates the ratio of 'care receivers' to 'care providers', which is the projection of the provision of informal care divided by the projection of the need for informal care. For example, if this value is 67%, then for every 100 people demanding care (a 'care receiver'), there is only 67 people able to supply care (a 'care provider').

Whereas Pickard assumes the prevalence rates for physical disability remain constant in the future, another author, Mayhew[33], makes projections with assumptions that prevalence of physical disability will increase over time. Mayhew looks at the impact of demographic changes, namely the increase in life expectancy and the decline in the ratio of adults of working age to the population aged greater than 65, on the UK. We look at how demographic change affects care requirements and the change in the disabled population up to 2025, with the definition of 'disabled' being someone with a moderate to severe disability, a value of 7 or greater on the Richayzen Walsh scale[34].

Another paper, by Dementia UK (2007), assesses the prevalence and cost of dementia and predicts that the prevalence of dementia in Wales will remain at the same level within each age group in the future.

The projections from Pickard and Mayhew are not specific to Wales. To construct our projections for Wales, we use Pickard's and Mayhew's projections in conjunction with population projections from StatsWales and ONS for Wales and England respectively.

- [28] Informal Care for Younger Adults, Pickard 2008 and Informal Care for Older People, Pickard 2008
- [29] Informal Care for Younger Adults, Pickard 2008
- [30] Informal Care for Older People, Pickard 2008
- [31] Informal Care for Younger Adults, Pickard 2008
- [32] Informal Care for Older People, Pickard 2008
- [33] Increasing longevity and the economic value of healthy ageing and working longer, Mayhew, 2009
- [34] The scale measures disability from 0 (healthy) to 10 (severely disabled) based on ability to undertake activities in daily living such as washing, dressing, cooking and getting up and down stairs.

Estimating the prevalence and expected growth of telecare is difficult because it is a relatively new service in Wales and its take-up is very much dependent on Local Authority funding. However, we attempt to estimate its change over time by using access to the internet as a proxy for telecare. The majority of telecare services require the internet and so the growth of the internet seems a sensible proxy for the growth of telecare. *Logged in or Locked out?*, a Consumer Focus Wales report, looks at internet access for users in Wales, and provides estimates for personal access to the internet by age group.

A3.2 Method

For this model, we created two different projections to try and estimate the number of people in need of intense informal care and the number of people actually providing intense informal care. These figures can then be used to estimate the demand and cost of respite care over the next 20 years. It is important to note that the data sources used all rely on different underlying assumptions (explained above). Moreover, all of the Scenario's give a proportion (i.e. a percentage of the population) and therefore we multiply their value by the population projections from StatsWales to give an absolute number of people demanding or supplying informal care.

A3.2.1 Projections of people in need of care and of carers provided

Projection 1

Data from Pickard on the number of people who received intense informal care for a number of years up to 2041 was used to project the number of people in need of care. For the years missing we interpolated the estimates. The data was specifically for England and so we divided it by population projections from the ONS, to give us the proportion of people in England that receive informal care. Since we are looking at Wales specifically, we make the assumption that the distribution of people needing care in Wales is the same as in England. We were unable to obtain data on informal care for children (those aged less than 20 years old). Therefore, we made the assumption that the proportion of people that receive care for the age group 20-64 is the same as for the age group 0-19.

The number of younger adults and older people receiving intense informal care in Pickard is based on the assumption that the proportion of those receiving care remains constant in future years, by age, gender, severity of disability and household composition. Moreover, it is assumed that prevalence rates of disability remain unchanged over time. This means that in this projection, the only factor affecting the absolute number of people needing care in the future is the size of the age groups in the population and how they change over time.

In order to attempt to predict the supply of informal care, we now take this projection of people in need of care and multiply it by Pickard's ratio of 'care receivers' to 'care providers'. This then gives us an estimate of the supply of intense care needed.

Projection 2

Since Mayhew makes an assumption that physical disability increases over time which is different to that of Pickard, we also estimate projections using point estimates of the proportion of people in the UK that have a 'moderate to severe' disability in 2008 and 2025 from Mayhew. We then interpolated these estimates between 2008 and 2025 and extrapolated to 2030. We were unable to obtain data on informal care for children (those aged less than 20 years old). Therefore, we made the assumption that the proportion of people that receive care for the age group 20-64 is the same as for the age group 0-19.

Mayhew's estimates take into account the idea that when life expectancy increases, people who are disabled will be living for longer and therefore receiving care for a longer period of time. This is especially the case for those aged between 20 and 64. Consequently, this projection uses the same starting point as Pickard, but the change in receipt of care over time follows the Mayhew prediction; namely that there will be an increase in the proportion of people receiving care for those 20-64, no change for those aged 65-84 and a slight decrease in those aged 85+.

In order to attempt to predict the supply of informal care, we now take this projection of people in need of care and multiply it by Pickard's ratio of 'care receivers' to 'care providers'. This then gives us an estimate of the supply of informal care needed.

A3.2.2 Additional Projections

We also looked at the expected evolution of telecare in the future. To do this, we applied our predictions of the growth of telecare to each projection. Telecare has an important impact on carers and their lifestyles. It often gives them the opportunity to leave their care recipient for a few hours and know that they are in safe hands. In this way, telecare drops carers out of the 'intense informal care' category to a lower intensity of informal care, because they are now caring for fewer hours. Therefore, if telecare grows by 2% a year, then intense informal care now only grows 98% of what it did previously, because 2% of carers have dropped from the intense informal category to a lower intensity of informal care.

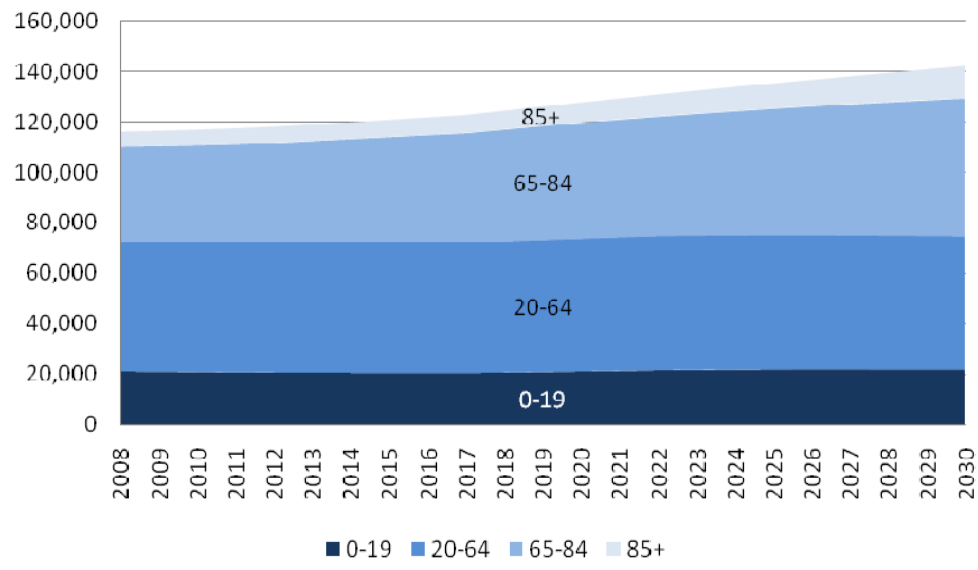
We predicted a 'central' estimate, where internet access was used as a proxy for telecare use. For example, if internet access was expected to grow by 1% year-on-year, then telecare would grow at the same rate. We also estimated a low and a high estimate, to give us an upper and lower bound, or in other words, a best case scenario (fast growth of telecare) and a worst case scenario (slower growth of telecare). The best case scenario is a 5% faster rate each year than the central estimate. This may occur because older people may become more internet aware than previously predicted because of more local internet classes available or encouragement to use the internet by friends and family, for example. The worst case scenario is a 10% slower rate than the central estimate, and this may occur of older people become less interested in using the internet or do not see its relevance. When the telecare estimates were applied to the model, the results did not change by a large amount. This is mainly due to the fact that the proportion of people currently using telecare is very low.

Moreover, we also used lower and upper bounds for the population projections supplied by StatsWales. However, when applied to the model, again the results did not change significantly.

A3.3 Results

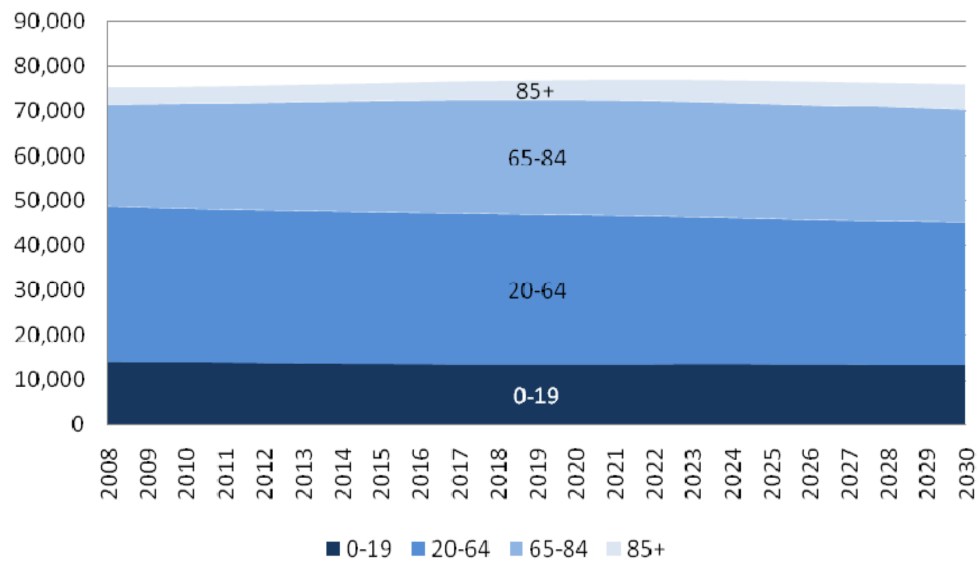
Over the next 20 years, the number of people that need care is likely to increase for those aged 65-84 (Figure 15). However, for those aged less than 64, the number of people that need care is projected to remain relatively constant.

Figure 15:Pickard projection of people in need of care



Note:
Source: Pickard 2008, StatsWales, ONS

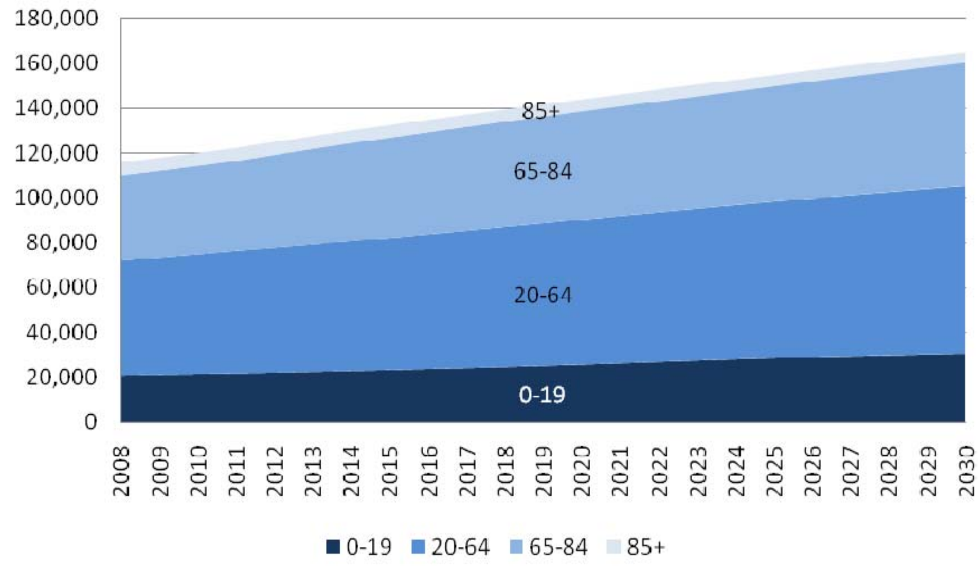
Figure 16:Pickard projection of carers provided



Note: Pickard's figures were only for England; therefore we make the assumption that the distribution of people that need care in England is the same as in Wales.
Source: StatsWales, Pickard 2008

The projection of carers provided is relatively stable for all age groups (Figure 16) when applying the ratio of 'care receivers' to 'care providers' to the projections from Pickard.

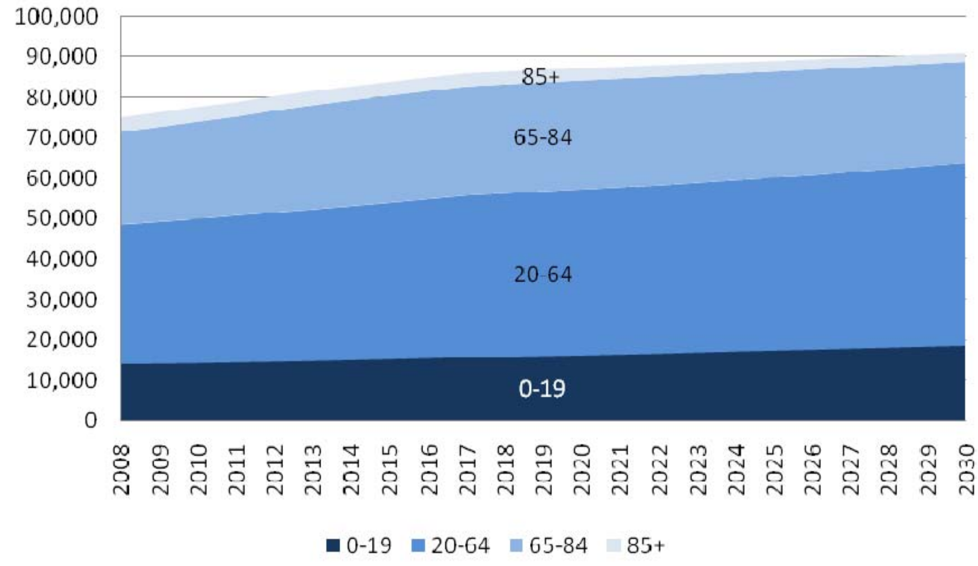
Figure 17:Mayhew projection of people in need of care



Note: The ages in the graph above are the ages of those cared for rather than the carers.
Source: Mayhew, StatsWales, ONS

When we look at the effect of life expectancy on the need for care (Figure 17), we see that all age groups have a growing need for care over time, except for the 85+ age group which remains relatively stable. The increase is most profound for those aged 20-64.

Figure 18:Mayhew projection of carers provided



Note:
Source: StatsWales, Mayhew

Moreover, when we use the projections from Mayhew, it can be seen that there is a gradual increase in the provision of carers, especially for those aged 20-64 (Figure 18).

Our central estimate of telecare showed that telecare was expected to grow from 0.22% in 2008 to 1.62% in 2030. Therefore the substitution from intense informal care to less intense informal care due to telecare only occurs for a small proportion of people providing care.

A3.4 Other factors

There are a number of sociodemographic factors that could influence our results that we have not considered here. For example, the evolution of the demand and supply of respite care in Wales depends on the characteristics of those supplying the care, as well as the life expectancy of the cared for persons.

Education

Pickard notes that there is a significantly negative relationship between educational qualifications and the probability of providing informal care. The recent trend in education is that the proportion of people without educational qualifications is falling which would imply a decline in informal care in future years.

Age

The provision of informal care by carers is related to their age, with the majority being working adults. Pickard states that 15% of the care provided to younger adults is provided by people aged 65 and over. Moreover, the population of those aged 65 and over is increasing at a faster rate than the working age population.[35] Consequently, the supply of people providing care to younger adults could potentially exceed demand for care in future years.

Marital Status

There is a strong association between marriage/partnership and care provision.[36] The proportion of people who are married/co-habiting is projected to decline in future years for those aged 45 to 64 and this is the age group that is most likely to be providing care.

Gender

In general, women are more likely to provide care than men are.

- [35] Plum
- [36] Pickard 2008

Annex 4 LE Wales Survey of Carers

A4.1 Introduction

As part of our research we undertook an online survey of carers. We had not initially planned to undertake a survey, but stakeholders persuaded us that it would be worth doing even though carers can be difficult to access through surveys and an online survey might be difficult for some carers to respond to. We used an online survey method in order to limit costs.

Many organisations (both public and voluntary sectors) active in respite care assisted us by circulating details of our survey to the carers with whom they were in contact. The following introduction to the survey was circulated by them.

> *LE Wales are conducting a survey of carers as part of a study for the Welsh Assembly Government to review the provision of respite services in Wales. We would like to find out a little about the circumstances under which you provide care, what respite care services you would ideally want to have and what you think about any such services you currently receive. It is important that carers have a chance to express their views on this and we hope that you will find this a good opportunity to provide some input into the planning of services aimed at benefitting carers. It will take about 10 minutes to complete the survey, which is available to complete in English or Welsh, and which you complete anonymously. The survey will be open from Thursday 17 June 2010 to Saturday 31 July 2010.*
>
> *Mae LE Wales yn cynnal arolwg gofalwyr fel rhan o astudiaeth ar gyfer Llywodraeth Cynulliad Cymru i adolygu'r modd y darperir gwasanaethau seibiant yng Nghymru. Hoffem gael gwybod ym mha amgylchiadau y byddwch chi'n darparu gofal, beth yw'r gwasanaethau gofal seibiant delfrydol yr hoffech eu gweld, a beth yw eich barn am unrhyw gyfryw wasanaethau yr ydych yn eu cael ar hyn o bryd. Mae'n bwysig bod gofalwyr yn cael cyfle i fynegi eu barn am hyn, ac rydym yn gobeithio y byddwch yn manteisio ar y cyfle hwn i roi eich sylwadau chi am y modd y cynllunnir gwasanaethau sydd â'r bwriad o ddwyn budd i ofalwyr. Ni ddylai gymryd mwy na 10 munud i lenwi'r arolwg. Mae'r arolwg ar gael yn y Gymraeg a'r Saesneg, a gellir ei lenwi yn ddienw. Bydd yr arolwg yn agored rhwng dydd Iau 17 Mehefin 2010 a dydd Sadwrn 31 Gorffennaf 2010.*

The survey questionnaire was made available in both the English and Welsh languages with the survey website available for respondents to complete their responses between Thursday 17 June 2010 and Saturday 31 July 2010. We received 202 responses, of which 8 were in Welsh and 194 in English. Not all respondents completed all parts of the questionnaire – 147 did so (141 in English and 6 in Welsh).

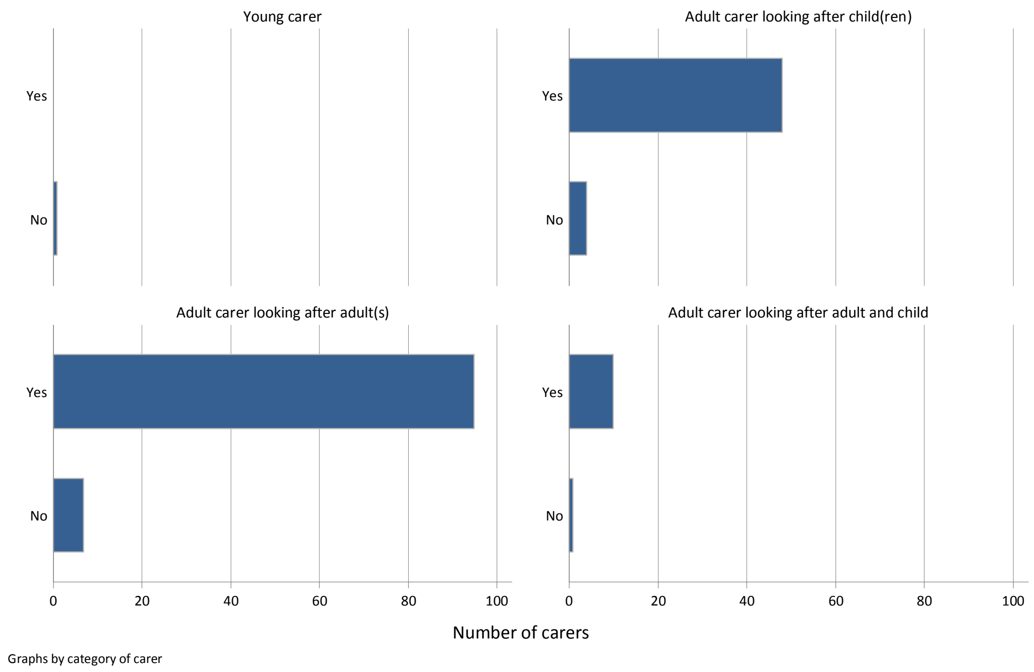
The English language version of the survey questionnaire is included as an Appendix to this Annex.

A4.2 Characteristics of respondents

In this section we summarise the main characteristics of the survey respondents. Only one respondent was a young carer and they did not regard themselves as the main carer. Most of the adult carers who responded did regard themselves as the main carer (Figure 19). Most respondents were also female, though a significant minority were male (Figure 20). Most of the respondents were adults in the 25-64 age band though in the case of adults caring for other adults a significant minority where aged over 65 (Figure 21).

The geographical spread of respondents is shown in Figure 22. We received responses from all local authority areas in Wales.

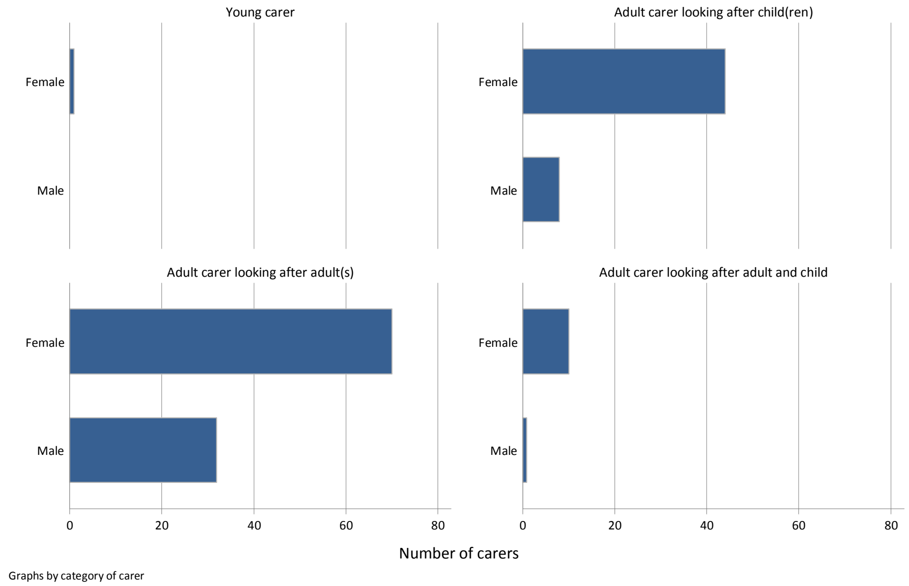
Figure 19:Whether respondent is the main carer



Note:

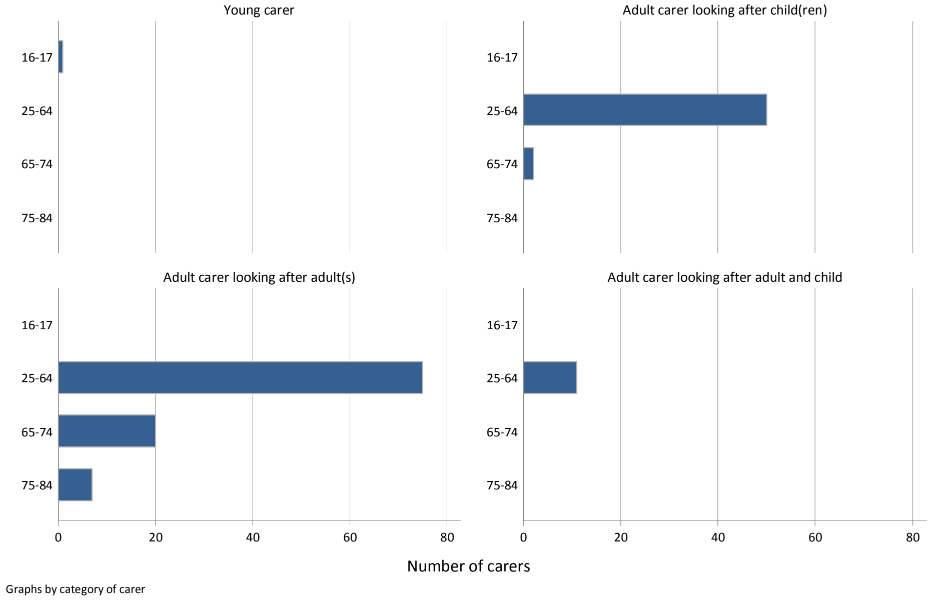
Source: LE Wales Carers survey

Figure 20:Gender of respondent



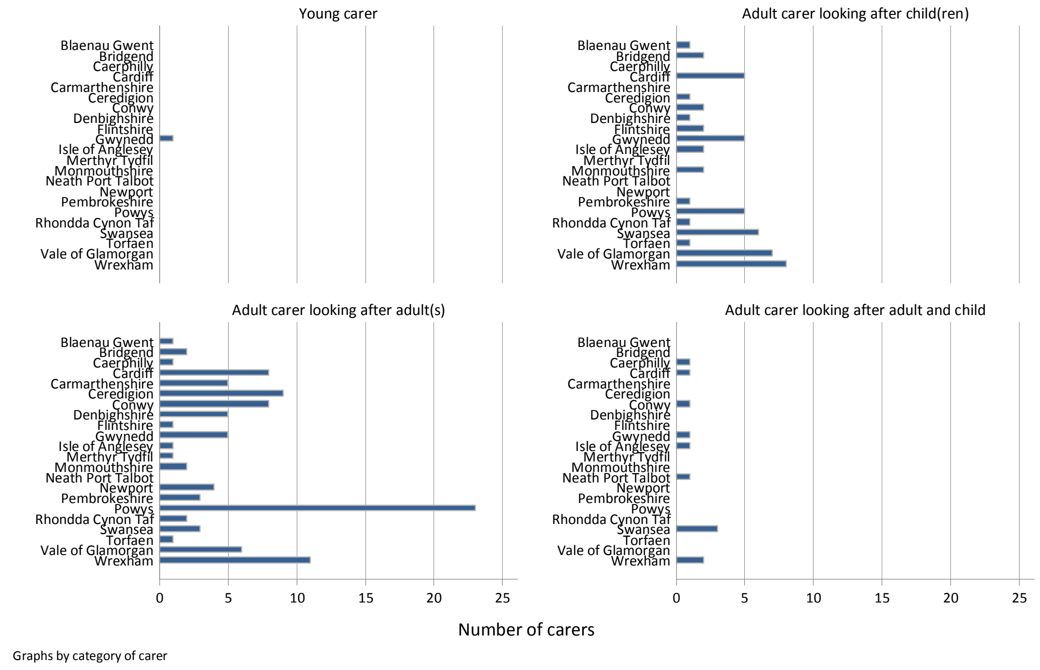
Note:
Source: LE Wales Carers Survey

Figure 21:Age of respondent



Note:
Source: LE Wales Carers Survey

Figure 22:Respondent's local authority



Note:

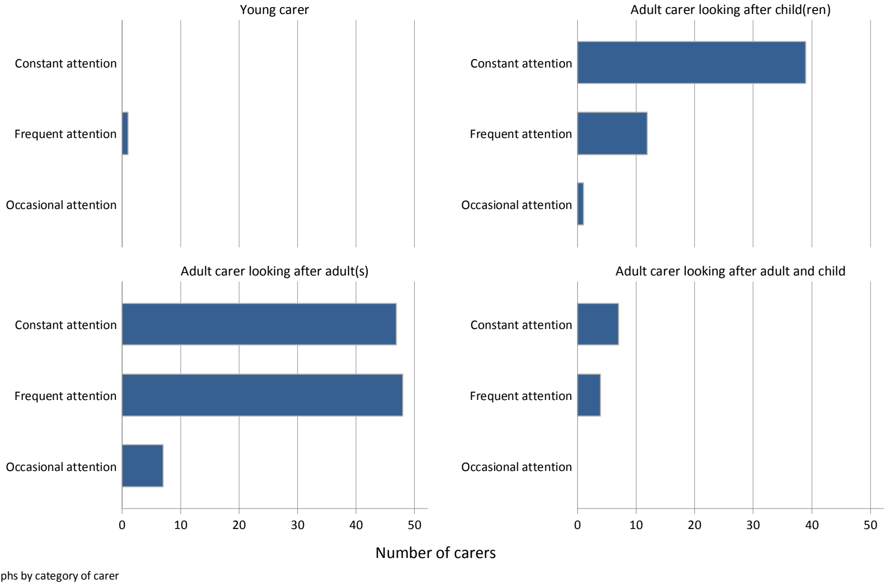
Source: LE Wales Carers Survey

A4.3 Caring responsibilities of respondents

It is clear that the majority of carers who responded to the survey feel that their care recipient(s) require either constant or frequent attention. Very few carers reported that their carer recipient(s) only required occasional attention (Figure 23). In most cases, respondents were either the main source of caring or share this role with only one other person (Figure 24).

The majority of carers look after only one care recipient, though some care for two or three people (Figure 25). Most respondents did not have other employment or education commitments, though a significant minority did. Of the latter the commitment was more likely to be more than 16 hours per week (Figure 26).

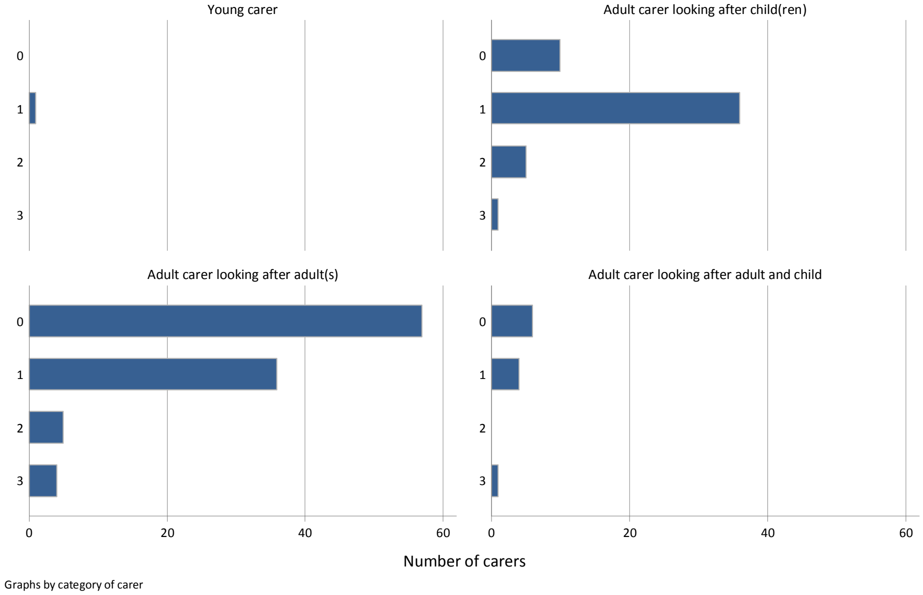
Figure 23:Amount of attention required of respondent in providing care



Note:

Source: LE Wales Carers Survey

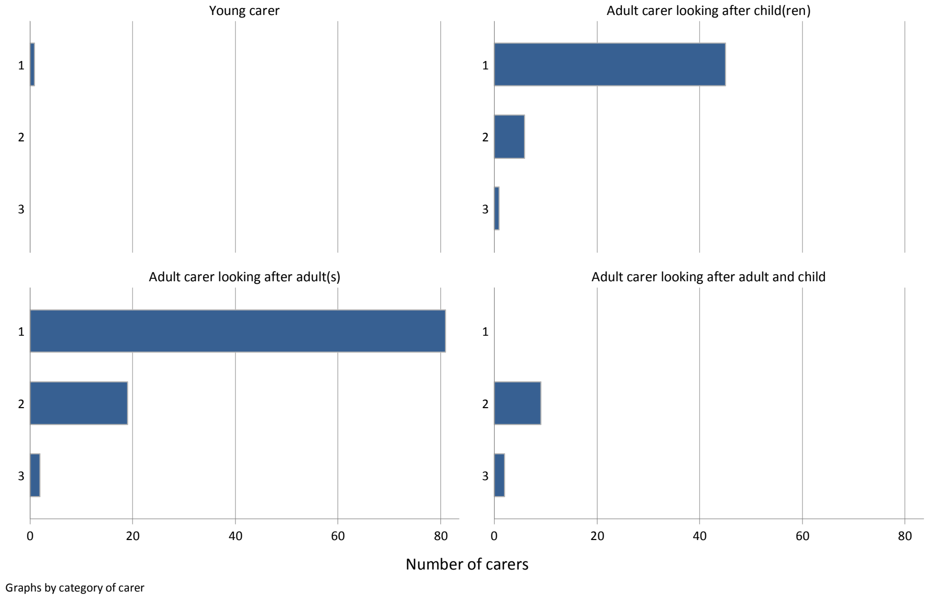
Figure 24:How many others share the caring role with the respondent



Note:

Source: LE Wales Carers Survey

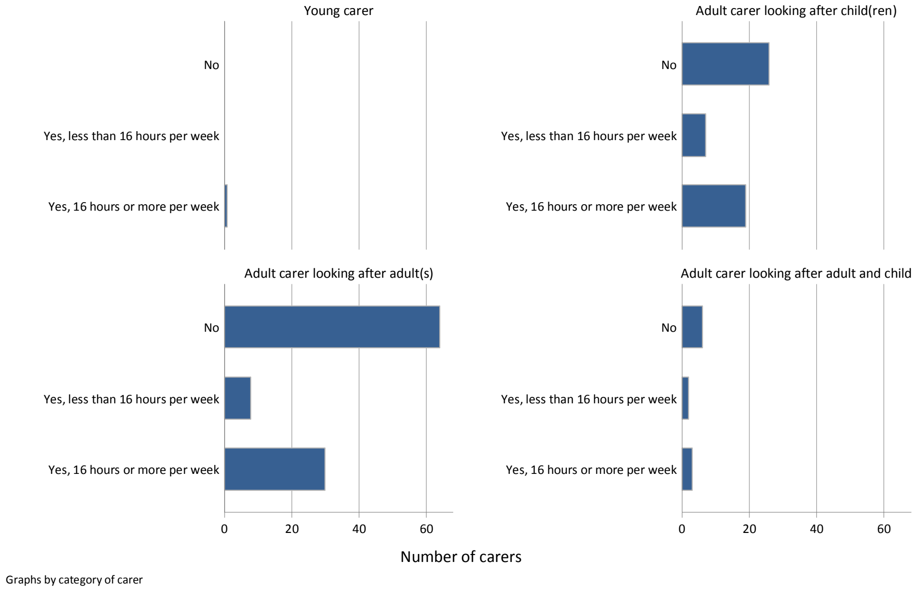
Figure 25:Number of people for whom respondent provides care



Note:

Source: LE Wales Carers Survey

Figure 26:Respondent's other time commitments (in education or employment)



Note:

Source: LE Wales Carers Survey

A4.4 Views on respite services received and desired

Respondents were asked which were the most useful services that they currently received in order of usefulness - first, second and third. They were also asked which services did they most want to receive (including both services that they currently received and services that they did not currently receive) again in order of usefulness - first, second and third.

The following 'sunflower' graphs summarise respondents' response to these questions. Figure 27 shows, on the top, the first-most useful service received and, on the bottom, the first-most useful service wanted. The left hand side graphs summarise responses from adult carers looking after children and the right hand-side graphs summarise the responses from adult carers looking after adults. The horizontal axis gives a code to different service frequencies, for example '1' corresponds to two hours a day and '7' corresponds to one day/night a month. The vertical axis gives a code to different service types, for example '5' corresponds to day care centre. When these are plotted on the graph, each pair of coordinates gives us the number of observations from the carers survey that want (or receive) a service type at a certain frequency. The 'sunflower' observations show that more people want (or receive) this service type at a certain frequency, and the darker the sunflower, or the more petals it has, the more observations at this pair of coordinates. For example, if there is a sunflower at (2,5) with 3 petals on it, this means that 3 respondents wanted overnight care in cared-for person's home for one day/night a fortnight. The key to the service and frequency codes is provided in Table 45.

Figure 28 and Figure 29 show the same information but in respect of the second and third most useful services (received and wanted) respectively.

These graphs show that there are a large number of carers that did not receive a service but wanted a service (Figure 27). This can be seen by the flower in coordinate (15, 1). In the most useful service received graph, the flower on (15, 1) had a lot of petals for adult carers looking after children or adults, showing a large number of adult carers did not receive a service. However, when looking at the most useful service wanted by carers, there are few (only one or two) carers that actually want no service at all.

The most wanted service by adult carers (of adults or children) is activity days out or holidays, with one week a year being the most commonly demanded frequency of this service. Moreover, daytime care in the cared for persons home was wanted, but also received on many occasions (albeit at a different frequency to what it is demanded). This suggests that more funding should be directed towards respite care in the form of activity days out or holidays. Additionally, care needs to be taken to ensure carers receive services at the frequency that they want.

Again, a large number of carers do not receive a second service (Figure 28). However, a lot of carers actually want a second service, with the most wanting daytime care in cared-for persons home, activity days out or holidays, a befriending service and after school activities at different service frequencies. However, one day/night a week was the most demanded service frequency across a number of services. Despite some carers wanting a second service, there are still a number of people who do not want a second service.

The majority of people do not receive a third service, but they also do not want a third service. This shows that while people want respite services, there is a limit to how many services they want or need. Of those that did want a third service, some of them wanted direct payments.

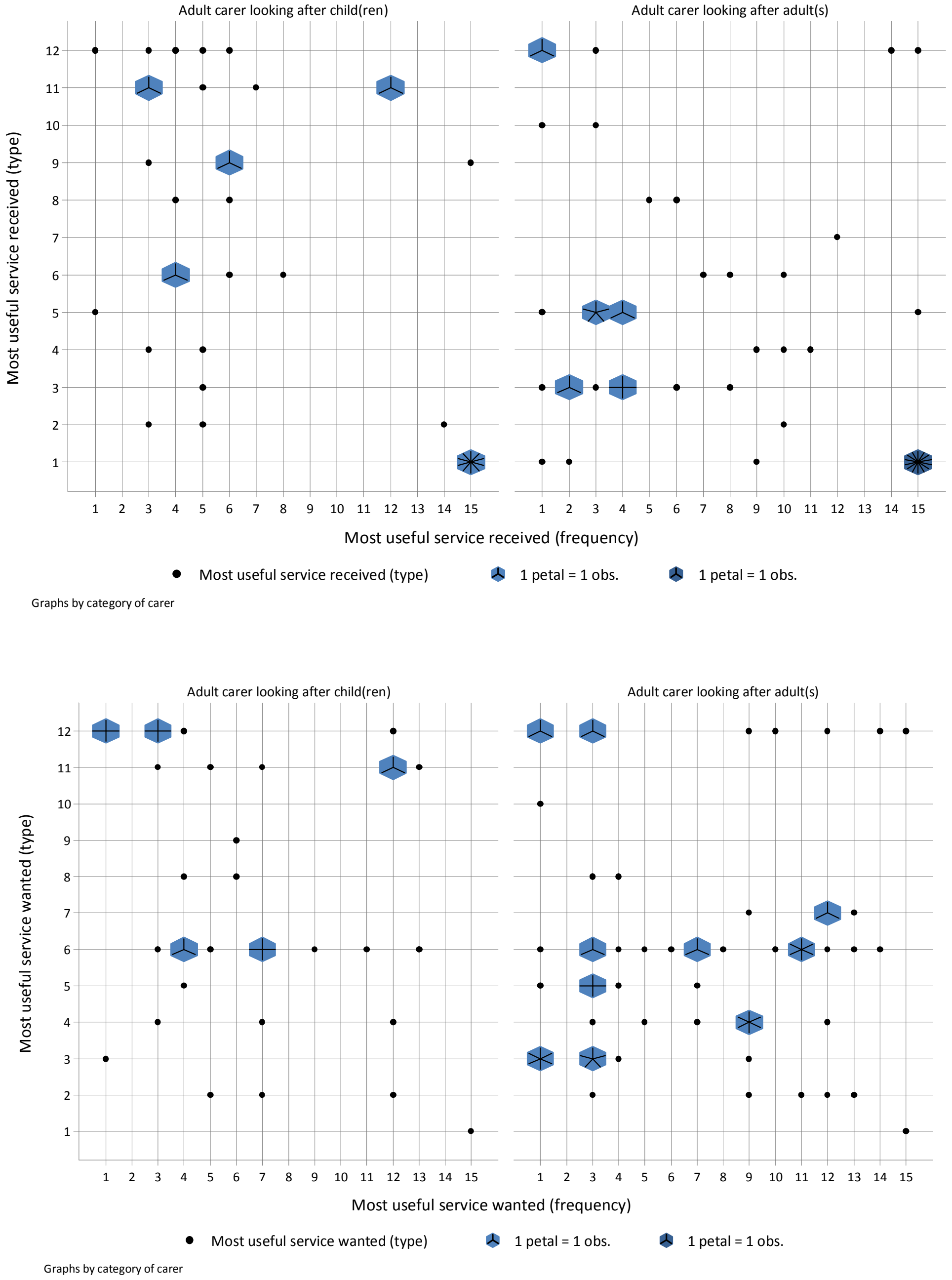
Table 45: Key to codes in Figure 27 to Figure 29

Service Type		Service Frequency	
1	None	1	Two hours a day
2	Overnight care in cared-for person's home	2	An hour a day
3	Daytime care in cared-for person's home	3	One day/night a week
4	Residential care centre (overnight care)	4	Half a day a week
5	Day care centre	5	One day/night a fortnight
6	Activity days out or holidays	6	Two hours a week
7	Adult placement (overnight short break care for adults)	7	One day/night a month
8	Befriending service	8	One day/night every three months
9	After-school activities	9	One week every three months
10	Education/employment for cared-for person	10	One week every six months
11	Overnight shore breaks for disabled children	11	One week a year
12	Direct payments (for you to choose how to spend)	12	One weekend a month
		13	One weekend every two months
		14	One weekend every three months
		15	None

Note:

Source: LE Wales Carers Survey

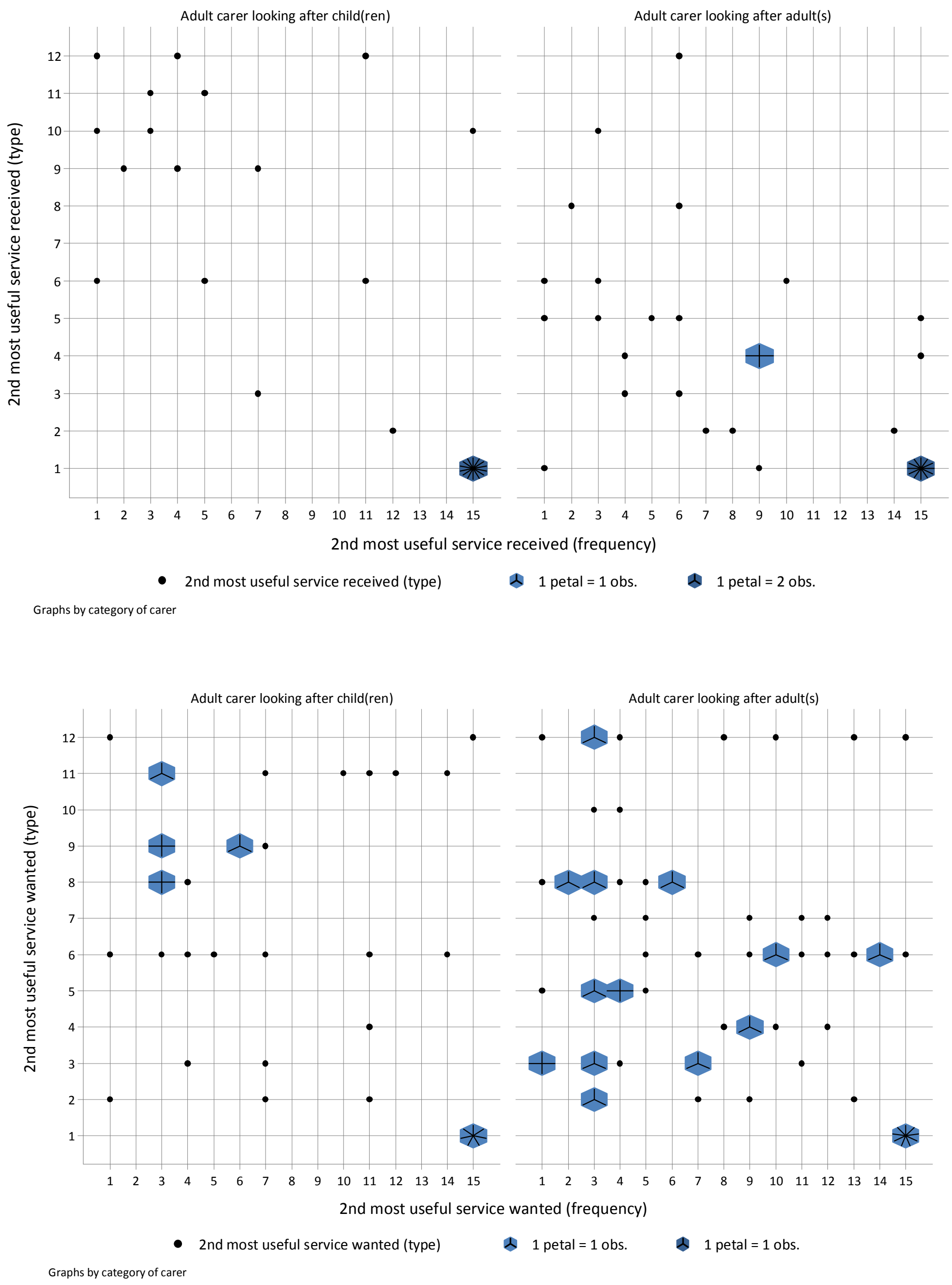
Figure 27:First-most useful service received and wanted



Note: See Table 45 for key to codes.

Source: LE Wales Carers Survey

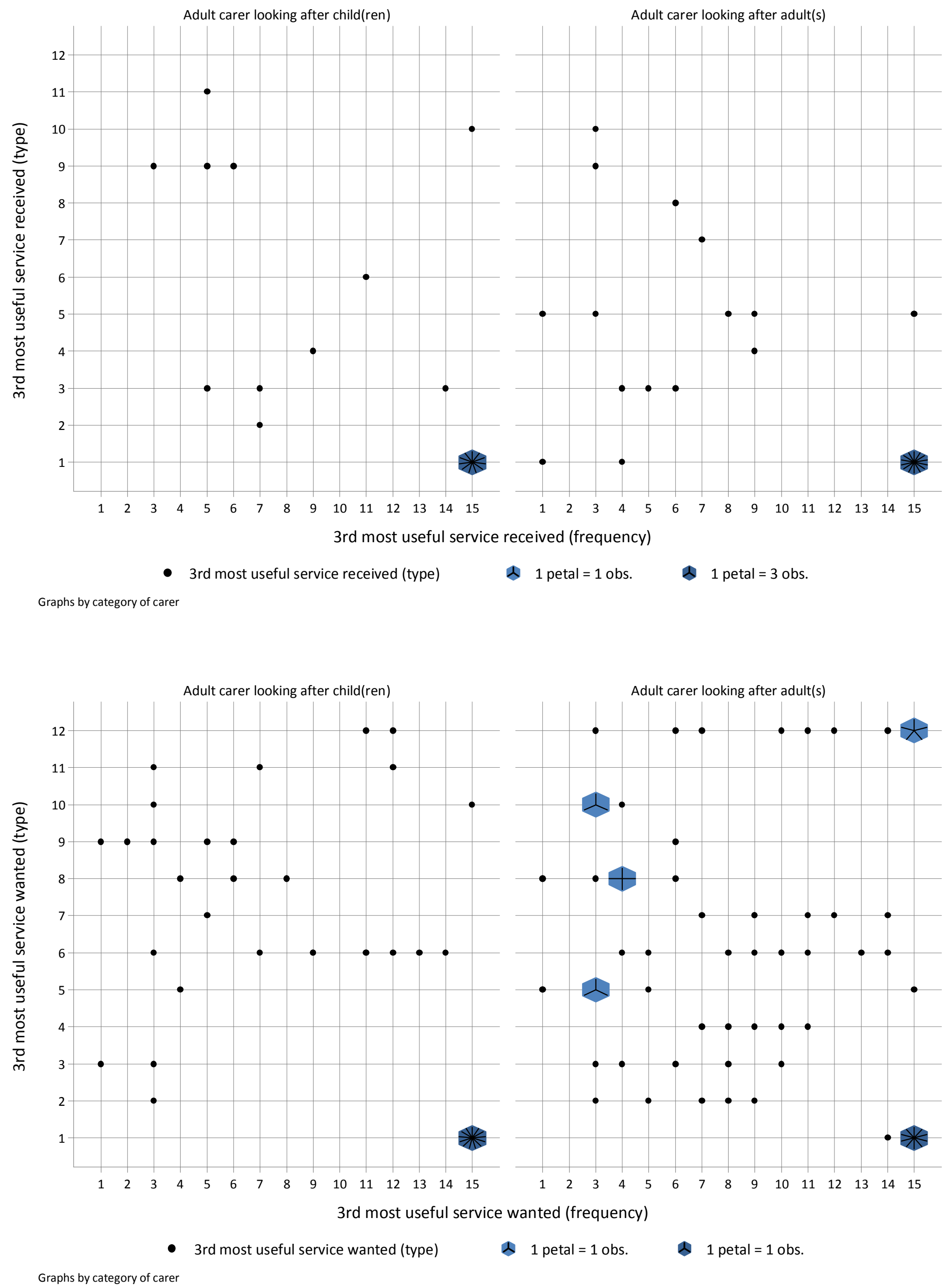
Figure 28:Second-most useful service received and wanted



Note: See Table 45 for key to codes

Source: LE Wales Carers Survey

Figure 29:Third-most useful service received and wanted



Note: See Table 45for key to codes.

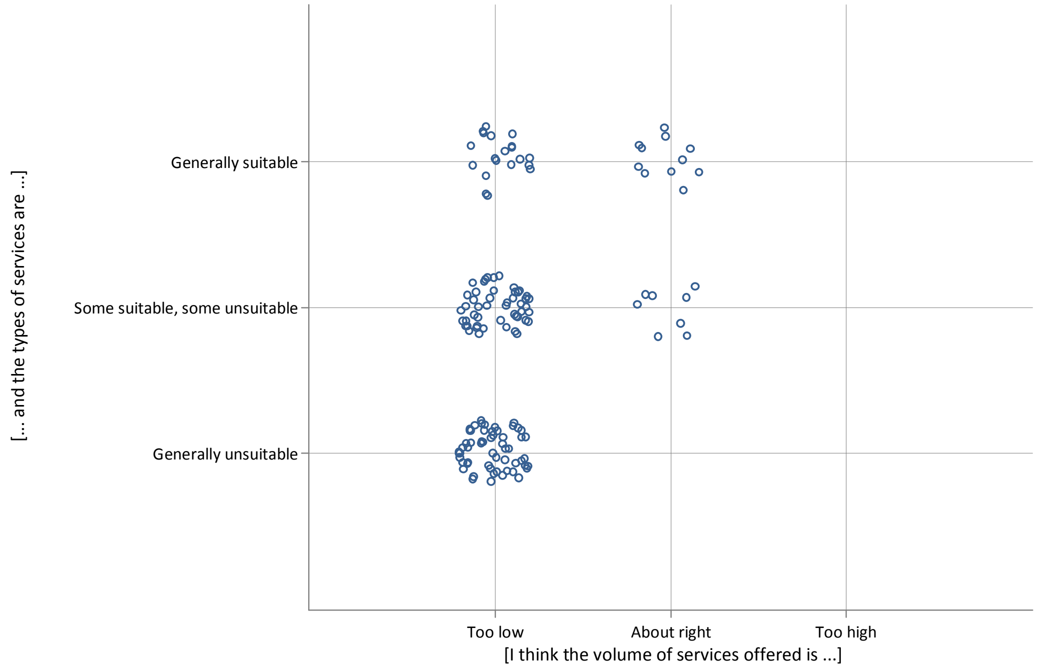
Source: LE Wales Carers Survey

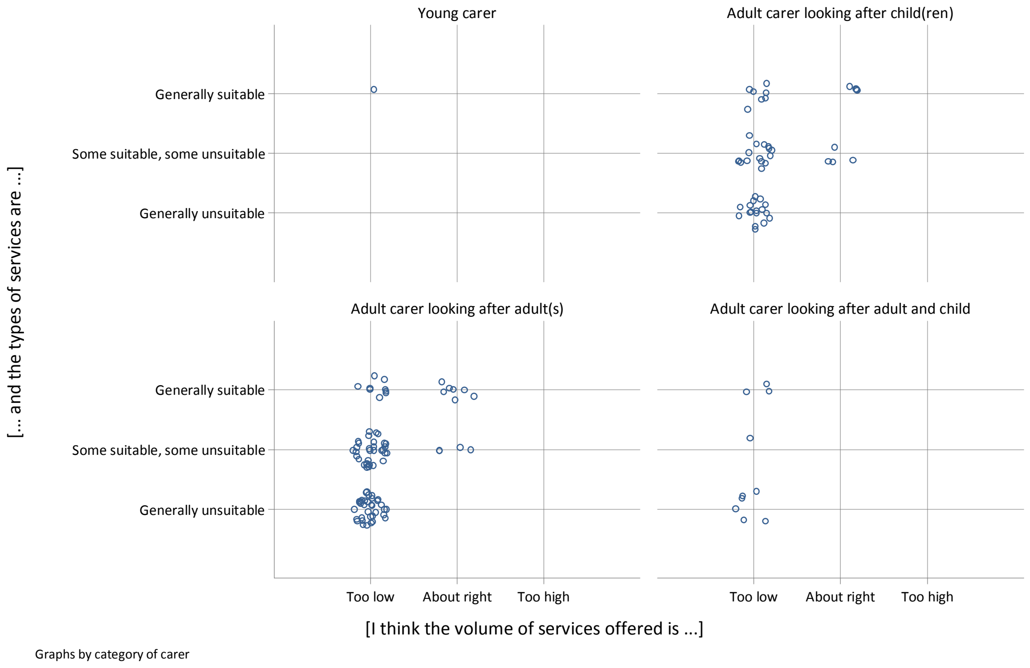
A4.5 Overall opinions of respite services

Respondents were also asked to give an overall opinion on the volume and types of respite care services available to them. Their responses are summarised in Figure 30.

The results show that the large majority of respondents of all types thought that the volume of respite services available to them was too low. When asked about how suitable available services were, responses were more mixed though it is clear that many more respondents thought that the available services were generally unsuitable than thought that they were generally suitable. A large number also thought that some were suitable and some were not.

Figure 30:Overall opinion of carers of respite services provided





Source: LE Wales Carers Survey

A4.6 In the words of carers

The last part of our survey asked carers to provide us with their views of respite care services in their own words. The question was:

Are there any ways in which you think the provision of respite services could be improved? Please describe any shortcomings with the current provision.

We have provided below the anonymous responses to this question. They describe the situation in which carers find themselves much more eloquently than we have been able to in the remainder of this report. They are worth taking some time to read through.

1. Cael mwy o gymorth seibiant - does na ddim digon o adnoddau gan yr awdurdod lleol na'r bwrdd iechyd. Roedd y wasanaeth a chafon ni (dwy flynedd yn ol) o safon uchel.
2. During the past 12 years of caring for two disabled people we have not had ANY respite or any help, all the professionals do is fill in forms which in turn just becomes yet another paper exercise. Help for carers and disabled people is a JOKE!
3. Mae angen amrywiaeth o ddewisiadau gwahanol ar gyfer unigolion gydag anabledd dysgu ar draws y sir ac nid yn unig yn Arfon. Gan nad oes digon o ddewisiadau does gennym ddim dewis ond i ddefnyddio ein cartref fel bas i wasanaeth dydd fy mab. Mae'n rhaid cofio bod ein cartref yn gartref i bob aelod o'n teulu - ond ar adegau dydi o ddim yn teimlo fel ei fod.
4. mwy o hyblygrwydd - dewis pryd, lle a sut math o ofal a derbynnir. Consistency efo'r pobl sy'n darparu gofal - yr un gweithiwr ar gael neu'r un cyswllt. Rhywfaint o ofal munud-olaf ar gael pob blwyddyn er mwyn delio gyda crisis/argyfwng.
5. Nid yw'r dewis yma ar gael sef hospis plant sydd wedi rhoi y gofal a'r gefnogaeth fwyaf i ni fel teulu - mae'r gwasanaethau gofal ysbaid eraill wedi achosi mwy o bryder i ni oherwydd safon y gofal a'r ffaith fod angen cwffio am oriau. Gresyn nad yw hosbisau plant yn flaenoriaeth cyllido gan y Cynulliad.
6. my mother has to pay for her own care and so that her funds don't run out, we have had to limit the care to enable the care to continue into the future
7. Respite provision for children with challenging behaviours is nil. The stress of caring for a child with these issues affects the whole family and support should be available for siblings of the child as well as the parents. Caring for a parent who is now beginning to need more caring responsibilities and knowing how to access services is crucial. I have registered with Wrexham Carers Service who have provided me with a lot of support and have been able to help me with various issues I have encountered. There are occasions when caring needs have suddenly been forced upon you due to a sudden illness and when you have a family to care for which includes a child with behavioural issues then all sorts of problems raise their heads.
8. The problem with this kind of survey is that it will only give you the answers to the questions that you ask. My wife and I are carers for each other and at the moment are able to meet each others needs, but I can see the time coming that this will change in the not to distant future. Thank you for your interest.
9. There is very limited respite services available for children with physical disabilities, due to equipment shortages. Similarly for children with mental health issues, there is a severe lack of provision available. It would be useful to have a short break residential facility for children.

10. For me , one or two nights off a week would be of great help so that I could catch up on sleep. As my father is so confused , he would need to be cared for at home.
11. It seems a struggle to find out how to access respite care. You need to arrange a good while in advance and when you feel most in need there are no places available.
12. More help getting ready for school, some after school activities. Some overnight care so we can have a break as he is a bad sleeper.
13. To actually have the chance to have respite would be a bonus as it seems to be non existent in Cardiff
14. Services provided are unable to fit around the carer/cared for needs; services need to be made more flexible to the cared for and carers needs and issues. Although carer organisations are extremely good; finances/resources are not available for them to work to the best of their abilities.
15. More opportunities to be flexible with time of service
16. the waiting lists are far too long. Matching a family to link with my child proved difficult. It has proved difficult to find someone we trust to look after our daughter for overnight stays although we desperately need the break.
17. I have 2 boys with autism, both receive high rate dla for care and mobility and sen's. I have no support from social services, and was told I do not meet the criteria for respite. I have also received poor advice on direct payments from social services ranging from 'here's the number, phone them yourself' to 'oh, you'll never qualify for that'. I think the service is poor in Wrexham, and I am sick and tired of trying to get help
18. There is total lack of provision where my mother lives for her to take part in any local social activities where she can get a lift there and not be treated as if she is an idiot as well as elderly. Other people seem to be scared of dealing with an elderly person if she is alone and not with me. She sometimes wants to go to an event, church service etc by herself without me and is capable to doing this if others take some notice and care of her. Local council services assume that I will, and can, do everything for my mother and so they do nothing, unless we pay full costs. They provide no support free and their care company charges £12 an hour which adds up and so we use them less to reduce costs. Respite care is not the problem so much as lack of basic care services to share the load.
19. sack all the social workers
20. There is just not enough respite available, although the person I care for has been granted an allocation of 28 days of respite per year, we have been unable to use this are there are no places for him
21. Would be great if there was more respite provided. Would prefer if transport could be provided out of school term as well as during, as the respite centre is 45 minutes drive (Mumbles, Swansea). Alternatively, provide a centre in the Neath Port Talbot area.
22. I currently get none and no offer of any.
23. It is now very difficult to get cover for medical/dental appointments from Crossroads, as their staffing has been drastically reduced over the last couple of years. It is therefore difficult to maintain my own health at a realistic level to ensure that my mother is appropriately looked after.
24. OUR DAY CENTRE CLOSES NEXT FRIDAY _ THEN I WILL HAVE NO RESPITE - NO TIME FOR MY OWN NEEDS. FACILITIES WERE PROVIDED BY CHARITY. THE COUNCIL SHOULD PROVIDE IN ALL AREAS< NOT JUST THE FEW IN LLANDRINDOD WELLS.
25. Unable to get a longer break
26. Direct payments is our answer. If parents can\'t push for it or are not eloquent other services were non existent

27. After school club not suitable for child with communication difficulties. Staff need more training and better supervision. Management needs to listen to parents
28. funding for the activity as I pay for my daughter to attend a special needs activity once a fortnight and in the holidays for a day a week, it is not a big amount but is still a struggle
29. GIVE RESPITE TO FAMILIES WHO HAVE TO WORK AND CANNOT GET BENEFITS BUT HAVE THE RESPONSIBILITY OF LOOKING AFTER SOMEONE DISABLED IT SEEMS ONLY THE BENEFIT PEOPLE GET IT AND THE ONES LIKE ME WHO HAVE TO WORK ARE LEFT OUT OF THE SYSTEM TO GET ON WITH IT. I HAVE NOT BEEN ABLE TO GO AWAY IN YEARS BUT MY BROTHER IN LAW AND FAMILY ARE ON BENEFITS AND GET RESPITE TWO TIMES A YEAR AND MY SON IS MUCH MORE DISABLED THAN THEM THE SYSTEM NEEDS TO FOCUS ON THE REST OF US NOT THOSE ON BENEFITS I HAVE TO WORK TO KEEP MY HOME
30. more and longer
31. There is no money to access respite care either for carers or cared for
32. I don't know anything about what’s on offer. That's got to be the main problem- no information and difficult access to information
33. Major problems going from children’s to adults services despite all the rhetoric about transitions
34. Too great a burden to organise before and after any break
35. The funding seems to be very good, but the availability of services is very poor. Some of this is inevitable in a rural county with a small population (we have great difficulty finding people to do respite care, especially overnight, which we greatly desire but have not been able to access because of lack of provision rather than funding--as I understand it. Frequent turnover in staff in the respite care section of the county\'s disability team (which is excellent) is also a problem, again for reasons that are entirely understandable (but this impacts on access to services).
36. We have two hours a week project worker, which is inadequate, as our son is getting older life becomes harder, as parents we are getting older, our friends and family's children have all become independent and we remain with our son whose needs are the same of a toddler. There seems to be very little in support and care for carers, sometimes help such as traditional home help would be valued, help with laundry etc. We don’t see any improvements in our situation as funding in the next few years is going to be very limited due to the current economic climate. we are depending on our daughters to care when we as parents want to go away on a weekend break(which is once a year)which is unfair for a 20 and 19 year old.
37. Offer respite services appropriate to the person\'s needs, including increasing disability respite. There is nothing for adults with an average IQ who have autism regardless of useful -intelligence and self-care/life skills, and equally nothing for people who care for more than one person- not even Carers Allowance .
38. The biggest problem is financial. To pay towards the cost of weekly care leaves no money for the carer to take a break away from home.
39. There appears to be no respite care at all unless the case becomes an emergency. My son does attend the Saturday club but this has recently been reduced from fortnightly to only once a month and is not really suited to physical as opposed to learning disabilities so does not enable him to build meaningful relationships with other participants. The worst times are when I become ill as there is still simply zero help and the same amount of work.
40. Very difficult to access in the first place. My son has Mental Health, Serious health needs as well as his learning disability, I had to refuse to have him home from hospital so that I could access Direct Payments to pay for respite services. I work 30hrs a week , I had

several weeks off because of my sons illness, I was in danger of loosing my job. It caused my son and myself huge distress.

41. No choice
42. I don't need overnight respite care for my son and find it difficult to trust other people but he would benefit from after school and holiday activities that would allow him to do things with other children his age and younger people and not always be with his family.
43. Day centre is fine for the cared for, but it is only late morning to mid afternoon; really not enough time for me to take part in some other formal activity. Then cost of residential care is ever a consideration that limits the ideal.
44. My son will be 18 in November and is physically disabled, I find it unbelievable that come November there will be no respite services available to him because he is physically disabled, if he had a mental disability there would be. The amount of children/young people that will not be provided for in rhondda cynon taff is astounding. Why does this happen in this day and age? By the end of a week I am exhausted, all the help I get at the moment is 2 nights of respite every 6-8 weeks, come November it all stops, what do I do then, I take it just carry on till I drop, then who will take care of him??????
45. We don\'t receive any so have no experience, it would be lovely for our seven year old daughter to have some appropriate after school or holiday play activities.
46. to not receive magazines about children in care would be most helpful; being listened to; carers doing what I do.
47. We do not get to choose when they go to O/N respite facilities. The staff are poorly trained in specific disabilities (although I have offered to run training sessions it has been ignored) There is a general lack of understanding of what makes my boys 'tick\ and what upsets them. And the funding provided is inadequate for staff to do much with them.
48. More frequent better staff and not having to fight for these services
49. My mother is about to go into respite care for the first time, but I have just been told that respite care will be cut out for everyone except those who are on the highest level of 24 hour care. She is 93, registered blind and has limited mobility, and we cannot find any professional carers to come to our farm, but really need a break form time to time.
50. We should have children services like England have set up!
51. our local sp needs school had a respite facility attached for year. It was closed because of govt guidelines stating that it must gain 'proper status' which means a very expensive ticket to say it is what it is!!...the school could not afford it, especially after having their school budget cut. why do people keep being asked for views after the event of disaster? the problems in services are transparent, the carers know it because the local providers usually have to come clean and say that its a miracle if you get anything, so what's the point to all this? I hope the govt don't use it as another way of means testing people out of benefits and the meagre services they may already have. I have recently bee awarded 15 nights respite a year and need to open a separate ac for it..i am constantly declined because i am on a low income, so, after 13 years of 'caring' i see respite in sight and still cannot access it...its a sick joke, no wonder people don't bother asking!
52. I don't know what respite services are available. My wife has dementia and the amount of care over the last three years has gradually increased and I have only recently started to think about respite services. I am unable to give a proper informed answer to the last 2 questions
53. Would like the option of a holiday club for Autistic children
54. My son is in receipt of a direct payment care package and we therefore organise his own respite. If we did not have a financial support care package, the volume of service would

be too low and generally unsuitable. We are happy with the way things are although it would be nice for the service user to engage in activities with young people of his own age.

55. having to mange wages in relation to the direct payments
56. Emergency cover when required
57. The services are there if you have a child aged 8 or over. If you have a disabled child under this age, the support isn't available (other than direct payments).
58. After initial contact when we saw social worker and banister and hand rails were fitted we are told we have to wait 12 months for a further assessment visit for direct payments, This is not good enough! At the moment I am sole carer for my husband and can get no help whatever, he has many Disabilities physical and mental.
59. My son was diagnosed with Autism and i have not received any offer of any help at all from my local authority. So i would like to see it improved by them actually offering their services to carers.
60. More respite in the home and in particular end of life
61. Away from home overnight respite service has a current 3 to 4 year waiting list. We have direct payments, but that means we always have people in our home and we never actually have a 24 hour break from caring (we may have help with the physical side, but we do not have a mental break). To even have one weekend off twice a year would be so wonderful. We have 2 other children and this would allow us to do other activities (we cannot do some activities because our disabled child cannot do them, therefore we don't do them, or it is too physically tiring to include our disabled child, eg going swimming with a disabled child is time consuming and tiring) with them and give them our time.
62. i have no had the opportunity of trying any of the services mentioned as until this survey, i had no knowledge that they existed
63. My mother does not qualify for any care as she is too well off
64. More times for cared-for person to access activities for own age and be accompanied by someone their own age. We are both in our sixties and do not have the energy at the end of the day to take the person, who because of going away to a residential college has had a very good social life with peers will miss out, causing us guilt feelings and a feeling of helplessness. We would like whole days respite, rather than hours as they fly by so quick.
65. Tried residential respite and respite at home between 2004 and 2007. Was so poorly organised and provided that other when I am at work do not have assistance with care. Have refused respite since 2007
66. The service is provided by a private company who use a bank of people, over the last year we have had 4/5 different support workers. It would be nice if they would allocate 1 worker so a relationship of trust could be developed with our child and us.
67. Better Access to what may be available, even when we fill in carers assessment nothing ever comes of it especially in mental health.
68. Services are not based around the carers specific needs or the specific needs of the cared for person therefore carers need to be listened to ensure respite that is provided is \'appropriate\' and meets the needs of both carers and those cared for, otherwise respite causes more problems than it solves for the carer. Carer's Assessments need to be more specific in describing the carers need for respite services. Respite care is offered but it is taken away again before the carer receives the respite care, this should be avoided at all costs.
69. We have no respite services, how does one find out about them? The two last responses are a reflection of that. There were no 'None' boxes.
70. not too sure how to respond to this part.

71. More availability of home care services would be a great help to me in terms of times that they were available.
72. Accessibility not as good as it could be. Cost can be high if residential respite as this is not counted as carer need for charging. Not always easy to access when carers do not live with cared for person.
73. IN MONMOUTHSHIRE THERE IS VERY LITTLE PROVISION. THERE IS A RESPITE CARE HOME IN THE SOUTH BUT WHEN YOU HAVE A CHILD WITH VERY LITTLE COMMUNICATION AND VERY VUNRABLE YOU DO NOT FEEL SAFE LEAVING YOUR CHILD THERE. IT IS NOT IN A VERY NICE AREA A LOT OF DRUG ABUSE. WE DO NOT EVEN HAVE A SCHOOL IN MON. FOR CHILDREN WITH SEVERE LEARING DIFFICULTIES THEY HAVE TO GO TO SCHOOLS IN OTHER AREAS AND THAT IS WHERE I AM ABLE TO SEND MY CHILD FOR PLAYSCHEME AT HALF TERMS AND ONE WEEK IN THE SUMMER. IT IS ABOUT A 50/60 MILE JOURNEY. I FEEL IN MON. WE ARE VERY LET DOWN WITH RESPITE CARE. I AM ALLOCATED 1.25HRS A WEEK. YOUR QUESTIONAIRE IS DIFFICULT TO ANSWER AS THE RESPITE CARE IS WHEN MY CHILD GOES TO SCHOOL AND I USE MY HOURS EVERY 2WEEKS FOR MY CHILD TO BE TAKEN OUT FOR 3HRS.
74. 5 years ago I contacted Social Services and asked for 1 week respite per year via Direct Payments so that my husband and I could leave my son in the care of someone of our choice and go on holiday. I was assessed as a carer and refused.
75. Week long holidays would be useful, to properly recharge batteries to carry on with caring.
76. Information about provision difficult to locate. Difficult to access- not enough variety. limited provision. In some instances there may be an adequate service poor staffing ratio. In many cases not person-centred. Address these issues and then there may be an adequate service.
77. I have no idea what is available, other than through the Charity Crossroads. I've been waiting weeks for a Social worker to visit to assess our needs, & understand the O.T. assessment may take even longer - possibly up to 18 months!!
78. great lack of suitable facilities and care in he Carmarthenshire area
79. I have had to make repeated requests for help over a number of years when feeling very desperate and exhausted with the level of care needed for my son. It took my husband threatening to leave me and therefore my son would have had to be taken into care as I would have been unable to cope on my own in order for my local service provider to offer the amount of support I am currently receiving. This current support is making a big difference to my ability to cope and keep my whole family happy and together. I am told that this support is temporary. I wish it had been available for a long time and I very much hope it is not taken away from me. There is always this worry and pressure.
80. There should be a more rapid response for requests for respite care, also one should be able to select a preferred care home and have funding, if only a top up, even if the care home is a private one not directly contracted to Social Services.
81. Would have preferred a weekend service as one overnight on the week does not allow us much opportunity to spend quality time with the other two children, which was the intended aim of the respite care.
82. not enough specialist respite carers
83. Social services do not listen to Carers. Social workers just expect relatives to do the caring without offering any support. Social Workers and Doctors Bully relatives into looking after disabled relatives without giving the carers sufficient information. Social Workers do not care about Carers.

84. Options to suit individuals, we are entitled to help but the help we are offered does not fit in round schooling etc so we miss out. Therefore it would be good to be able to choose the help that is offered in the form of direct payments or finding respite care that fits in with child's lifestyle.
85. My son has mild learning difficulties and just needs someone to pop in for an hour or two to see if he has taken his meds and has eaten (perhaps help make a meal), if my husband and I go away overnight or few days. At the moment his sister helps out, but we have to arrange any trips around her work etc. We have to phone home to make sure he is up and gets to work (voluntary). So you don't really switch off and relax, sometimes seems pointless going away! He does get 6hrs with support worker every week, but she wouldn't be able to call in daily as she has young family. We have tried respite care, but he is not happy with it and having to leave his home and go out of the area.
86. In the Vale of Glamorgan only children with an IQ of below 70 get respite, my daughter has severe autism yet does not receive respite.
87. in my circumstances i care for a young adult with severe epilepsy, learning and behaviour problems. i find it increasingly difficult to care for him and suffer with exhaustion. respite care is invaluable but i can only have 5 nights and then have to wait 28 days before the next break. we cannot access any other services because of the complications around his problems. if we have extra respite then we lose some of our benefits and we cannot afford to do that. i sometimes think it would have been better to have put him into care as this is not a life and nobody seems to care what happens to us full time carers anyway.
88. My son has an IQ of over 80 hence he does not qualify for help from children with disability services nor does he qualify from help from children's services as he is not at risk. He is not alone. He has ADHD and Aspergers Syndrome and they seem to be a very "grey" area when respite provisions are provided. I am a single parent of 3 and work to support my children. I often feel isolated and let down by the system. Come when he goes to comprehensive school this Sept he no longer qualifies for a playscheme place that I already pay for at a cost of Â£16 per day , as he is too old. No childminder will take him as he has complex needs. What can I do then but give up my job and live on benefits. My only respite, besides the 2 hours a week of direct payments, is going to work. I use my 2 hours a week of direct payments to do something my other 2 children choose often leaving my need for respite ignored.
89. BOOKABLE respite nearer to home and in Powys, at present the only 1 bookable respite available in a nursing home is in Shropshire
90. We need a break for quality time together instead of me being tired after doing all the household jobs. In a hotel for a couple of days. just being on holiday normally. Shortcomings-it's hard to access the information needed
91. my child is constantly with me, she would love to spend some time away from me, even a couple of hours to be with people her own age group. every time you ask her social worker for support. oh there is no funding and anyway you take her out five nights a week, yes i do as her passion is swimming, but she is not socialising with her peer group as swimming is a solitary sport. she is losing out on the rights to her teenage years, because of her profound learning disability. i cannot remember the last time i went out at night without her, as i have no one to look after her.
92. more choice of types of respite according to the needs of the carer and the lifestyle. In Denbighshire there is NO respite care for carers , the belief of the service providers is that if the cared for is say in hospital this counts as respite for the Carer!! completely not understanding that the carer will choose to visit and worry when not visiting, guilt belief

sets in for the carer that they could have done more to prevent hospitalisation (but not true) this is perhaps just one example of how respite care for Carers is viewed in Denbighshire(also lack of funding is another reason given) Government needs to provide specific funding for this support as if the carer caves in through the caring role the cost to the services would be HUGE.

93. I need help to support me in the daytime as my employment is frequently compromised. Support to my employer so I can have paid time out for regular appointments, or emergency provision that can be bought in for college holidays would be helpful. I\'d like a rest through respite, but I need my job a lot more and paid support for that is a real problem for me to organise.
94. A larger service to a wider range of disabled children, high functioning autistic children seem not to be catered for. LACK OF GROUP ACTIVITIES such as youth clubs and Saturday clubs to help them socialise and feel less isolated. MAINSTREAM children have various activities provided e.g. clubs, swimming and team sport and disabled children are denied access to them mainly because of lack of supervision. ARE DISABLED CHILDREN not entitled to make friends and have fun without having their carer present.FOR 10 YEARS PEOPLE HAVE said how unfair it is that our son cannot access swimming without his father yet are easy but action nothing has altered even after attending many meetings. Platitudes are easy but action requires a lot of effort.
95. More of the same please
96. Lack of availability and choice for older people in residential respite care.
97. The overnight care is exactly that and not for 24 hours. During school holidays arrival time is 14.30hrs and departure is 13.00hrs the following day which is fine. But during term time children arrive at 15.30hrs and depart at 08.30hrs the following morning because they are attending school. so you get one evening off and perhaps an hour to yourself in the morning of the day your child is due to return home.
98. Provision of Carers Allowance in ADDITION to my State Pension to assist in allowing me to choose and afford my own system of targeted respite service.
99. Overnight on call social care to cover nights when carer away from home.
100. There are no provisions for weekly overnight respite - sometimes we just need to know we are going to get one decent night\'s sleep
101. We in RHYL DENBIGHSHIRE DO NOT HAVE RESPITE CARE for cared for if they have a MENTAL HEALTH PROBLEM AND THEY ARE UNDER 65 ALSO most have physical and mental health conditions. There is no crisis intervention, although the authorities claim there is a \"care pathway approach\" I have asked social workers for respite care for the cared for to no avail. I await the outcome of my complaints to social services, I have waited x3weeks since I first complained and 11 yrs for respite care. I have begged for help but have been told that there are no beds for respite for under 65yr olds in nursing homes anywhere in Denbighshire. My carers assessment claims that I cannot continue giving care at the same level.....
102. The boxes about care received don’t fit into the type of respite we have. Crossroads provide a carer who takes our daughter out and we ourselves are able to go out. Our daughter goes to a resource centre 2 days a week plus vol work with support so we don’t feel answers give true picture for a survey but we had to fill them in to carry on questionnaire. Because of government funding we have recently been notified that our respite is being cut which doesn't value the role of carers, sometimes there is a very fine line between coping and not and if family members cant cope the government will have an even bigger bill.

103. Lack of suitable overnight provision of dedicated respite beds.
104. The activity days out that I have selected are actually provided by a care agency (3 hrs per week, twice a week) which actually works out at under half a day every week. These sessions should be more frequent, particularly as my son is getting older and needs to be participating in outdoor activities more often. I also feel strongly that there is not enough service provision for older children and teenagers with special needs/disabilities in Cardiff and it is important that the assembly focuses on respite care for older children and teenagers.
105. I feel that the choice on offer to young adults is limited, there should be more emphasis on integrating people into mainstream work opportunities and leisure facilities.
106. providing different aspects of respite to suit different circumstances
107. Don't know, at the moment my wife is happy as she is, and would not be happy to have anyone standing in for me. I have to honour that.
108. Lack of funding for specialist charities to provide good quality Dementia care within the cared for persons home. When using residential care the cost is now prohibitive.
109. Very little for people with MS in the area. Carers Allowance could be increased to help me do more things with my wife. Services could be better funded to allow me to have more care in the home for her.
110. Judged through the type of need of the person being looked after and not by the needs of the carer. Difficulties always arise because of the previous relationship between the carer and the cared for especially if the cared for person refuses services.
111. There are no short-comings in the care provided. The persons involved are always exactly what is needed - friendly, reliable, patient, competent and good-humoured. The system is a godsend for me. I would like to be able to get away more often as a grandmother, with 4 children and 8 grandchildren, and keep in touch with the little ones as they grow. Ceredigion is far from them all. An occasional long weekend is what is needed, but the local Crossroads service is very stretched, and I do not like to impose, especially for overnight relief. If they had more resources I would have more of a family life. My husband is immobile.
112. Carers like myself who are on their own and whose cared for is very high dependency often can't manage to do simple things like going out to do their shopping, paying bills, going to doctor etc. There should be a system where of a short period during the day where they could do essential items even if it is only for half an hour. With the number of single children families the situation will only become more acute with time.
113. At times of family bereavement some extra help might be appreciated
114. WE NEED QUALITY TIME TOGETHER AS I AM SO BUSY DOING DAY TO DAY LIVING THINGS THAT I AM TOO TIRED TO SPEND TIME WITH MY HUSBAND. A WEEKS HOLIDAY IN A HOTEL A COUPLE TIMES A YEAR WOULD GIVE US A BREAK.HUBBY HAS MENTAL ISSUES AS WELL AS PHYSICAL AND SENSORY ISSUES. SURVEY DOED NOT ALLOW FOR THAT ANSWER. I LOOK AFTER HIM 24/7 AND HAVE DONE WITHOUT A BREAK FOR 3 YEARS!!!!!
115. I would not want to leave my husband with someone else -- but extra money may allow us to buy in extra help ie. to pay for some help with house work and cleaning

Annex 5 Discussions with stakeholders

This Annex lists the stakeholders we spoke with over the telephone and face to face during this research and provides the topic guide that we used for telephone interviews.

A5.1 Telephone interviews

We held formal telephone interviews with a range of organisations and individuals active in respite care issues in Wales over the period between June and September 2010. By 'formal' interviews we mean that discussions centred around a topic guide that had been sent to interviewees in advance of the discussion. Formal interviews with people working at the following organisations took place.

- Hafal
- Care Forum Wales
- UK Home Care Association
- Abertawe Bro Morgannwg Health Board
- Stroke Association Wales
- Care & Social Service Inspectorate Wales
- Crossroads Care Wales
- Carers Wales
- MS Society Cymru
- Contact a Family Wales
- Barnardo's Cymru
- Ategi
- Shared Care Network Cymru
- Powys Carers Service (affiliated to Princess Royal Trust for Carers)
- Neath Port Talbot County Borough Council
- Vale of Glamorgan County Council
- Wrexham County Borough Council
- Children in Wales
- Age Concern Gwent
- British Medical Association Bro Taf Local Medical Committee
- Action for Children
- National Autistic Society Cymru
- ABCD (Access for Black and minority ethnic Children and young people with Disabilities and or chronic illnesses)
- Fostering Network

In addition we had other discussions, either face to face or on the telephone with a number of people/organisations. Although these discussions did not centre specifically on the topic guide similar issues relating to respite care were discussed. These discussions were held with people at the following organisations:

- Carers Learning and Information Network of the Welsh local authorities
- Job Centre Plus Wales Regional Care Partnership Managers
- Gwent Frailty Programme
- North West Wales Carers Outreach Service (affiliated to Princess Royal Trust for Carers)
- Carmarthenshire County Council

- Health Inspectorate Wales
- Hywel Dda Health Board

A5.2 Topic guide for telephone interviews

Topic guide for LE Wales discussions with stakeholders on respite care services in Wales

LE Wales has been commissioned by the Welsh Assembly Government to undertake research into the provision and demand for publicly-funded respite services in Wales. We are seeking to put together a picture of the range and volume of publicly-funded respite care services provided across Wales and on the views of carers and other stakeholders on whether existing services meet their needs in terms of types of service available, quantity and quality.

By respite care, we mean services aimed mainly at carers and that allow them to take a break from their caring responsibilities. These services are sometimes also known as replacement care or short breaks. By carers we mean informal carers who provide unpaid care to friends or relatives. We are interested in adults and children as both carers and care recipients. We are principally interested in carers that provide a substantial amount of regular care.

We are consulting with stakeholders through several means. We are meeting a number of carer groups across Wales; we are organising an online survey of carers in Wales; and we are undertaking a number of telephone interviews with stakeholder organisations.

The online survey for carers will be open from Thursday 17 June 2010 to Saturday 31 July 2010 at the following links.

English:	*http://survey.londecon.co.uk/index.php?sid=88268&lang=en*
Cymraeg:	*http://survey.londecon.co.uk/index.php?sid=56835&lang=cy*

LE Wales are due to report to the Welsh Assembly Government in Autumn 2010.

Proposed telephone interview structure:

1. Introduction to LE Wales and contract with WAG

2. Interviewee's role in respect of respite care
    a. Expertise in any specific group of carers/care recipients?

3. Discussion of how useful respite services can be to carers.
    a. How important are they?
    b. Are there other services for carers that are as important?
    c. What are the main benefits for carers?
    d. What are the impacts on care recipients?

4. Discussion of the range and quantity of respite services available in Wales

   a. Is there a sufficient range and quantity of respite care available to meet the needs of carers in Wales?
   b. Are there particular types of service where there are more shortages (e.g. holidays, activity days, sitting services etc)?
   c. Are there particular locations in Wales where there are more shortages?
   d. Are there particular types of carer/care recipients whose respite care needs are particularly poorly addressed (e.g. mental health problems; learning difficulties; physical impairments; children etc)?

5. Discussion of the quality of respite services available in Wales
   a. Do carers have concerns about the quality of respite care available to the people that they care for?
   b. What types of concerns do they have?
   c. What could be done to overcome any quality problems?

6. Discussion of barriers to take up of respite services, e.g.
   a. Lack of information about services
   b. Lack of services
   c. Unsuitability of services
   d. Cost
   e. Language or cultural barriers
   f. Best route into learning about respite care e.g. via social services/GP's/other
   g. Role of direct payments as a mechanism for accessing respite care e.g. to overcome less flexible statutory provision

7. What measures could the Welsh Assembly Government take that would most improve respite services for carers across Wales (bearing in mind the current public expenditure constraints)?
   a. Examples of good practice in Wales?
   b. Examples of good practice elsewhere?

8. Other comments

9. Suggestions for other stakeholder organisations appropriate for this study?

10. Thanks and close

A5.3 Face to face discussions with carers

We held face to face discussions about respite care with a number of groups across Wales during the period June to September 2010. The groups we met were:

- carers from minority communities attending an Upna Centre group in Cardiff;
- carers of people with mental health problems in South Powys (organised by Powys Carers Service);
- MARG in Carmarthenshire, a mixed group of providers of services for carers (LA, health board and other) and carers;

- A mixed group of carers in Conwy, organised by North West Wales Carers Outreach Service;
- A group of young carers from Ceredigion who were on a respite break in Hampshire (organised by the Shared Care Network);
- A visit organised by the Red Cross to two families in the Bridgend area including parent carers/young care recipients;
- A mixed group of carers in Gwynedd, organised by North West Wales Carers Outreach;
- Attendees at the Butterflies after Stroke Group in Ewloe, Flintshire, both carers and care recipients.

Discussions were held through the medium of English except for the group in Gwynedd, where the discussion was held through the medium of Welsh. The format for the discussions was generally a brief introduction to the research by a member of the LE Wales team followed by an open discussion on what members of the group though were the main issues of importance to them.