Appraisal of carer services in Somerset

Final report

Peter Fletcher Associates
July 2010
Appraisal of carer services in Somerset

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Appraisal of carer services in Somerset

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Acknowledgements

We would like to thank the many carers, staff and volunteers who have given their time to provide us with information and feedback about carers’ services in Somerset in carrying out this review. A list is provided in Appendix 5.
Executive Summary

Somerset County Council and NHS Somerset commissioned Peter Fletcher Associates (PFA) to undertake an appraisal of services for carers against the Somerset Multi-agency Carers Strategy. The review was undertaken between September 2009 and May 2010 and covered carers of all ages who where supporting all service user groups.

The population in Somerset is 530,000 of which there are over 50,000 carers within Somerset providing varying levels of care. This represents approximately 9.43% of the population of Somerset. It is estimated only 7,000 of carers are known to statutory agencies in Somerset, which leaves a possible 43,000 unknown carers. The older people population in Somerset is set to grow markedly in the future with a 35% projected increase in people with dementia over the next 10 years. Similarly the numbers of carers aged 85 plus providing unpaid care will increase by an average of 41%. Approximately 1,650 adults with learning disabilities are supported by the Somerset Adult Learning Disability Service of which approx 42% people remain at home with parents or carers. There are approximately 3,300 children under 18 years old living in Somerset who have been assessed as being “in need”.

Research by Carers UK, suggests carers save the UK economy over £15,000 per carer each year. The cost of not supporting carers in Somerset would equate to over £750m per year to the wider economy. The cost of replacement residential care for the those carers in Somerset who provide more than 50 hours per week (20%) is estimated to be approximately £312m set against a 2009/10 budget of approximately £6.47m in all carers services. Investing in carer services, even in the current financial climate makes sound financial sense and supports the “Putting People First” prevention agenda.

Rurality and low population density presents challenges for carers due to difficulties with transport, accessibility of local services, and employment opportunities, all of which will need to be taken into account when developing the best model to meet the future needs of carers in Somerset.

The Somerset Multi-agency Carers Strategy was developed following the introduction of the National Carers Strategy in June 2008. There are a number of national and local policy drivers which impacted on the appraisal.

The appraisal was undertaken by a team of consultants from Peter Fletcher Associates based on an agreed project plan supported by a small Carers Advisory Group which was set up for the appraisal. The appraisal was overseen and the

2 Somerset Multi Agency Strategy 2009
3 POPPI information system Dept. Health
4 Source: Somerset County County Council
5 Source: Somerset County County Council
quality monitored by a Project Management Group which comprised of representatives of statutory agencies, community and voluntary sector and a carer. Progress was also reported to the Carers Strategy Group. As a basis for the review PFA drew upon The Kings Fund Quality Standards for Carer Services and the National Carers Strategy: Carers in the 21st Century.

The review team were asked to consider the following issues:

- Are services delivering what carers actually need and the priorities set out in the Somerset Carers Strategy?
- Consistency of carer experience
- The current assessment, care management and review process
- Value for money
- To make a minimum offer to carers as a universal service
- A comparison of services provided by other local authorities with a similar demography to that of Somerset, highlighting opportunities to share best practice

The review was structured in such a way as to put carers at the centre of the process and included:

- A review of best practice nationally in terms of service models which included contact with ten other local authorities
- Mapping of existing service provision in Somerset
- A questionnaire survey of adult carers with a separate questionnaire for young carers
- A series of semi-structured interviews and meetings with key stakeholders including hard to reach groups
- Five stakeholder workshops to feed back on initial consultation and consolidate a suggested model for Somerset with recommendations and priorities

The review undertook a widespread consultation and appraisal of carer services with approximately 1,500 carers being contacted and in the region of 850 direct responses via questionnaire and face to face meetings, as well as feedback from voluntary and community organisations and staff involved in the provision of services to carers.

Somerset has over recent years developed a range of high quality carers support services. These services were often cited as innovative and leading in best practice. Examples include Carers Support Workers, Carers Assessment Workers, a network of carer support groups, a Carer Assessment process, recent GP pilot, a full-time carers lead and a Somerset Multi-agency Carers Strategy.
However, services for carers across the county were described as patchy with variations in the level and quality of service dependent on where someone lived. The review noted a lack of a single specialised reference point for carer information in Somerset that is easily accessible by all communities. The majority of carers wanted to access information and advice more locally e.g. via their GP practice and without necessarily being assessed. The need for formal assessment to access many services was off putting to many carers.

Carers often feel undervalued, lacking influence, recognition and excluded from decision making at a strategic and individual level.

When researching other areas, greater choice regarding assessment routes had proven valuable, with a more proportionate approach which prevents carers coming into contact with the statutory sector unnecessarily. Support for young carers, parent carers and carers of people with learning disabilities and mental health is better linked to mainstream carer provision and carers have a voice on local carers forums and a strong Carers Partnership Board.

In Somerset, for the small number of carers who are supported by specialist carer workers, there was a high level of satisfaction. The face to face contact and emotional support provided by a trusted professional was highly valued by many carers; this was cited as one of their highest priorities both on a planned basis, and also in crisis. Many carers valued the support of other carers and wanted to be able to contact a known person to be able to talk to at times of crisis. Financial support and the difficulties with maintaining employment featured highly in carers’ day-to-day concerns.

A break from caring was considered the most valued service. Some carers felt breaks could be provided more flexibly, and carers themselves should have more control over the type of break and the booking arrangements.

Training for carers was considered useful and very relevant. However, not all groups within the community were able to access training. There were some gaps for carers of some specialist conditions, although it should be noted that these deficits are already beginning to be addressed, such as for drug and alcohol and carers of people with dementia. The role of the community and voluntary sector is significant both in terms of information and advice as well as support. However, this contribution is largely uncoordinated and could be focused better to provide a more comprehensive and accessible range of services for carers.

As a result of this appraisal it is suggested that the Somerset Multi-agency Carers Strategy (2008-2011) should be revised in order to ensure a higher probability that it will deliver better outcomes for carers within a reasonable time-frame. There are a total of twenty nine recommendations in the final report which include:

- A Carers Hub to be developed as a focal point for carers across the county
- Clear eligibility criteria for carer services
- Carers who meet the eligibility criteria be provided with an annual entitlement to fund a break
- Establish a Carers Partnership Board with an independent paid chair and the majority of members being active carers
- Improved carer assessment process to include a simple screening tool which a carer can complete themselves
- Changes to the role of Carers Support Workers in adult social care to be split between “assessment” function and “practical and emotional support” with the latter being provided by the new Carers Hub network

A financial modelling exercise took place as part of the review to ensure that the above recommendations were affordable and sustainable within the existing budgets and population projections. The appraisal identified a number of areas of duplication which could yield some potential efficiency savings. The PFA review team have a high level of confidence that should the recommendations be implemented, then the resulting changes will bring about improved outcomes for carers.
1. Introduction

Peter Fletcher Associates were commissioned by Somerset County Council and NHS Somerset to undertake an appraisal of carer services in Somerset. This report outlines the review of existing carer services in the County against the priorities set out in the Somerset Multi-agency Carers Strategy. The report provides analysis of the feedback gathered during widespread carer and other stakeholder consultation and provides analysis of research carried out into best practice across the UK with potential options for business models to deliver carer services in Somerset. The report was completed in two parts:

- **Part 1**
  The Interim report is contained in sections 1-7 and covers the work undertaken between September 2009 and January 2010.

- **Part 2**
  Section 8 onwards covers the work completed between February 2010 and June 2010 and includes the final recommendations.

The two reports have been combined to form the final report.

The brief for this appraisal required the recommendations to take into consideration the issues of:

- Delivering services which carers actually need and the priorities set out in the Somerset Multi-agency Carers Strategy
- Consistency of service user / carer experience
- The current assessment, care management and review process
- Value for money
- To make a minimum offer to carers
- A comparison of services provided by other Local Authorities with a similar demography to that of Somerset, highlighting opportunities to share best practice

On completion, Somerset County Council and NHS Somerset will consider the recommendations and begin to maintain/de-invest/re-invest carer services within the budgets available and in line with the Somerset Multi-agency Carers Strategy.
2. Background & Context

2.1 The National Carers Strategy

The National Strategy for Carers was launched in June 2008: ‘Carers at the heart of 21st century families and communities’. This highlights the need for carers to be respected as equal and expert care partners who have easy access to integrated and personalised services to support them in their caring role and sets out a ten year programme and vision of what should be in place for carers by 2018. The National Carers Strategy places a greater emphasis on a wider range of agencies contributing to the carer agenda, especially NHS Trusts, in relation to maintaining the carer’s health in order that they can continue to carry out their caring role.

2.2 The Carers Grant 2008-11

One of the key actions from the National Carers Strategy was the introduction of the Carers Grant to enable councils in England to increase the level of support that they provide to carers in children and adult services, particularly through the provision of planned carers breaks. The Department of Health indicate that the Carers Grant has three main purposes:

- To enhance the provision of community care and children’s services to allow carers to take a break, by stimulating greater diversity of provision
- To stimulate greater awareness by Local Authorities of the need for services to be more responsive to the needs of carers
- To provide carers with services other than breaks in keeping with the 2001 Carers and Disabled Persons Act

2.3 Other national policy drivers

Since 1999 there have been a range of national policy initiatives and legislation which further support the need for carer’s services to be in place. These include:

- The Disabled Persons Act 1986
- The 1990 NHS and Community Care Act
- Carers (Recognition and Services) Act 1995
- The National Strategy for Carers, 1999
The National Service Framework for Mental Health
The Carers and Disabled Children’s Act 2000
Carers (Equal Opportunities) Act 2005
Work and Families Act 2006 - further extended right to request flexible working for employees
Our Health Our Care Our Say - White Paper 2006
Drug interventions programme (DIP) Home Office 2003
We Count Too (2005) Good practice guide and quality standards for work with family members affected by someone else’s drug use
Every Child Matters - Department for Education and Skills, 2004
Putting People First, 2007
The Mental Capacity Act 2006
World Class Commissioning -Department of Health 2009

The Kings Fund Quality Standards for Carer Services

There are recognised quality standards identified by carer groups across the country which the Kings Fund7 published in 2000:

1. Information and Advice: information to carers, which is comprehensive, accurate, appropriate, accessible and responsive to individual need.

2. Providing a break: services offer breaks to carers by working in partnership with the carer and the person being cared for, which is flexible, gives confidence and can be trusted.

3. Emotional Support: either on a one to one basis or in a group setting. It is sensitive to individual needs, confidential and offers continuity and is accessible to all carers.

4. Support to maintain carers own health and well being - by offering training, health promotion and personal development opportunities and responsive to individual needs.

5. Having a Voice: supports carers to have a voice as an individual or collectively and is accessible to all carers. It is able to act in an independent way.

6 World Class Commissioning: Competency 3 - Proactively build continuous and meaningful engagement with the public and patients to shape services and improve health.
7 Kings Fund Quality Standards for Local Carer Support Services, February 2000
2.4 National Demographic context

The Somerset Multi-agency Carers Strategy is set in the context of the national demographics outlined by the Department of Health in 2006:

- There are around 6 million carers in the UK
- Every year 2 million people will become a carer
- 1.25 million people caring more than 50 hours a week are twice as likely not to be in good health as those who are not carers
- Three quarters of carers are financially worse off because of their caring responsibilities
- In the UK, 400,000 people combine full time work with caring for more than 20 hours per week
- Over 3 million people juggle care with work
- There are also estimated to be 50,000 young carers in the UK
- Carers save the economy £87 billion per year, which is what it would cost to replace them if they stopped providing care
- By 2037, it is estimated that the number of carers would have to increase by half to 9 million to keep pace with the rising levels of frailty and disability
- One in three carers are not able to return to work because the right alternative care is not available
- One in five carers is forced to give up work because of their caring responsibilities, losing on average £11,000 in income. This can lead to isolation and poverty
- 625,000 carers suffer mental and physical ill health as a direct consequence of the stress and physical demands of caring
- Carers Allowance – is just £50 a week for a minimum of 35 hours, equivalent to £1.44 an hour

2.5 Key Local Policy & Strategy

There are a number of local policies and strategies which have an impact on the Somerset Carers Strategy; most importantly:

- The **Somerset Sustainable Community Strategy** looks further ahead to 2025. It focuses on long term sustainability of Somerset and plans for future generations and how Somerset will fulfil its potential to become one of the south west’s most vibrant counties for people who live, work and visit
• The **Local Area Agreement** is a three year, countywide agreement by central Government, the local authorities, Government Office South West (GOSW) and Local Strategic Partnerships. The agreement identifies priorities for action to improve the most important issues in Somerset.

• **The National Service Framework** is the driver for ensuring service improvement and implementing strategy with developments via Local Implementation Teams\(^8\) and most have a carer representative, and/or links with voluntary and community sector organisations which represent carers.

• **NHS South West** requires self assessment and performance frameworks (including questions on carers – either identification or evidence at Carer Assessments are being offered) to be undertaken by all Primary Care Trusts on:
  - Mental Health
  - Long Term Conditions
  - Learning Disability

• **The Strategic Ambitions Framework for NHS South West** has carers referenced but currently no separate performance framework specifically on carers.

• **Position statement for joint commissioning for NHS Somerset and Somerset County Council**

There is joint planning and commissioning in progress by NHS Somerset and Somerset County Council around carers needs in each of the following strategies with cross cutting themes also listed below:

• **Somerset Dementia Strategy**
• **Self-Care Strategy**
• **End of Life Strategy**
• **Stroke Strategy**
• **Falls and Bone Density Strategy**

\(^8\) There are Local Implementation Teams for Mental Health; Long Term Conditions; Older People; Stroke, Coronary Heart Disease, Diabetes; Respiratory Disease; and Cancer.
Cross cutting themes:
- Extra care housing
- Assistive technology
- Sensory loss
- Home improvement agency
- Double-handling
- New initiatives with the NHS
- Equipment
- Care home planning
- You First – a programme of transformational change in health and social care

2.6 Somerset Multi-agency Carers Strategy 2008-2011

The Somerset Multi-agency Carers Strategy and Charter state that in Somerset, you are a carer if...

'If you give up your time, without pay, to look after a family member, a friend, or a neighbour who is ill, frail, or has a disability, then you are a carer.'

‘You may be a young carer, parent carer, or care for an older person or other adult with care needs.’

Source: Somerset Multi-agency Strategy 2008-2011

This definition does not cover paid care workers or people who provide care on a voluntary basis through a third sector organisation.

Carers are a diverse group with many people moving in and out of the caring role, possibly a number of times during their life course. Some may only provide care for a short time, whilst others may have caring responsibilities for a long period of their life, or the whole life of the person they support, for example parent carers. Caring involves, or has the potential to involve, each and every member of society.

2.7 Somerset vision

The Somerset Multi-agency Carers Strategy states that Somerset will provide a universal offer to all carers, self or publicly funded that means they can identify the outcomes they want to achieve in their lives, with the information and advice they want, to enable them to take control and have choice about how those outcomes are achieved.
Somerset County Council is developing a Personalisation and Transformation programme and the views and needs of carers are central to this. Opportunities will develop as the programme is implemented to access greater flexibility, choice and control to carers, whilst also ensuring that vulnerable carers are protected and supported around risk.

2.8 Key Objectives of Somerset Multi-agency Carers Strategy

The Somerset strategy sets out some key objectives based on 10 priority areas:

1. Information, Identification and Recognition
2. Assessments and Ongoing Support
3. Health and Wellbeing
4. Work, Leisure and Lifelong Learning – opportunities beyond caring
5. Giving Carers a Voice
6. Carers of those with Mental Health Needs
7. Carers of those with Learning Disabilities
8. Young Carers
9. Providing Third Sector Support
10. Equalities

2.9 Somerset Carers Strategy Group

The Somerset Carers Strategy Group is a Multi-agency network of commissioners, providers and carer representatives with broad priorities and objectives to ensure that the Somerset Multi-agency Carers Strategy is delivered and that services for carers meet their needs.

It was this group which identified the need for widespread consultation with carers and stakeholders of all service groups and an appraisal of the current service provision for carers against the strategy priorities.

Somerset Carers Strategy Group has seven broad objectives:

- To review evolving legislation, guidance and national policies relating to carers
- To provide the strategic direction for services for all carers across the county
- To co-ordinate effective and structured carers consultation
To make recommendations regarding the use of the Carers Grant
To develop, monitor and evaluate the implementation of the Somerset Multi-agency Carers Strategy

2.10 Somerset Carers Charter

There are two Carers Charters in Somerset:

1) The main charter devised by the Somerset Carers Strategy Group
2) The Somerset Partnership NHS Foundation Trust Charter for people using their services

There are four key principles contained in both these Charters which are:

- **Recognising your expertise and knowledge**: the carer’s role and expertise should be recognised and respected
- **Welcoming involvement in care planning** – carers should be involved in planning and agreeing the care plan for the person cared for
- **Responding to your needs as a carer**: carer’s needs should be recognised, responded to and reflected in the care plan. Carers should be given the right sort of help and support and be told about their right to a carer’s assessment under the Carers and Disabled Children Act 2000; other commitments outside the caring role should be recognised. Carers should be told about opportunities to take a break from caring; be given details of local support groups and advocacy services; services should be right for carers needs, good quality, and provided at an agreed time
- **Valuing your involvement in service development**: carers should be given the opportunity to be actively involved in the planning, development and evaluation of services

The Somerset Partnership NHS Foundation Trust Charter has exactly the same four principles but contains more detail under each about what carers can expect – e.g. it states that carers will be given a copy of a care plan (with consent) rather than just be involved in the planning and agreeing this.

2.11 Somerset Carers Strategy Action plan

There is a draft action plan in development which covers all aspects of the Somerset Multi-agency Strategy. The findings of this appraisal will inform taking action planning forward.
2.12 Number of carers in Somerset

As of the 31st March 2010, 7,309\(^9\) carers are recorded by Somerset County Council and 5933\(^10\) by Somerset Partnership NHS Foundation Trust, it is unknown how many of these may be double counted and both agencies may be involved with some carers. In the census figures in 2001 approximately 50,000 people have defined themselves as carers; this suggests a significant hidden population of carers by the statutory agencies within the county and there may also be more carers who have not defined themselves as such in the census. Somerset must be able to reach out to all carers in terms of service accessibility and support options.

Somerset is a rural county with sparse population density in many places and the rural challenges of the geography and population projections for the future are discussed in the Demographics Section 8 of this report.

Whilst carrying out this review we have attempted to make contact with both known and unknown carers and recognise that carers may include relatives, friends and neighbours, some of which may live with the cared for person and others visiting on a regular basis.

\(^9\) Number recorded on Somerset County Council Swift IT system March 2010
\(^10\) Number recorded by Somerset Partnership NHS Foundation Trust on RIO IT system in March 2010
3. **Methodology**

This section of the report provides a brief outline of the methodology which has been used by Peter Fletcher Associates (PFA), to carry out an independent appraisal of current service provision against the priorities set out in the including Somerset Carers Strategy and the ability to deliver this.

How the project was carried out:

Peter Fletcher Associates established a specific team for this project:

- Peter Fletcher (Quality Control)
- Heather Eardley (Joint Project Lead and Manager)
- Trevor Eardley (Joint Project Lead and Manager)
- David Hess (Researcher)
- Avis Duncan (Administrative support/data analyst)
- Serena Dyer (Project Support)

The Project Team has carried out the work in the following manner by:

- Understanding the local context and how the strategy fits into the wider strategic planning and change agenda in the county; achieved by face to face discussions with commissioners and other key stakeholders
- Making use of information already available, including reports, documents and contracts
- Talking directly to carers and other stakeholders involved with the provision of services to carers
- Undertaking further quantitative and qualitative research to reach a broader range of carers via two carers questionnaires distributed to young carers and adult carers
- Actively using examples from other authorities and a growing body of consumer research to provide case studies and benchmarking data
3.1 Accountability arrangements through the project

The project was set within the following accountability framework:

- A tender specification and business case to the consultant from the project commissioners
- A Somerset County Council Project Initiation Document endorsed by the existing Carers Strategy Group
- A Project Plan submitted by the consultant and accepted by the client
- The establishment of a Project Management Group with specific and agreed terms of reference to ensure the project remains on track. This group meets monthly, its membership comprising:
  - Anne Anderson, NHS Somerset
  - Barrie Fitzpatrick, Somerset County Council, Adult Social Care (joint chair of Project Management Group)
  - Julia Ingram, Somerset County Council, Adult Social Care (joint chair of Project Management Group)
  - Mel Lock, Somerset County Council, Mental Health and Learning Disability
  - Jo Taswell, Alzheimer’s Society and Voluntary and Community Sector representative
  - Alison Templeton, Somerset County Council, Lead for Somerset Carers Strategy
  - Caroline Toll, Carers UK, East Somerset Branch – carer representative
  - Tim Woods, Project Support, Somerset County Council

3.2 Project timescales

The project has been split into two phases with key project milestones:

- Phase 1: consultation/research and delivery of interim report by 15th February 2010
• Phase 2: consolidation of findings, financial modelling and further consultation at stakeholder events to agree final recommendations for delivery of Final Report by 29th May 2010

**Phase 1: September 2009 – January 2010**

This involved consulting with a wide range of carers and other stakeholders across Somerset about current needs, satisfaction with current services and against the priorities in the Somerset Multi-agency Carers Strategy.

### 3.3 Consultation with carers

In total we have consulted with over 1,500 carers across Somerset for the purpose of this review with direct responses from at least 850 carers from the following groups shown in Fig. 3-1. Fig. 3-1 outlines the types of carers contacted and the numbers who gave a direct response.

**Fig. 3-1: Type of carers contacted and number of responses**

<table>
<thead>
<tr>
<th>Type of carer</th>
<th>Number of carer responses (by questionnaire and face to face)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent carers</td>
<td>20</td>
</tr>
<tr>
<td>Young carers</td>
<td>48</td>
</tr>
<tr>
<td>Carers of people with learning disability</td>
<td>60</td>
</tr>
<tr>
<td>Carers of people with physical disability</td>
<td>157</td>
</tr>
<tr>
<td>Carers of people with a sensory loss</td>
<td>12</td>
</tr>
<tr>
<td>Carers of people with mental health issues</td>
<td>78</td>
</tr>
<tr>
<td>Carers of older people and people with dementia</td>
<td>93</td>
</tr>
<tr>
<td>Carers of people with Asperger’s and Autism</td>
<td>15</td>
</tr>
<tr>
<td>Carers of people who have substance misuse</td>
<td>58 (plus 48 from previous survey(^{11}))</td>
</tr>
</tbody>
</table>

\(^{11}\) Supporting Carers and Family Members affected by the Substance Misuse of Others - A Somerset Study on Behalf of Somerset Drug and Alcohol Action Team; Dr Sharon Collins and Helen Begum; January 2009.
<table>
<thead>
<tr>
<th>Type of carer</th>
<th>Number of carer responses (by questionnaire and face to face)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers who are Gypsy or Travellers</td>
<td>0</td>
</tr>
<tr>
<td>Carers from Black Minority Ethnic groups</td>
<td>27</td>
</tr>
<tr>
<td>Carers from Lesbian, Gay, Bi-sexual and Transgender groups</td>
<td>0</td>
</tr>
<tr>
<td>Canal Users</td>
<td>1</td>
</tr>
</tbody>
</table>

This was carried out in a number of ways:

- A review of best practice nationally in terms of service models
- Mapping of existing services provision in Somerset
- A questionnaire survey of adult carers which was designed by the Somerset Carers Advisory Group and distributed to 1000 carers across Somerset with 323 respondents (32.5% response rate)
- A separate questionnaire designed by young carers and distributed to 100 young carers across Somerset with 16 returned (11% response rate) and two adult questionnaires returned by carers under 18
- 15 young carers “day in the life of” diaries completed by young carers
- A series of semi-structured interviews and discussions with key stakeholders
- Carers Panels held in five local areas and one countywide strategic panel. These provided the opportunity for two way discussions between two and four carers, a Peter Fletcher Associates facilitator and a range of different staff (Adult Social Care - Social worker and/or Occupational therapist; Carers Support Worker; Carers Assessment Worker; Care Provider; Primary health care representative). These staff providing services to carers were invited in at 45 minute intervals throughout the period of one day to discuss a range of themed questions raised by the Carers Advisory Panel
- Briefing event for 25 carers in preparation for their involvement in the Carers Panels
• A Carers Rights Day consultation event held in Taunton in December 2009 for 60 carers facilitated by Peter Fletcher Associates consultants
• Meeting with approximately fifteen voluntary and community sector representatives held in January 2010 (see Appendix 5 for list) and six carer representatives
• Attendance at five Carers Support Groups including generic, parent carer, Asperger’s and Autism, drug and alcohol and learning disability carers between October 2009 and February 2010
• Attendance at Somerset Partnership NHS Foundation Trust Carers Participation Group in December 2009
• Attendance at two specially convened groups of carers from Polish and Portuguese communities and attendance at Somerset Racial Equality Council
• One meeting with a canal boat user who distributed 20 questionnaires
• Attendance at Somerset County Council, Adult Social Care Operational Team Managers meeting in January 2010 with approximately 80 managers present
• Meetings with Senior Management Team for Somerset County Council Adult Social Care in December 2009
• Meetings with nine Senior Managers across Somerset County Council Adult Social Care, Somerset Partnership NHS Foundation Trust and NHS Somerset
• Attendance at Carers Support Worker meeting in December 2009
• Attendance at Carers Assessment Worker team meeting in December 2009
• Attendance at Wyvern Health Co-operative board meeting in December 2009
• Attendance at Local Medical Committee, Practice Managers meeting in March 2010
• Phone conversations with eight unknown carers who phoned in as a result of posters or press releases
• Phone conversations with a range of other staff, managers and networks. Distribution of short pro forma to other groups not covered by questionnaire circulation: In Touch, Lesbian, Gay, Bisexual and Transgender network; National Autistic Association, Mencap groups
• Attendance at a carers of people with sensory loss support group meeting
• Attendance at the Somerset Partnership NHS Foundation Trust Carers Conference 2010
• Circulation to 200 people from the Lesbian, Gay, Bisexual and Transgender Network asking for their comments

3.4 Stakeholder consultation

This phase also included consulting with key stakeholders and specialist groups:

• Age Concern Somerset
• Alzheimer’s Society
• Asperger’s and Autistic support groups
• Carers UK
• Compass Disability services
• In Touch
• Marie Curie
• Mencap
• National Autism Society – Somerset Branch
• Rethink
• Somerset Older Citizens Alliance
• Somerset Sight
• St Margaret’s Hospice
• Stroke Association
• Somerset Skills and Learning
• MIND

For a detailed list of all stakeholders consulted with see Appendix 5.

Phase 2 - February 2010 – July 2010

This phase involved the facilitation of five stakeholder workshops to feed back results of the initial consultation and to shape the final recommendations for the suggested future model of service delivery in Somerset. It also involved financial modelling to identify how resources are best configured to meet the priorities of the Somerset Multi-agency Carers Strategy within the constraints of public sector
budgets and taking into account demographic changes. It also included attendance at the Somerset Partnership NHS Foundation Trust Carers Conference with 85 carers present. This phase ended with the completion of the final report.

3.5 Appraisal of current services against key priorities in the Somerset Multi-agency Carers Strategy

In carrying out this appraisal Peter Fletcher Associates have used the priority areas of the Somerset Multi-agency Carers Strategy to evaluate how current services are meeting the outcomes required for this (see Section 4).

Peter Fletcher Associates has also appraised services across a wider range of carer categories than is listed in the Somerset Multi-agency Carers Strategy and make suggestions about the modifications required to the strategy in Section 11.

Peter Fletcher Associates therefore has developed the list of priorities and suggest this is used as a modification to the Somerset Multi-agency Carers Strategy and as a framework for this appraisal.

The modified set of priorities identified and used in this appraisal is:

1. Identification of carers
2. Information and advice
3. Assessment
4. Practical support and provision of short breaks
5. Emotional support
6. Health and wellbeing
7. Finance
8. Employment/Leisure; Learning
9. Recognition - giving carers a voice
10. Equalities
4. Current Services in Somerset

This section of the report contains an outline of current services including how they are commissioned, who provides them, and those funded from non-statutory sources such as charitable funding, against the priorities listed in the Somerset Multi-agency Carers Strategy.

As part of this appraisal Peter Fletcher Associates has carried out a detailed mapping exercise which includes the name of the provider; contact details; type of contract; which area of the Somerset Carers Strategy is met by the service and activity levels if this is available.

The detailed map of all services for carers across Somerset can be found as a stand alone Microsoft Excel spreadsheet document which can be built on over time. There is a summary version in Appendix 1.

4.1 Commissioning for Carers Services in Somerset

Somerset County Council and NHS Somerset are the main commissioners of carer services in Somerset and in partnership with other agencies are commissioning services to meet the requirements of Somerset Multi-agency Carers Strategy. A full time Carers Lead has recently been appointed by Somerset County Council to work to the Somerset Carers Strategy Group.

Somerset County Council both commissions and provides a range of services and funding for carers through its statutory responsibilities and these will be further developed by their Transformation and Personalisation Programme. This will include personal budgets and increased focus on choice and independence, use of assistive technology and prevention.

Currently the Carers Grant provides services to both young people and adult carers in Somerset to a total of just over £2 million. This is set to rise over the next two years to a total of just over £2.5 million. The grant will no longer be ring-fenced but will form part of the Area Based Grant supporting the delivery of the Local Area Agreement and is therefore subject to Somerset County Council budgetary processes. Section 8 of this report provides more detail about the level of funding and spends in Somerset.

Somerset was at the forefront of service development in identifying carers as a separate group requiring dedicated support and resources when the Carers Project, as it was known, was set up Somerset County Council in 1993. This put an emphasis upon a need for distinct services for carers with separate needs, which has been strengthened over time by national legislation aimed specifically at carer support.
Specialist carer services have consequently developed and Somerset County Council was one of the first authorities to employ Carers Support Workers. There are now a variety of services available providing a range of functions and for different types of carers. Some of these services are accessible only if users are in receipt of services, others are available universally through self-referral.

NHS Somerset receives government funding specifically for the provision of carers breaks and its budget of £973,000 for 2010/11 is yet unallocated in anticipation of the outcomes of this appraisal.

NHS Somerset performance monitoring process provides a mechanism for ensuring community service providers meet the statutory duties of health services, and deliver the services as outlined within the service specification and contract.

NHS Somerset and Somerset County Council each contribute £9,000 to a joint contract with the Expert Patients Programme which involves the provision of four Looking After Me courses - see Section 4 on Training.

4.2 The map of services across Somerset

Services for carers in Somerset are provided by a range of different providers in the statutory, voluntary and community sectors for each of the different types of carer groups. This section outlines the main services available in Somerset for carers but it must be noted that services provided for the cared for person also have an impact upon support for the carer and it is not always possible to separate the two.

4.3 Numbers of carers in Somerset

Although GPs are required to keep Carers Registers, NHS Somerset holds no information as to the numbers of GPs with a Carers Register or what percentage of carers is on this register. Somerset County Council Adult Social Care use the SWIFT IT care management system and record known carers on this which to date has approximately 7,00012 carers recorded.

Somerset Partnership NHS Foundation Trust use the Rio IT system and have 593313 carers recorded though some of these may be double counted with Somerset County Council.

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12 Numbers recorded on Somerset County Council Swift IT system- March 2010
13 Number recorded on RIO system as at 5.3.10
GPs are independent practitioners working closely with the NHS Somerset Primary Care Development Directorate. There is a requirement for GPs to collect carer information on a Carers Register via the Quality Outcomes Framework. The Board of WyvernHealth.Com, the Somerset Practice Based Commissioning Consortium, reported that all GPs collect this information but it tends to be easier to gather data for those practices using the EMIS IT system which includes all but 12 GP practices.

NHS Somerset does not hold any information on what percentage of carers are on practice registers. An increased focus on the needs of carers with GP practices could result in a better estimation of the number of carers in the practice population and ensure carers were better supported to access relevant information and advice. Work is currently taking place with St John Ambulance, Carers UK and Wyvern Health to raise awareness amongst GP practices about carers (see section 4.7)

### 4.4 Information and advice

**What does the Somerset Multi-agency Strategy say?**

1) Information, Identification and Recognition

Carers should be recognised and enabled to identify themselves as carers and be supported by information and advice from a range of sources in their caring role. Carers need access to clear and up to date information on carer assessments, services and benefits early in their caring role.

**Source: Somerset Multi-agency Strategy 2008-2011**

Most organisations involved with carer services in Somerset provide some form of information to carers. Somerset County Council, NHS Somerset and Somerset Partnership NHS Foundation Trust are probably the largest information providers to carers (see Section 6 for feedback from carers) but there is no central place that carers can go for information about carer services in Somerset.

Somerset Direct is a general information, signposting and advice customer contact centre which is commissioned by Somerset County Council for all members of the public. Although not specifically for carers it is identified in the Somerset Multi-agency Carers Strategy as the initial point of contact for carers and referrals in order to:

“Reduce the level of confusion experienced by carers in trying to access information and services.”[^14]

[^14]: Somerset Multi-agency Carers Strategy 2008-2011 p9
Fig. 4-1 shows numbers of contacts to Somerset Direct from carers or relating to carers in 2008/09 and breakdown by type of request.

- The biggest reason for contact is the need for information about support with 52.7% of contacts
- The second largest request is for information about respite breaks and sitting services, 23.6% in total

### Fig. 4-1: Somerset Direct contacts by type of request

<table>
<thead>
<tr>
<th>Type of request</th>
<th>Percentage of contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice for Carers</td>
<td>9.4%</td>
</tr>
<tr>
<td>Carers Assessment</td>
<td>14.2%</td>
</tr>
<tr>
<td>Short Residential Breaks</td>
<td>13.2%</td>
</tr>
<tr>
<td>Sitting Service</td>
<td>10.4%</td>
</tr>
<tr>
<td>Support for Carers</td>
<td>52.7%</td>
</tr>
<tr>
<td>Totals</td>
<td>2273</td>
</tr>
</tbody>
</table>

Source: Somerset Direct 08/09

In Somerset there is an infrastructure of approximately 110 local Active Living Centres, with the aim to improve local access to both primary and secondary prevention. The concept of ‘Active Living’ is used to engage ‘younger’ older people (typically 50 plus) and to promote the benefits of keeping active and healthy.

The Active Living Service has been set up in partnership with statutory, voluntary and community groups. The service is governed through a board with representation from NHS Somerset, Somerset County Council, District Councils, Disability Federation, Age Concern Somerset and older people. During 2009 the Active Living Service has included working in partnership with the Somerset Alzheimer’s Society to support the development of additional Memory cafés which also benefit carers but has not specifically focused on carers. Only two of the carers support groups currently run from Active Living Centres (Street and Glastonbury), yet they have the potential to provide a wide range of information and advice to carers at easy access points in rural locations.

Somerset County Council provide a basic carers information pack which is given out mainly by Carers Support Workers or Adult Social Care workers, plus additional information which is condition specific and tailored to the needs of the individual. The information pack is also on the Somerset County Council website under Carers. Carers Support Workers can signpost to various voluntary organisations and back to the GP if necessary.

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15 This figure is gradually increasing with more being developed
There is a network of Carers Support Groups across Somerset run by a range of different organisations depending on the carer type (see separate mapping document). These support groups provide information and advice for carers and often invite a range of speakers to update carers with relevant information. Many are attended by Carers Support Workers or Carers Assessment Workers to provide information about Adult Social Care or mental health issues.

Care First, is a counselling service which is commissioned by Somerset County Council for its own staff and for use by carers. This service has professional Information Specialists who can help individuals to identify what they need and can provide information on a wide range of subjects, using up-to-date directories and databases and to assist with the sheer volume of information and knowing where to start. They are also debt management trained and can provide financial advice and debt counselling.

Somerset County Council Financial Benefits and Advice Team also provide information about financial benefits and give talks to Carers Support Groups.

Within NHS Somerset provider contracts there are mandated sections about information to carers, surveys and carer rights. There are also generic statements within each service specification. GP practices and hospitals have information that can be given out but often do not know who the carers are and many report that they may forget to ask about whether the person is a carer with so many other priorities.

Somerset Primary Link provides information for professionals including GPs who can phone the Primary Link number when considering hospital admission to see if there are any alternatives. At present, information requested by Somerset Primary Link does not include information regarding carers but it is anticipated that when the planned End of Life Care Coordination Centre, which will be an extension of Somerset Primary Link, is established, data will be collected about the carer in the overall profile of the patient. There may be scope here for better use of carer information for other conditions.

NHS Somerset could potentially be used for carer information, advice and support at the following sites:

- The 13 community hospitals across Somerset offer opportunities for the provision of more effective support for carers. These include the recently opened Frome Community Hospital and Minehead and South Petherton hospitals currently being redeveloped. The new South Petherton Community Hospital will include a health and wellbeing centre and community education facility

- The Victoria Centre in Bridgwater which has a GP practice, pharmacy, community facilities, children’s centre and community café. The centre promotes a range of health related initiatives including, Active Living Centres, Alzheimer’s Society memory café,
stop smoking services, a community enabling service and health trainers

- NHS Somerset also intends to continue to develop closer partnership working with the Active Living Centres across Somerset which as yet have not focused activity around carers specifically but provide an excellent way to reach people in rural communities

Somerset Partnership NHS Foundation Trust provide a range of information for carers in different formats such as a website, zap packs, web cards, emergency contact cards (which include social services) and a Carers Charter, in a well presented plastic folder information pack. This information is available in all units and on the website. Information is also disseminated via roadshows, the Big Bus and other events and courses. Often the Carers Assessment Worker will provide additional information specific to needs of the individual which is researched prior to a visit and there are fact sheets available which can be downloaded from the website for condition specific information. The Somerset Partnership NHS Foundation Trust website is a popular resource and in April 2010 hits on the site are up by 33,000 over the last year to over 93,000.

Care providers, voluntary and community sector organisations reported that they provide a range of information to carers in the form of leaflets, roadshows, websites and presentations to various groups as a way of highlighting their services. They also visit Somerset County Council Community Teams, GPs and other staff to raise awareness of their work. The RightCare Index 2009-10 is a useful health and social care directory which states that it offers “all the solutions that fall in line with the Government’s personalisation agenda” and St John Ambulance has recently been distributing this to carers.

A small booklet and directory of useful contacts compiled by St John Ambulance called “If only I’d known that” was written by an ex-carer for other carers and is based on experience of the type of information which would have been useful but was never given; this has been very positively received by many carers. 40,000 copies have been printed to date and distributed through GP Surgeries, Somerset Direct, St John Ambulance and others.

16 If only I’d known that – booklet and directory of useful contacts – Susan Hartnell-Beavis
4.5 Assessment

What does the Somerset Multi-agency Carers Strategy say?

Assessments and Ongoing Support

Carers Assessments should form the foundation of both immediate and ongoing support to carers and should include:

- An opportunity for carers to explore how they feel about caring
- Information on benefits and support
- An opportunity to explore work/life balance
- An opportunity to discuss the future implications of their caring role
- An opportunity to identify the outcomes carers want in their roles

Assessments

- All carers will be offered an assessment on their caring needs
- The carer will be asked if they would like to discuss their needs with or without the person that they care for
- The carer’s right NOT to assume the caring role will be acknowledged, as will the fact that they may not want to continue their current caring role

Source: Somerset Multi-agency Carers Strategy 2008-2011

What is currently being delivered in Somerset?

There are a variety of ways in which Carer Assessments are carried out in Somerset depending on the category of the cared for person.

For carers of adults who have contact with the local Adult Social Care Teams the Carer Assessment is carried out by the cared for person’s Social Worker or Occupational Therapist or by a Carers Support Worker if a carer requests a separate assessment.
A Social Worker or Occupational Therapist would not usually complete a separate Carer Assessment form but whilst undertaking a holistic single assessment of the cared for person, will ask about carer’s needs. This is recorded on the Somerset County Council SWIFT Care Management IT system under the name and case number of the cared for person.

If a Carer requests a separate assessment then the majority of these 72.6% (379/522) are completed by a Carers Support Worker using the Carer Assessment Form SS755 which is input onto the SWIFT Care Management IT system as a separate carer record. The SWIFT system does not enable the carer’s record to be cross referenced with the cared for persons file.

Some complex cases, such as large packages of care or multi-agency input, are not referred to a Carers Support Worker and a separate Carer Assessment is then completed by a Senior Social Worker, Social Worker or Occupational Therapist (6%). However 116 assessments were not clearly categorised and stated Carers Support Worker/Social Worker so this figure may be slightly more or less.

There is no formal care or support plan drawn up for carers following an assessment. Sometimes a letter is sent outlining what support will be provided but this seems to be at the discretion of the particular worker or team.

It was unclear what the current practice standards are for carer reviews and these appeared to vary from one area to another. If a carer requires a large amount of support or is vulnerable then a review would be set in 11 months time and the case would remain open. The majority of carer reviews are recorded on SWIFT as being carried out by Carers Support Workers (80%) yet there is now an expectation by Adult Social Care Team Managers that Carers Support Workers will close cases after three or four sessions; the role of reviewing carer’s needs therefore appears to be left to the worker of the cared for person.

- The total number of overdue reviews in Somerset at March 2010 is 47% (3,016) with 1,403 of these having carer involvement
- 80% of carers reviews are carried out by Carers Support Workers

The opportunity to ask about carer’s needs at point of reviewing the service user’s care and support plan is important and could more formally be built into the process with prompts for care management staff on the review form.

17 Source- Somerset County Council Management Information Team
18 This includes ‘OT reviews’, ‘comprehensive reviews’, ‘carers reviews’ ‘package reviews’ amongst others. Source: Somerset County Council Information Management Team
By ensuring reviews are carried out on time this will provide a better safety net for carers to receive the right amount of support required to continue caring and relevant questions need to be asked about carer’s needs at the review.

Service providers can identify any carer’s needs and bring these to the attention of care management staff and also request a re-assessment of the person cared for or the carer if their circumstances change. Service providers can also provide relevant information and signposting for carers by being better aware of carers’ issues.

In Learning Disability Teams all Carer Assessments are carried out by the care management staff with no referrals to Carers Support Workers. The SS755 is still used if the carer requests a separate carer assessment and this is input onto SWIFT as in Adult Social Care teams.

- The total number of Learning Disability assessments in 2008/09 was 9461
- 60% of these had a separate Carer Assessment carried out by the cared for care manager

In the Somerset Partnership NHS Foundation Trust the mental health care co-ordinator for the cared for person will undertake the assessment or refer to a Carers Assessment Worker to undertake a separate Carer Assessment using the Somerset Partnership NHS Foundation Trust Carer Assessment Form. Following the assessment a Carer Recovery Care Plan is completed and given to the carer; this outlines how the needs of the carer will be met.

- 94% of Carer Assessments in Somerset Partnership NHS Foundation Trust are undertaken by Carers Assessment Workers
- Carers Assessment Workers have a caseload of about 300 carers in total in the team
- Until recently Carers Assessment Workers were completing annual reviews but it is now only if carers request this due to high workloads
- All carers are seen within four weeks as per the Trust obligation including if they request a re-assessment and often the Carers Assessment Workers will work with carers in crisis
- A Carers Assessment Worker takes about three hours to complete a Carer Assessment and there is an offer to work with the carer until they get to the stage of setting up a Carer Recovery Care Plan or ongoing support with goals are set for carers
- After an agreed period of support is completed, depending on need, a carer can contact the Carers Assessment Worker at any time, either by phone or email. A carer also receives a Carer Recovery Care Plan in their own right following the assessment
Somerset Partnership NHS Foundation Trust has electronic case records and carers have their own section which can be highlighted as a hyperlink with the carer on but which can be cross referenced on RiO.

Carers Assessment Workers have access to all Somerset Partnership NHS Foundation Trust training and are supervised by the Carer Assessment Team Manager who is the Users & Carers Development Manager. Team meetings are held monthly and are well attended and well structured. There is also a peer support meeting monthly which managers do not attend.

The annual returns to the NHS South West Strategic Health Authority on numbers of Carers Assessments is taken from Somerset County Council SWIFT IT system as NHS staff do not currently undertake Carers Assessments, other than those employed by the Somerset Partnership NHS Foundation Trust. An electronic personalised care planning tool is currently in development and NHS Somerset will ensure carer information is included within this where relevant.

NHS Somerset's largest contract regarding carers is with Somerset Partnership NHS Foundation Trust which stipulates that Carer Assessments must be undertaken. At present this is carried out by Carers Assessment Workers employed by Somerset Partnership NHS Foundation Trust and funded from the Carers Grant (see Section 5 for more details about Carers Assessment Workers).

**Parent carer assessments**

Parent carers do not receive a separate assessment but are considered as part of the holistic Children and Young Person's Common Assessment Framework (CAF) in the Initial or Core Assessment unless they are carers of young people with mental health problems. There and two mental health Carers Assessment Workers for parent carers within the Somerset Partnership NHS Foundation Trust as part of an 18 month pilot project.

For carers other than those receiving services from Somerset Partnership NHS Foundation Trust it is apparently extremely rare for a parent carer to ask for a separate Carer Assessment and staff in the Childrens Disability Team seem somewhat unclear about what they would do or what form to use. Children's assessments are input onto the Somerset County Council Protocol IT system and parent information is recorded on the child or young person’s file.

**Young carer’s assessments**

There is a Somerset Young Carers Assessment Form, which has been designed specifically for Young Carers and completed by Young Carers Project Workers.

A Young Carer Assessment usually takes up to two hours to complete and is carried out with the child and their parents, usually in their home; this provides a
holistic approach to the whole family’s needs. If unmet needs are identified a project worker will refer to another service for further support, or initiate a Common Assessment Framework (CAF)\textsuperscript{19} for that young carer.

Young carer needs are reviewed annually and linked with the original assessment. Both Young Carer Assessments and Reviews are now being inputted onto Protocol – the Integrated Children’s IT system for Somerset.

Common Assessments are used by a variety of agencies when identifying Children and Young people with additional needs (early identification of young carers). The Young Carers project in Somerset works with agencies completing this form and will now consider completing a Common Assessment if needs can not be met through the project.

Children and Families Social Care teams tend only to deal with high priority referrals, mainly safeguarding, which therefore misses many young carers who do not come under this system. However local service teams and the Young Carers Project could offer support to young people falling below the social care threshold.

The length of time a Young Carer Project Worker works with a young carer is based on their individual needs and will also continue to support a young carer if there is a bereavement of a cared for person.

**Drug and alcohol**

Turning Point use the Somerset County Council Carer Assessment as a framework but then ask more relevant questions for carers of people who misuse drug and alcohol. The numbers of assessments are stored electronically on their CIM system (but not the actual assessment). As part of the contract review process, service activity information is shared with commissioners and with quarterly reports to the Drug and Alcohol Teams. Between Jan - March 2010 there were two Carer Assessments completed.

\textsuperscript{19} The CAF is a standardised approach to conducting assessments of children’s additional needs and deciding how these should be met. It can be used by practitioners across children’s services in England see Every Child Matters, Dept of Children, Schools and Families, July 2009.
4.6 Practical Support (including Short Breaks and Crisis Support)

There is a range of service providers that provide practical support and short breaks for carers or the person cared for with an indirect impact upon the carer. These include services provided by Somerset County Council and Somerset Community Health Services, Somerset Partnership NHS Foundation Trust, voluntary and community sector providers and independent sector providers. There are also organisations such as Compass Disability Services and A4E which can arrange payroll and brokerage for direct payments and individual budgets.

Short breaks providers range from care homes in the independent sector, sitting services provided by independent domiciliary care agencies and voluntary and community organisations and holidays organised by the voluntary sector or charitable trusts depending on the service user type as outlined under each specialist carer group.

Support in a crisis is made much easier if a contingency plan is in place. This should be carried out by the care co-ordinator such as the Social Worker, Occupational Therapist or Community Nurse in collaboration with a Carers

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**What does the Somerset Multi-agency Carers Strategy say?**

<table>
<thead>
<tr>
<th>Breaks</th>
</tr>
</thead>
<tbody>
<tr>
<td>All carers providing substantial and regular care will be made aware of their entitlement to a break</td>
</tr>
<tr>
<td>The barriers that prevent carers taking a break will be recognised and ways to overcome them explored</td>
</tr>
<tr>
<td>Carers will be able to identify the needs of the cared for person ensuring that their care is appropriate. This will relieve the potential for anxiety and will therefore not undermine the value of the break</td>
</tr>
<tr>
<td>Carers will be able to access breaks, with or without the person they care for, in flexible ways that achieve their desired outcomes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emergencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers will be provided with ‘crisis’ services available to them. This will link with the Short-Term response work and the ‘emergency respite’ addition to the Carers Grant</td>
</tr>
<tr>
<td>Systems for the identification of carers will be promoted so that if there is an issue with the cared for, others can be alerted</td>
</tr>
</tbody>
</table>

*Source: Somerset Multi-agency Carers Strategy 2008-2011*
Support Worker or Carers Assessment Worker if working with the carer. These are not performance monitored and there is a need for a greater emphasis to be given to the importance of these in times of crisis.

Help in a Crisis is a sitting service which was set up by Somerset County Council to enable domiciliary care to be provided at very short notice in each of the five localities to carers in need. This is funded out of the Carers Grant at a cost of £15,850 and paid as part of the Home Care Contract. Providers report that they do not identify these sits separately in their contracts but anecdotal evidence suggests this service is only accessed about two or three times a year in each area. There have been occasions when Carers Assessment Workers have tried to access this service for carers but been told that there are no staff available.

4.7 Health and Wellbeing

*What does the Somerset Multi-agency Strategy say?*

**Health and Wellbeing**

Within this Carers Strategy, ‘health and wellbeing’ refers to the physical and mental health of the carer, staying safe, enjoying and achieving and making a positive contribution.

**Key Objectives:**

- Ongoing support for carers will be provided by a network of Carers Support Workers (CSWs), Carers Assessment Workers (CAWs) and carers support groups across the County
- A dedicated carers counselling service will be made available to all Somerset’s carers
- Through the Somerset Carers Strategy Group, opportunities for improved partnership working will be developed. By looking at services that are provided specifically for the ‘cared for’ we can look at the implications and opportunities that this may have the carer too. For example, the provision of free flu jabs by the Primary Care Trust
- Ensure that carers are able to have the same opportunities as people who do not provide a caring role to maintain healthy lives and access the NHS and Social prevention initiatives
- That vulnerable carers and the people they care for are protected from abuse
- That carers are able to inform End of Life Strategies, carers receive information, advice and support in preparation for death for the person they care for
What is being delivered in Somerset?

Emotional support has been identified as a key factor for carers to preserve their mental health needs and carers throughout Somerset have access to an independent telephone counselling and information service which is available 24 hours a day every day of the year via Care First contract which is an extension of the Somerset County Council employees counselling helpline contract.

This includes:

- Free phone access to 24 hour telephone counselling helpline answered by a qualified counsellor
- Face to face counselling - six free sessions which can be accessed directly by carers and an appointment given within five working days with no waiting list
- Finance advice - Care First Information Specialists are debt management trained and can provide financial guidance and debt counselling
- Online Counselling - Care First is constantly striving to ensure as many routes into the service as is reasonably possible are available to Carers and, with this in mind, has recently developed the ability to access counselling using real time, online chat

Somerset Community Right Steps\(^{20}\) is an emotional health and wellbeing service which is provided by Somerset Community Health which carers can self-refer for a range of psychological therapies, workbooks, support groups and other interventions free of charge. The service does have a waiting list which depends on the geographic location and the level of care required. These are currently being addressed, both the inherited waiting list and newly incoming referrals and this is affecting service user waits. On average the wait does not exceed 15 weeks and this is expected to decrease markedly once all inherited cases have been completed. Whilst extensive demographic information is collected on its service users, the number of carers is not captured.

Other aspects of health and wellbeing as identified in the Somerset Carers Strategy are around partnership working with the NHS for access to health checks, free flu jabs etc. The GP Carer Registers are designed to enable easy identification of carers and access to health checks and other health services.

Carers have been raised as an important issue at the recent WyvernHealth.Com Advisory Group Meetings and local Patient Participation Group meetings. Wyvern is also keen to offer training to all practice staff. A recent bid for funding to Carers UK was successful and in conjunction with St John Ambulance training has taken place with 47 GP practices participating. Phase 1 requires each practice to

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\(^{20}\) [http://www.somerset.nhs.uk/rightsteps/index.htm](http://www.somerset.nhs.uk/rightsteps/index.htm)
identify a Carers Champion. This person is likely to be from reception team leaders or middle managers, but could also be a health care assistant or a carer who is working in the practice. The Carers Champions have attended a half day training session which has been delivered by St John Ambulance. In Phase 2 the Carers Champion together with support from St John Ambulance and/or a volunteer carer will deliver a one hour Carers Awareness Session in the practice, identifying themselves as a practice resource for carers, a communication channel for carers issues, providing flowcharts and free resources to all staff members.

The Carers Support Workers and Carers Assessment Workers are listed under this category in the Somerset Carers Strategy with their roles to improve the health and well being of carers by offering a network of support. Their roles now cover many functions and these are discussed separately in Section 5.

Carers Support Groups are also under this priority and are well established in most locality areas. These provide emotional support and information to about 10-20 carers per support group, many carers of which have been attending for several years, including ex-carers who continue to find the groups of value. Traditionally these support groups were set up and facilitated by Carers Support Workers or run by Somerset Partnership NHS Foundation Staff, volunteers or carers themselves.

In recent times there has been a move towards enabling volunteers or carers to run the groups. Previously the Carers Support Worker would arrange the programme, organise and attend day trips etc. This role is now diminishing with the drive by Adult Social Care Managers to encourage the groups to be run by volunteers and Carers Support Workers only dropping in to provide information when required. However this has caused some disquiet as some carers who attend the groups dislike having to run the groups themselves with so many other responsibilities. Other carers have suggested these should be run by an independent body such as voluntary organisations as happens in some other parts of the country.

### 4.8 Finance

*What does the Somerset Multi-agency Strategy say?*

**Financial Security**

- Carers will be given information and support on the range of services and benefits available to them leading to an increased take-up of Carers Allowance in the county
- Carers will be given the opportunity to exercise choice and control
The Somerset County Council Financial Benefits and Advice Team (FAB) provides assistance with benefits information and completing benefits claims with 40 staff in post based in Frome, Taunton, Bridgwater and Yeovil. These are employed either by the Department of Work and Pensions or Somerset County Council operating as a joint service.

The Financial Assessment Benefit Team has a new computer system soon to be installed; the current system does not provide any carer specific information or information about any resulting increase in benefit take. All that is known is that in the last year there were 5194 claims from Somerset Direct for benefit checks of all types and that the Financial Assessment Benefit Team look at all benefits entitlements when they do an assessment, which includes the Carers Allowance.

Care First Information Specialists are debt management trained and can, therefore, provide financial guidance and debt counselling though this is a small proportion of the service provided to carers.

4.9 Work, Leisure and Lifelong Learning

What does the Somerset Multi-agency Carers Strategy say?

**Work, Leisure and Lifelong Learning – Opportunities Beyond Caring**

- Carers will be assisted in managing an effective work/life balance and be provided with development opportunities both within and outside of the context of their caring role.

Source: Somerset Multi-agency Carers Strategy 2008-2011

The Department of Work and Pensions operate the Job Centre Plus which has a role in supporting carers returning to work. In Somerset all Job Centre Plus staff will be trained in carer awareness and support to carers returning to work in the next 18 months. All applicants for working age benefits will be able to contact a national call centre for advice and information regards employment but also receive advice on how to manage work and caring responsibilities. Carers will be allocated a personal adviser who will stay with the carer throughout the life of contact with the Department of Works and Pensions. Carers will receive a tailor
made pack of information which includes opportunities to undertake voluntary work, free training and an element of funding to allow carers to access training.

Somerset County Council Employees Carers Network provides support to approximately 30 Somerset employees who are carers with a core group of seven to eight carers. This is a support mechanism with the aim to raise the profile of carer issues in the workplace and support Somerset County Council employees who are carers, through the distribution of information, informal support, arbitration with line managers and development of a Yahoo networking site all carried out by an unpaid co-ordinator. The group reports to the Somerset County Council Human Resources Group and has good links with the Somerset Partnership NHS Foundation Trust Carers Employment Support Officer.

Somerset Partnership NHS Foundation Trust Carers Employment Support Officer supports about 40 carers of people with mental health issues and who are receiving support from Somerset Partnership NHS Foundation Trust. This post is not solely for carers (two days per week) and Figure 4-2 shows the numbers of referrals to this service and Fig. 4-3 the outcomes for carers in contact with the service.

**Fig. 4-2: Number of referrals to Somerset Partnership NHS Foundation Trust Carers Employment Support Officer (April 09-Sept 09)**

<table>
<thead>
<tr>
<th>Type of contact</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers referred</td>
<td>25</td>
</tr>
<tr>
<td>Contacts with Carers</td>
<td>97</td>
</tr>
<tr>
<td>Carers Meetings and Forums Attended</td>
<td>4</td>
</tr>
<tr>
<td>Number of Carers Services Team Meetings Attended</td>
<td>4</td>
</tr>
</tbody>
</table>

**Fig. 4-3: Somerset Partnership NHS Foundation Trust Carers Employment Support outcomes**

Proportion of Outcomes - Carers Employment Support

- 60% Information and Signposting
- 20% Onward Referral
- 20% Paid Work
4.10 Training for Carers

There are a number of training courses for carers which run across Somerset to enable carers to be better equipped to meet their caring role.

The courses currently available:

- St John Ambulance – run a four week course for carers: The Carer Support Programme, accredited by the Royal College of Nursing (RCN) covering: Carer’s Role & Basic First Aid; Benefits Advice & Managing Continence; Safer Moving and Handling & Preventing Falls; Stress Management & Relaxation Skills. Each course comprises of four mornings of three hours each for a maximum of 12 carers. Number of carers who attended in 08/09 = 593

Fig. 4.4 shows the main groups of carers receiving training from St John Ambulance

**Fig. 4-4: Percentage breakdown of types of carers attending St John Ambulance Training**

- There are separate parent carer courses run by St John Ambulance but gaps have been identified in courses for carers of
people who substance misuse and of Asperger’s; carers prefer not to mix with other types of carers for these groups

- St John Ambulance has also run six courses, in association with Somerset County Council Young Carers Project, covering First Aid and Looking after Themselves. Over 70 young carers attended

- St John Ambulance does not currently record ethnicity data for those carers attending training courses but this is to be introduced from April 2010

- The Expert Patients Programme Community Interest Company (CIC) - provides four Looking After Me carers courses funded by NHS Somerset and Somerset County Council for the period March 2008 to March 2009 with 44 carers attending in 2008/2009

- The Expert Patients Programme CIC is also working with the Department of Health to deliver Caring with Confidence modules in Somerset by the end of 2010. Caring with Confidence is part of the new national strategy for carers and provides courses free of charge to carers and carers’ organisations as funded by the Department of Health which also may cover alternative care arrangements and travel expenses for carers. Each course is a three hour session and there are a total of seven modules available. Anyone who has completed this course can apply to train to become an accredited tutor

- Somerset Skills and Learning – has previously run two courses for carers and recently set up a new carers group, which meets every five to six weeks; the theme of the sessions is Armchair Travel. Attendance ranges between 10-20 plus. Carers are invited to bring along the person they care for if they wish, which some do, whilst others prefer the time away from caring duties. Carers UK (Taunton) gave a donation of £250 to help towards set up costs; a contribution of £3 is paid by carers, which includes refreshments; some pay a bit less if they find this too costly. Other costs include venue hire, Armchair Travel sessions which are delivered by Reminiscence Learning at £85 per session, and staff time plus another helper

- Somerset Partnership NHS Foundation Trust:
  - 8 week Carers Education course on a rolling programme throughout the county
  - 6 week specialist carers courses around caring for people with dementia in all localities for 10-15 attendees at a time
  - Managing difficult behaviour – all day course for carers. Four per year run by specialist trainer for violence and aggression
- Turning Point is developing a family and friends course and will be training staff to deliver this. It will involve teaching strategies to family and friends, to use when living with a person who misuses drugs or alcohol.

4.11 Giving Carers a Voice

**What does the Somerset Multi-agency Strategy say?**

<table>
<thead>
<tr>
<th>Giving Carers a Voice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers will be supported in ‘having a voice’ immediate to their caring situation as well as influencing and shaping future policy developments</td>
</tr>
<tr>
<td>Source: Somerset Multi-agency Carers Strategy 2008-2011</td>
</tr>
</tbody>
</table>

There are a number of initiatives to ensure that carers are given a voice and involved in planning and decision making. These include:

- Somerset Multi-agency Carers Strategy Group - two Carers UK carer representatives, one from Taunton and District branch and one from East Somerset branch
- Somerset Partnership NHS Foundation Trust Carer Participation Group - to ensure that those carers of people with mental health needs are fully involved in the planning provision of mental health services
- Somerset Partnership NHS Foundation Trust Carers Steering Group – involvement in putting together the Trust strategy, implementation plan, policy issues
- Carer interview panel – panel of eight carers who can be drawn on to be involved in tender and job application interviews to influence decisions about appointments – Compass Disability Services are able to facilitate this as required

4.12 Specific services for different types of carers

This section looks at services provided in Somerset for specific carer groups some of which are mentioned in the Somerset Carers Strategy and some are not.
**Services for Parent Carers**

**What does the Somerset Multi-agency Carers Strategy say?**

There is no reference to parent carers in this strategy.

The main services for parent carers of children with disabilities in Somerset are provided by Somerset County Council, Children and Young People Directorate who are currently dealing with about 500 children with disabilities and their parents.

There are four Children and Disability Teams which consist of social workers and social worker assistants who carry out holistic assessments on the child and their family and provide information, advice and support. Previously there were coffee groups which no longer run through lack of interest and parents now tend to attend local groups based around the disability of their child.

Information is provided by the Social Workers and Social Work Assistant and the “Finding your Way” booklet is usually given out, although it was reported that this is now out of date but still a useful source of information for parents as a guide to what is available. Both staff and parents suggest this should be updated.

There is a new initiative called Aiming High for Disabled Children, which has been set up to provide a different approach to short breaks with an emphasis on prevention and engaging disabled children positively in the local community. This project is targeting 1300 children and commissioning a range of different short breaks, such as attendance at local scouts or cubs and other alternatives to avoid the need for residential provision.

If a residential short break is required then this is provided at The Elms in Curry Rivel and Beech Trees in Wellington which can be accessed via the social care teams.

The Somerset Parent Partnership is a free service providing impartial information, advice and guidance to all parents and carers of children with special educational needs (SEN). The service is statutory and funded by Somerset County Council but works closely with other agencies and the voluntary sector in Somerset. It provides a range of support to parent carers of children with special educational needs such as:

- A trained volunteer (Independent Parental Supporter) to provide support in a variety of ways in discussing and considering the child's needs
- Links to other services and agencies that may be able to offer additional support
• Advice on what to do if in disagreement about the child's educational needs
• Access to an independent and credible service for resolving disputes and disagreements

There are a range of parent carer support groups in place across the county and until recently a parent carer trainer at St John Ambulance running parent training and support groups.

There are two Children and Adolescent Mental Health Carer Assessment Workers on a pilot basis for 18 months which started in September 2009 and will be evaluated on an ongoing basis internally.

**Services for Young Carers**

What does the Somerset Multi-agency Carers Strategy say?

**Young Carers**

The following ‘key objectives’ relate directly to the work undertaken by the Young Carers Project.

**Key Objectives**

- Work will be undertaken to reduce disadvantage experienced by young carers
- Formulate plans regarding ‘hard to reach’ young carers
- Achieve more robust reviewing system to enable more young carers to participate in the Young Carers Project
- Employ a member of staff to work within Education/Schools to raise awareness and provide support in schools
- Secure long-term funding for young carers counselling support (separate to the service provided for adult carers)
- Improve the provision of information for young carers – using a variety of media

It is the aim of this strategy to be working towards there being no young carers actually providing caring hours/tasks. Caring hours/tasks should be provided with the young carers exercising choice and control alongside the person that they care for.

Source: Somerset Multi-agency Carers Strategy 2008-2011
The Young Carers Project was brought back into Somerset County Council Children and Young People Directorate in April 2003 from the National Children’s Home. The Project is currently managed by the Area Manager for Partnerships with two full-time Team Leaders and the equivalent of 3.75 full time project workers and two full time equivalent administrative staff. However, some of these posts are short- term funded and will end in 2011.

The Somerset Young Carers Project’s main aim is to support young carers to allow them to be a child first and a carer second. The priority is where the caring role is having a detrimental impact on the child or young person’s development e.g. difficulties at school, emotional difficulties, social isolation and to those children and young people who are sole (primary carers) in the household for five main carer types:

- Disability
- Long term ill health
- Mental ill health
- Problems relating to drug/alcohol abuse
- Diagnosed as HIV and or be experiencing illness relating to AIDS

The Young Carers Service has developed and works to link further with other services to ensure young carers are prevented from undertaking inappropriate caring. The aim of this is to ensure young carers are children first and carers second.

Since April 2003 the team has had approximately 900 referrals. Referrals are received from social workers, community psychiatric nurses, schools, health visitors or the young carer themselves. The Somerset Young Carers Project is currently working with 397 young carers.

The extended Pathfinder funding (ring-fenced until March 2011) is available to support young carers and their families and this has helped with the development of early identification/identification of hidden young carers. Prevention work in this area has been through raising awareness within schools, GP surgeries and the wider community. Staff meet regularly with adult services and offer support and advice to adult workers in helping them identify the needs of children in the families they work with.

Extra support for young carers, whose parents have complex health needs, is given by project workers co-ordinating the needs of the family with children and adult services.

There are 14 young carers support groups including two specialist groups – a sports group and a group for children affected by parental drug use.
• Taunton Juniors, West Somerset Seniors and Juniors, Bridgwater Seniors and Juniors, Axbridge Mixed, Street Senior, Frome Mixed, Yeovil Mixed, Wells Junior, Chard Mixed, Yeovil Bowling Mixed

• Some cover mixed ages and run on a fortnightly/monthly basis and are led by a Young Carers Project Worker supported by Youth Service/Sessional staff or Volunteers

• Also specialist days for instance Autistic, Mental Health, bullying issues etc

Each group offers support to up to 30 young carers at any one time, with an average of 20 young carers, except for Axbridge which is a small satellite group of about eight at present.

There is also a new Young Carers Forum with young carers across Somerset from different carer groups- e.g. parental mental health, sibling carer etc.

The Somerset Young Carers Project works to raise awareness within the community and works closely with approximately 16 community groups at present such as Rotary, Lions, and many individual beneficiaries who often donate, fundraise and support Somerset Young Carers through activities and events.

There is also a Friends of Somerset Young Carers Project that has charitable status and looks after money raised from community groups or from funding bids. The board of trustees allocates this money to various applications made by project workers which heavily benefits the service provision and opportunities for young carers across Somerset.

In the Somerset Carers Strategy there is reference to counselling support for young carers. The project has sought funding, however this is not long term and reapplications are being made. Children In Need funding was obtained for three years (£10,000 which is about to run out) and the intention is to reapply but with no guarantee of success. This provides five independent counsellors for young carers across the county and is not part of the Care First Adult Counselling service. The counselling service is well established and has supported many young carers so is seen as important.

**Services for carers of people with learning disability**

*What does the Somerset Multi-agency Carers Strategy say?*

**Carers of those with Learning Disabilities**

The following ‘key objectives’ relates directly to the work undertaken by the Learning Disabilities carers support service.
Key Objectives:

- Increase the numbers of carers receiving assessments
- Provide information and resources for families and carers
- Develop carer involvement and participation in the development of services
- Provide access to training and support for families and carers
- Carer awareness training will be included in all staff induction and development programmes (of partner agencies)
- Tackling ‘worklessness’ – carers that are economically inactive and that have low levels of self-confidence – will be a priority through the development of a countywide employment advice service

In achieving these objectives, work will be undertaken to align this Carers Strategy to the four principles of the Government White Paper – Valuing People: Rights, Independence, Choice and Inclusion.

Source: Somerset Multi-agency Carerers Strategy 2008-2011

Numbers of estimated carers of people with learning disability is approximately 693 in Somerset.

Carers of people with learning disability receive their assessment and support mainly from staff in the six Community Learning Disability Teams across the county who also deal with the person cared for. Carer Assessments can be carried out separately but the majority are completed via the single assessment for the person cared for.

Carers Support Workers or Carers Assessment Workers are rarely accessed by this group and carers receive their support from the worker allocated to the person cared for. However a Carer Support Worker is shortly to be recruited for the learning disability service but this person will take on more of a co-ordination role and will not be involved in Carer Assessments.

There are six support groups for carers of people with learning disability mainly facilitated by the Community Learning Disability Teams or Mencap and these are highly valued. There is also Somerset Learning Disability Partnership Board (SLDPB) which is co-ordinated by Somerset Advocacy.

Services for carers of people with Autism and Asperger’s Syndrome

What does the Somerset Multi-agency Carers Strategy say?

There is no reference to this group of carers in the strategy
There are an estimated 5300 people in Somerset with Asperger's and Autism and a large proportion of these will have carers. A commissioning strategy has been developed for 2010-2011 by Somerset County Council and NHS Somerset to address their needs.

Services for children with Autism and Asperger’s Syndrome in Somerset are provided by the Children and Young People Directorate, Somerset Community Health Services and Somerset Partnership NHS Foundation Trust. After a period of transition from age 16, adult services are provided by Somerset County Council Adult Social Care, Somerset Community Learning Disability Team, Somerset Community Health Services and Somerset Partnership NHS Foundation Trust.

In Children and Young People services in Somerset there are currently up to 18 month waiting lists for specialist services such as psychology, speech and language and occupational therapy. Families interviewed say they rarely see a social worker.

The Autism Outreach Team is made up of a Specific Language Impairment Team and an Autism Team. Both teams also include specialist resources based around Somerset as part of the Children and Young People Directorate. Parent carers report that this service works very well but only caters for children under 12 years old. The Educational Psychology team and the Autism Advisory Teacher is also described as very useful but with insufficient resources and overstretched.

Children with Asperger’s are dealt with via the Child and Adolescent Mental Health Services (CAMHS) and the Carers Assessment Worker who covers parent carers.

The Somerset Partnership NHS Foundation Trust has a specialist Asperger’s Team for adults based in Bridgwater; this receives referrals from all the Community Mental Health Teams within the Trust. The Asperger’s Team is currently very short staffed as apart from the full time manager and a psychologist (30 hours), the social worker and occupational therapist are on maternity leave and there is a nurse vacancy. The ability to expand and develop services for carers at present is therefore very limited. The team is unable to receive referrals directly as people first need to have been assessed as eligible for mental health services but Carer Assessments and support are referred to the Carer Assessment Workers. This service has recently been renamed and is the same service as the previously named Asperger’s Consultancy service.

For carers of adults with Autism support is provided by the Community Learning Disability Teams.

There are five specialist Autism and Asperger’s Carer Support Groups in Somerset (often combined) mainly run by volunteers. Those who attend highly
value these groups although numbers are very variable, often due to difficulties in finding suitable sitting services for the person cared for.

The National Autism Society operates the Burnham service which was developed to support adults with Autism and Asperger’s Syndrome in overcoming their isolation and becoming more involved with community activities and the Lynx Centre in Weston-Supermare provides advice and information, leisure activities, vocational training, support and befriending and work experience with some support for carers.

The Early Bird and Early Bird Plus Programmes run by the National Autistic Society, offers support to parent carers with children diagnosed with Autism or Asperger’s Syndrome for either pre school or 5-9 year olds.

**Services for carers of people with mental health needs**

*What does the Somerset Multi-agency Carers Strategy say?*

**Carers of those with Mental Health Needs**

The following ‘key objectives’ relate directly to the work undertaken by the Somerset Partnership NHS and Social Care Trust.

**Key Objectives:**

- Increase the numbers of carers receiving assessments
- Provide information and resources for families and carers
- Develop carer involvement and participation in the development of services
- Provide access to training and support for families and carers
- Carer awareness training will be included in all staff induction and development programmes (of partner agencies)
- Tackling ‘worklessness’ – carers that are economically inactive and that have low levels of self-confidence – will be a priority through the development of a countywide employment advice service
- In achieving these objectives, work will be undertaken to align this Carers Strategy to the Dementia Strategy and other key Mental Health strategies

*Source: Somerset Multi-agency Carers Strategy 2008-2011*

Somerset Partnership NHS Foundation Trust provides a dedicated service to carers via a team of nine Carers Assessment Workers and a manager, who carry out 58% of all Carer Assessments (see Section 5 for more details).
There is often a difficulty in identifying carers of people with mental health needs as most do not see themselves as carers but more dealing with family members who often have changing needs and support requirements at different times.

There is a range of practical and emotional support as well as assessment. The support provided helps reduce dependency on residential care and plays an important role in implementing the recovery model. Support is also provided with specific strategies around behaviour linked to emotional support.

Access to breaks for carers who are eligible for funding of £250 per year can be used flexibly and there is also access to emergency/crisis support. There is an advocacy role within the existing Carers Assessment Worker brief.

Support available for carers includes information, courses, free carers counselling, support groups, carer breaks, and more. There is a Somerset Carers Network website provided by Somerset Partnership NHS Foundation Trust for relatives and friends who care for people in Somerset with mental health needs.

Somerset Partnership NHS Foundation Trust also provides an employment support service to carers by allocating 25% of the Employment Advisor time to carers. (See Section 4 - Employment for more details).

The Carers Participation Group meets bi-monthly and is chaired by a carer with 20 carer members. The only staff who attend are the Somerset Partnership NHS Foundation Trust User and Carer Development Manager and the Employment Officer. This provides an opportunity for carers to influence future planning, policy and service developments and share information. Two members of this group sit on the Member Council for the Somerset Partnership NHS Foundation Trust. There is also a Patient and Carers Experience Group made up of service users and carers voicing feedback about services and a Carers Steering Group which consists of four carers and staff from each of the Trust directorates, which drives forward the Trust Action Plan and Trust Carers Strategy.

Rethink offers support to carers. It formally offers three Rethink carer groups in the county and informally is involved with others. These groups link to Rethink services to ensure carers are communicated with and are aware of the basics such as Health & Safety Risk assessments etc. Rethink generally supports carers by giving information, reassurance and sign posting as necessary. There are four registered Rethink groups in the county. Three of these (Windows Burnham on Sea), Ilminster, Chard and Langport and Somerset Carers and Relatives group are run by carers and are supported by Rethink nationally and are linked to a local staff member who provides support as and when required. These staff members take no part in the running of the group. These are not commissioned groups but self-funded apart from the occasional access to the £250 grant that is available on an annual basis from Somerset via Carers UK.

The fourth group is run by a Somerset Carers Assessment Worker and is part of the service provided by the Somerset Partnership NHS Foundation Trust. There
are other groups (not registered with Rethink) which are also run by the Carers Assessment Workers (see Section 5)

Rethink estimate that approximately 50% of their work is with carers providing support, information and signposting.

Mind is represented by three individual charities in Somerset, known as Local Mind Associations (LMAs): ‘South Somerset’, based in Yeovil; ‘Taunton and West Somerset’ and ‘Bridgwater’. Services in each Local Mind Associations vary and are commissioned through either application to tender or direct negotiation between commissioner and provider. Recent developments to the way in which the LMAs have worked together to cover the County allows for one Local Mind Associations to commission for and deliver services across the whole of Somerset.

All three Local Mind Associations have worked with carers and those that they care for either in the form of carers groups, providing support from a distance over the phone or encouraging people to engage with activities or projects that are ongoing at the centres. South Somerset Mind currently runs a project that promotes and introduces direct payments and individual budgets to carers.

**Services for carers of people with dementia**

<table>
<thead>
<tr>
<th>What does the Somerset Multi-agency Carers Strategy say?</th>
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<tbody>
<tr>
<td>The only mention about dementia is:</td>
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*Work will be undertaken to align the Somerset Carers Strategy with the Somerset Dementia Strategy*

The National Dementia Strategy, Living well with dementia\(^{21}\) and Somerset Dementia Strategy both outline the rising number of people with dementia and consequently carers over the next 20 years.

Somerset Dementia Strategy\(^{22}\) was developed with carers and identifies the key areas of service delivery for people with dementia and their carers across Somerset. Objective 7: Implementing the Carers Strategy states:

“Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This

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\(^{21}\) The National Dementia Strategy – Living well with dementia, Department of Health 2009

\(^{22}\) Somerset Dementia Strategy, March 2009
will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.”

The Somerset Dementia Strategy has two specific references to carers in its work programme:

- Existing services available to carers will be reviewed, gaps identified and recommendations made for improving services where appropriate in 2009/10
- To implement plans for improving support available to carers of people with dementia in 2010/11
- To monitor on an ongoing basis effectiveness of support available to carers of people with dementia in 2011/12

There are two specialist older people’s Carers Assessment Workers whose majority of work is with carers of people with dementia.

The Alzheimer’s Society is very instrumental in developing services locally with six memory cafés, five “Singing for the Brain” groups and involvement in the Dementia Advisor pilot which is developing in partnership with statutory bodies and proving beneficial for carers.

The new Dementia Advisor Service provides an enhanced service for people with dementia and their carers which encourages self referral. There is one full-time and three part-time (2.5 WTE) Advisers covering the whole of the County. The Advisers are mobile, although the three part-time Advisers (who cover the East) have a base in Taunton, and the full time Adviser has a base in Wells. The project is a partnership between Somerset County Council, NHS Somerset and the Alzheimer's Society who manage the service on a day to day basis through a Service Level Agreement.

The Alzheimer’s Society runs two main services across the county.

**Singing for the Brain (S4tB)**

This service is primarily aimed at the person with dementia to help stimulate and build confidence but the carer also attends; partly to give support, but also so that they are able to experience time with the person they are caring for which is not just about have to look after them. It gives a couple (whether spouses, or parent/child, siblings, friends etc) the opportunity to have fun together and put across the message that having dementia/caring for someone with dementia does not have to mean the end of a social life and having to face the future alone.

**Memory Cafe**

Memory Cafes are for the carer and the person they are caring for to gain information and support. They are peer support groups which also provide a
source of information such as printed information from the Alzheimer’s Society and other relevant organisations. There are also speakers to provide information such as Power of Attorney, Finance and Benefits, Home safety from the police and fire service, as well as more fun sessions such as pampering with mini manicures and hand massages, and introducing music etc. Again these are designed for the couple to come to together. The café provides an opportunity for the carer to have a break from caring whilst they are at the cafe as well as games, books, music etc to stimulate the person with dementia. Numbers can range from 8-40 people in attendance.

Both the Singing for the Brain and Memory café services are non-commissioned and provided through a range of different funding streams such as charitable trusts. Three are funded by Somerset Community Foundation via the Grass Routes grant (which only lasts a year), three have funding from Somerset County Council from a Health Improvement grant which will last for one year, and one is paid for with money raised through fundraising. One memory café is provided through an Active Living Centre in Yeovil and two Singing for the Brain (Wells and Castle Cary). There is a paid worker at each session but they both largely rely on volunteer support and ongoing funding is an issue. These services can be accessed directly and people can just turn up without the need to book in.

Rethink provide the Reconnect service, which is a floating support service for dementia and memory problems which covers four Supporting People areas: Somerset, North Somerset, Poole & Bournemouth. The purpose of the service is to provide housing related support to allow people to remain at home and independent for longer. Carers in North Somerset have approached Rethink to set up a carer’s group which is now taking place with a very motivated group of carers proactive in establishing the group and fundraising to support its development. This may be something which could be replicated in Somerset if required.

St John Ambulance has also added a Dementia and Memory Loss module to their Carer Support Programme from April 2010.

Services for carers of people who misuse drugs or alcohol.

What does the Somerset Multi-agency Carers Strategy say?

There is no reference to this group of carers in the Somerset Carers Strategy

The Somerset Drug and Alcohol Action Team (DAAT) is a strategic partnership responsible for implementing locally the national drug and alcohol strategies. Core partners include NHS Somerset, Somerset County Council, Avon & Somerset Constabulary and Avon & Somerset Probation. These partners pool their resources to jointly commission a range of services in relation to drug and alcohol misuse.
In October 2008, the Somerset Drug and Alcohol Action Team (DAAT) commissioned Evidence Base Ltd to conduct an in-depth study in order to identify the support needs of carers and family members in Somerset and to plan the delivery of effective, quality support services that reflect the needs of carers and family members in the county.

The study report “Supporting Carers & Family Members affected by the Substance Misuse of Others, A Somerset Study” (Collins, January 2009) details the findings from the work. However a number of key recommendations were made that the Drug and Alcohol Action Team (DAAT) is committed to take forward. These are outlined below:

- Develop a range of integrated and personalised services in Somerset to ensure that carers and family members can access the support they need
- Improve access to information about support services available for carers
- Family members in Somerset.
- Raise awareness in Somerset of the impact that a person’s substance misuse problems can have on the lives of carers and family members.
- Joint working in order to provide a seamless service
- Involve carers and family members in service planning and delivery

The implementation of these recommendations is part of the forward plans for the Drug and Alcohol Action Team (DAAT) partnership. At present, the availability of specific support services for carers affected by others substance misuse in Somerset is in the early stages of development following a variation to contract by the DAAT with Turning Point.

Turning Point was awarded the contract to provide an integrated drug and alcohol treatment service in Somerset in April 2008. During the first year of this contract Drug and Alcohol Action Team (DAAT) partners negotiated with them to enhance the services to carers & family members by providing carer assessments and support services.

Turning Point is also contracted to provide a telephone service and advice and information for service users, carers and family members; 9-5pm weekdays and until 8pm one day a week. It also runs support groups for carers called Family Support Groups, in Bridgwater and Yeovil (monthly) and in Taunton (fortnightly) with another group being set up in Mendip later in 2010.
Fig. 4-5: Attendance at Turning Point Family Groups

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<th>South Somerset</th>
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The Somerset Partnership NHS Foundation Trust and Turning Point operate a dual diagnosis joint working protocol to ensure that effective services are delivered for people with both substance misuse and mental health problems and this will impact on the carers of these service users requiring additional co-ordination of services for those carers.

In Touch Project is a small project set up by a group of volunteers who themselves have been affected by someone else's drug or alcohol use and found it difficult to find help and support. Their aim is to provide a confidential, supportive, informative and therapeutic range of support for anyone over 18 affected by someone else's substance misuse. They believe in getting more people in touch with a service and in touch with each other, and feel this will help reduce isolation. The Drug and Alcohol Action Team (DAAT) provides an annual grant to them for their development.

Based on the Recovery Wheel designed by one of the members, In Touch offers a range of options, including a telephone line, website, a range of books and videos, informal meetings to explore options of help and support including information on self help/support groups. They often 'buddy' along to a new group if desired. Information and education have been offered in a variety of settings, including a series of one day workshops. A recent Information Day brought together many services that provide support, enabling people to build their own support networks. There is also the opportunity to access Bowen therapy.

A range of respite opportunities have taken place and two people have been able to access residential family programmes via the project. The project carries out a number of fundraising activities which gives people an opportunity to have fun whilst raising funds to help maintain the project. At present the project is still small, but there are a number of ideas for the future, including a newsletter which is in process, and a range of new workshops. The project also gives an opportunity for people to become volunteers themselves.
4.13 Equalities

What does the Somerset Multi-agency Carers Strategy say?

Equalities

All carers within Somerset will have access to services and information appropriate to their caring needs irrespective of age, gender and ethnicity.

Key Objectives:

- Black, Minority and Ethnic (BME) groups carers will be given accessible information on the services available to them
- Those staff working with BME carers will be encouraged to make use of available resources for those whom English is not their first language
- The recommendations set out in the Equalities Impact Assessment will be implemented

Source: Somerset Multi-agency Carers Strategy 2008-2011

There are a few specific equality initiatives to ensure carers are not discriminated against in Somerset:

- Somerset County Council Employees Carers Network
- Somerset County Council and Somerset Partnership NHS Foundation Trust have reference to carers in their staff induction programme
- Somerset County Council supervision policy make reference to support to carers
- Care First counselling service was developed from the Somerset County Council employees counselling
- From 1st April 2010 new service level agreements to be in place with organisations yet to be agreed to represent the Black and Minority Ethnic community which will include carers
- The South West Lesbian, Gay and Bisexual Equality Network (SW LGB) is a forum of and for Lesbian, Gay and Bisexual (LGB) people within the South West with approx 211 registered contacts in Somerset although a proportion of these will be representatives of interested organisations
**Equalities**

The Somerset Multi-agency Carers Strategy makes reference to the fact that “All carers within Somerset will have access to services and information appropriate to their caring needs irrespective of age, gender and ethnicity” and then sets objectives for people from Black and Minority Ethnic groups. It does not make reference to other equalities groupings which is a gap which will need to be addressed in the revised strategy.

**Services for carers from black or minority ethnic groups**

All services in Somerset are available to Black and Minority Ethnic groups but the challenges are whether they are tailored appropriately. Somerset County Council works closely with the Somerset Racial Equality Council (SREC) to ensure its services meet the needs of people from black and ethnic minority groups. Within this organisation are associations linked to the various communities e.g Midwest European Communities Association.

A staff handbook has been produced to raise awareness amongst Somerset County Council staff to respond better to the needs of the black and ethnic minority population but it is beyond the remit of this review to identify how well used this is or what effect it has had.

E-quality 4 Mental Health provides a service for Black and Minority Ethnic Communities in Dorset and Somerset with a dedicated website providing information. There does not appear to be any other dedicated services for Black and Minority Ethnic groups in Somerset.

The Association of Directors of Adult Social Services (ADASS) study on hospital discharge and carers found relatively little evidence about the experience of carers from Black and Minority Ethnic groups (BME) within hospital discharge processes. Whilst there is material relating to the area of mental health, evidence of how discharges from acute hospitals impact on Black and Minority Ethnic carers appears to be very sparse and would be worthy of further consultation.

Peter Fletcher Associates were asked to make use of the local Somerset County Council consultation mechanism in consulting with Black and Minority Ethnic communities and attended the Somerset Racial Equality Council (SREC) to outline the review but unfortunately this coincided with the new tender process for commissioning this service and therefore only produced feedback from Polish and Portuguese Communities (see Section 6).

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23 Carers as partners in Hospital Discharge – ADASS February 2010
Services for carers from Gypsy and Traveller groups

In July 2009 there were 2486 Caravans in the Southwest of which 18% (447) are in Somerset across both approved site and illegal sites. The numbers have reduced by 119 caravans since 2007. The numbers have increased in South Somerset, reduced in Mendip and West Somerset and remain unchanged in Taunton and Sedgemoor.

There are no specific carers services for this group of carers who would access mainstream services depending on the type of illness or disability of the person cared for.

In planning or providing services for carers, the needs of Gypsy and Traveller groups must be taken into account with particular attention being paid to findings from previous studies:

- Ensure no prejudice or discrimination from professionals
- Build a relationship of trust with one person
- Ensure diversity training covered issues around Gypsies and Travellers
- Ensure GPs are allowing Gypsy and Travellers to register so that people are not forced to seek primary care through Accident and Emergency clinics
- Make use of hand held records for Gypsy and Traveller patients so that screening and treatment of patients can be more streamlined with information about carers readily available
- Recognise that Gypsy and Traveller’s attitudes to health services often demonstrate a cultural pride in self-reliance with more trust in family carers rather than in professional care; more support to enable carers to continue in their caring role may therefore be required
- Ensure services are available on an episodic basis, at times of crisis and with the ability to know how to make contact again in the future

4.14 Voluntary and community sector

What does the Somerset Multi-agency Carers Strategy say?

Providing Third Sector Support

To develop and work with Somerset’s voluntary and community sector organisations providing support to Somerset’s carers. This will be done in accordance with the Somerset Compact

Key Objectives:

- To support and work with Carers UK (Taunton and District) and Carers UK (East Somerset) respectively to ensure equity of service across the county
- To maintain and develop new partnership arrangements providing support to Somerset’s carers

Source: Somerset Multi-agency Carers Strategy 2008-2011

There are a number of voluntary and community sector organisations that also provide services and support to carers in Somerset. The type of services provided for carers can be broadly summarised as:

- Information and advice
- Counselling or emotional support
- Sitting or overnight stay respite
- Practical support such as shopping, transport, befriending or domestic care
- Financial assistance
- Brokerage or payroll support

The main organisations which provide these services in Somerset and that have been consulted in the appraisal are as follows though there may be others:

- Age Concern Somerset
- Alzheimer’s Society
- Carers UK
- Compass Disability
- Crossroads
- Headway
- Huntingdon’s Association
All of these voluntary or community organisations provide services both to people who are cared for and support to carers. Details of the services can be found in the separate detailed mapping document and summary in Appendix 1.

The voluntary and community sectors play an increasingly important role in providing services to carers across Somerset and feedback from carers in Section 6 shows this is highly valued. Current services play a key role in training and support around specific conditions, information and advice but this is often provided by charitable trusts and not commissioned. With the move towards more personalisation and choice there will be a need for a wider range of creative and diverse solutions to respond to individual needs and the opportunity for larger voluntary organisations to attract additional alternative funding not normally available to statutory agencies.

**Carers UK**

Carers UK are a national membership organisation which is led by carers for carers and has two branches in Somerset: Taunton and District and East Somerset. Carers UK local members have been fully involved in the Somerset review and members have been part of the Project Management Group, Carers Advisory Group, Carers Panels and other consultation meetings. No research has been carried out on how carers view the local or national Carers UK but Carers UK members receive:
• A quarterly member magazine called Caring, with the latest information on caring, carer stories and how Carers UK is making a difference
• A free telephone advice Carers Line which provides advice on all aspects of caring
• Free information booklets covering a wide range of topics from carer benefits to practical help
• An invitation to a Members Conference and Annual General Meeting
• A voting right on electing Carers UK Trustees, the majority of whom are carers themselves and who ensure Carers UK is carer-led

There are also over 30 courses offered to members on topics such as community care law, carer rights and benefits to health and social care professionals, advice workers, employers, lawyers and others who work with carers.

There are two Carers UK branches in Somerset both of which are commissioned through Service Level Agreements by Somerset County Council.

East Somerset Branch has 35 members and Carers UK Taunton & District Branch has about 60 members. Their main function is promoting awareness of carer issues, reaching unknown carers, raising funds for carer emergencies via recommendations of Carers Support Workers and Carers Assessment Workers.

Taunton and District branch administers a grant scheme across the whole of Somerset with funding from Somerset County Council; any organisation supporting carers in Somerset can apply.

Carers UK has been commissioned by the Department of Health through the Deputy Regional Director, to look at ways of improving training for staff on carers issues and a questionnaire was circulated in October 2009 and results are due out shortly.

Following a successful bid to Carers UK, WyvernHealth.Com (Somerset’s Practice Based Commissioning Consortium) and St John Ambulance are delivering Carers Awareness Training to practice staff through a two phased delivery programme. (See earlier section on Health and Wellbeing).

### 4.15 Independent providers

<table>
<thead>
<tr>
<th>What does the Somerset Multi-agency Carers Strategy say?</th>
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<tbody>
<tr>
<td>There is no reference to independent providers in the Somerset Multi-Agency Carers Strategy.</td>
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</table>
There are also a large number of independent domiciliary and residential care and support providers providing services to the cared for person and by doing so support a large number of carers. During the Carers Panel process four providers were interviewed: A4E, Brunelcare, Somerset Care and Wayahead (see Section 6).

The key services provided which benefit carers are short breaks and sitting services.

Anecdotal feedback from carers and care providers suggested that whilst there are formal arrangements for sitting services and crisis support etc. many of these are either funded privately by carers or absorbed into a wider support package for the cared for person. A sitting service is used as and when required from the Home Care Budget.

There are 33 respite care beds available in Somerset purchased at SCC rates for 52 weeks per year in a range of residential and nursing care homes. Fig. 4-6 shows the number and distribution of respite care beds across Somerset whilst Fig. 4-7 shows a map of Somerset and location of respite beds in residential or nursing care homes.

**Fig. 4-6: Number and distribution of respite care beds across Somerset**

<table>
<thead>
<tr>
<th>District</th>
<th>No. of beds</th>
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<tr>
<td>Mendip</td>
<td>5</td>
</tr>
<tr>
<td>Sedgemoor</td>
<td>8</td>
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<tr>
<td>South Somerset</td>
<td>9</td>
</tr>
<tr>
<td>Taunton</td>
<td>5</td>
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<tr>
<td>West Somerset</td>
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Fig. 4-7: Map of Somerset showing location of respite care beds
5. The role of Carers Support Workers and Carers Assessment Workers in Somerset

This section outlines and analyses the unique role that Carers Support Workers and Carers Assessment Workers play in the delivery of assessment and support for carers across Somerset.

5.1 Carers Support Workers

Background

A network of Carers Support Workers was established in 1993 as part of the Somerset County Council Carers Project. At that time Somerset was one of the few local authorities to provide a specialist professional for the carer who offered separate Carer Assessment, provide specific information for carers and support to help maintain their caring role. This role has continued to develop over the past 15 years in Somerset and Carers Support Workers today still play a valuable role in assessing and supporting carers to continue with their caring responsibilities and are seen by many as an important part of the Somerset Carers network. This section outlines their function, location, caseload, line management arrangements and their role in carers support groups.

Functions

The job description has recently been revised to include a more generic role of Adult Social Care Worker with a carers support role. There are four key functions of a Carers Support Worker role:

- Assessment
- Support – practical and emotional
- Educational/promotional
- Signposting

The assessment part of the role enables a carer to exercise their right to a Carer Assessment but also for this to be carried out by an independent member of staff other than the Social Worker or Occupational Therapist who care co-ordinates for the cared for person. In the majority of cases the Social Worker or Occupational Therapist will undertake a single assessment with the cared for person which includes an assessment of the carer’s needs but in 94% of cases the Carers Support Worker carries out the separate Carer Assessment if required (see Section 4 - Assessment).
The support function is provided by the Carers Support Worker either by meeting with the carer on a one to one basis for an open ended number of sessions or providing support via the Carer Support Groups which many Carers Support Workers used to facilitate and which several still attend. The support provided is both practical and emotional support and may also take the form of an advocacy role for the carer.

The education role of the Carers Support Worker provides a range of information to carers such as financial benefits in order to maximise take up; types of services available or condition specific information. The role also provides an educative and awareness function to other agencies and Adult Social Care teams about carer needs; this often prevents the need for a referral to a Carers Support Worker.

**Location**

Carers Support Workers were originally located in GP surgeries with the aim to ensure that the GP Carer Register was not only kept up to date and used proactively, but that carers had a chance to be recognised as such. It was envisaged that awareness amongst GPs would be raised and that carers would also receive health checks without having to request them.

In reality Carers Support Workers were thinly spread and covered about four GP surgeries each, therefore not based in every surgery and often given a base out of reach of the GPs who they rarely saw. This differed between GP surgeries, some of which report they greatly valued the Carers Support Worker role which prompted them to ask about carers’ needs when seeing a patient that day.

More recently there has been a move to bring Carers Support Workers back into Adult Social Care teams which GPs, some Carers Support Workers and some carers see as a retrograde step whilst others see as a positive move. Although Carers Support Workers were based in GP surgeries they were often not recognised as part of the clinical team and a recent example sited that a Carers Support Worker who had left the GP practice 18 months ago was not known to have left and rent still being charged for. Similar examples have been given at the St John Ambulance /Carers UK carers’ awareness training in March 2010 which found that several GP practices named their Carers Support Worker as staff that had left their post but practice staff were unaware of this.

There are still a few Carers’ Support Workers based at GP surgeries but some practices charge for this, others charge a peppercorn rent whilst others are free. The total cost for the current financial year is £7,956 for Carers Support Workers based in GP practice bases.

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25 Evidence obtained from talking to 10 GPs at a Wyvern Health Board meeting.
Some Carers Support Workers have found the move back to Adult Social Care Teams very positive by raising awareness of carers issues in the teams, enabled easy access to Carers Support Workers and more opportunity for separate assessments although it is still too early to identify any difference in referral rates at this stage.

**Line management**

The Somerset County Council Carers Lead previously line managed the Carers Support Workers via a Senior Carers Support Worker. There was one Senior Carers Support Worker in each of the four local areas who each line managed four Carers Support Workers in each local area. There were regular countywide meetings and Carers Support Workers valued the opportunity to meet with their peers. There has recently been a change in arrangements and Carers Support Workers are now line managed by the Adult Social Care Team Managers; having been brought under the umbrella of these local teams and moved out of GP surgeries. The Adult Social Care Team Managers (most of which attended an Operational Managers meeting attended by a Peter Fletcher Associate), seemed unanimous that this arrangement is working well from their perspective and allows them better access to the Carers Support Workers but there are clearly mixed views about this arrangement by Carers Support Workers.

**Caseloads**

The Carers Support Workers caseload is generic and originally was designed to cover all carers whether of adults, children or any type of disability, though carers of people with learning disability, drug and alcohol and parent carers do not appear to receive this. During November 2009:

- 330 hours were deployed of Carers Support Worker time
- Total Carers Support Worker caseload was 273 carers
- 74 referrals were received in the month
- There were vacancies in Mendip and South Somerset though these may now have been filled (posts not frozen)

Source: Somerset County Council Information Team - November 2009

There has been some confusion about whether the Somerset Carers Strategy and the Carers Support Workers also covered parent carers. Many parent carers were not aware of the Carers Support Worker role but is has been confirmed by the Project Management Group that this service is available to parent carers which is an area that needs development.

Whilst Carers Support Workers carry out Carer Assessments and provide support to carers, feedback suggests that this involves visiting a maximum of three times before closing the case or offering ongoing support in a limited way via Carers...
Support Groups. The Carers Support Workers carry no waiting lists at present and anecdotal feedback from the adult team managers is that Carers Support Workers are not as pressurised as social workers and able to provide a support service which social workers are no longer able to do. However this is now changing and Carers Support Workers are encouraged to close cases and have a faster throughput with a more generic role in some teams. Unless the case is open, if the carer makes contact they must go via Somerset Direct as a new referral, though usually this is allocated back to the same Carers Support Worker again.

Approximately 33% of Carers Support Worker posts are currently vacant equating to 50 hours per week; although in some cases these hours have been re-allocated within the existing staffing group or advertised as more generic adult posts with a Carers Support Worker focus.

There are times when the Somerset Partnership NHS Foundation Trust Carers Assessment Worker will refer on to the Carers Support Worker. There are two reasons for this:

i) When a carer is referred to attend a generic carers support group where no mental health carer’s group exists

ii) When joint working with the Carers Support Worker is required due to a carer caring for more than person or where the person has a complex physical disability and mental health problems which require the skills of both workers.

Support groups

In the past Carers Support Workers ran support groups as part of their remit to reach out to unknown carers and offer information groups. There is now a view by commissioners that Carers Support Workers should not be running Carers Support Groups, but are able to attend some meetings to provide information and advice.

There appears to be a difference in how this is interpreted across the county with some Carers Support Workers still running groups, others taking the view that if they do not dip into groups regularly carers would not get information about Adult Social Care, whilst in some areas carers or volunteers are running the groups themselves. We identified at least two Carers Support Groups which are now run by former Carers Support Workers on a voluntary basis having left their Somerset County Council posts.

Many support groups consist of carers who have been attending for several years and also a number of ex-carers in attendance who value the ongoing support once their caring responsibilities have ceased.
In many other counties Carers Support Groups are run by volunteers or voluntary organisations and the pros and cons of this option will be further discussed in Section 8-12 of this report.

### 5.2 Carers Assessment Workers

Carers Assessment Workers are employed by Somerset Partnership NHS Foundation Trust and offer a similar role to the Carers Support Worker but only to carers of people with mental health needs and occasionally people with learning disability and mental health problems who are known to Somerset Partnership NHS Foundation Trust.

There are three full-time and two part-time Adult Carers Assessment Workers who are based in Mendip; South Somerset; Somerset Coast; one job share in Taunton; two full time Older People Carers Assessment Workers based in South Somerset; Somerset Coast and East Somerset; two Children and Adolescent Mental Health Services Carers Assessment Workers based in East and West Somerset.

Carers Assessment Workers carry out the majority of all the Carers Assessments for Somerset Partnership NHS Foundation Trust (94%); the rest are carried out by other professionals within the organisation.

Carers Assessment Workers all have a mental health background and most have had experience of working in mental health services for many years.

**Functions**

The function is similar to that of Carers Support Worker with more of an emphasis on assessment and specialist mental health support but with a range of other functions which include:

- Specialist assessment
- Signposting
- Emotional support
- Support groups
- Crisis response
- Support programmes
- Carers Breaks - financial support
- Employment advice
- Networks and links, including GP practices
Each Carers Assessment Worker takes about three hours to complete a Carer Assessment and there is an offer to work with the carer until they get to stage of setting up a Carer Recovery Care Plan or ongoing support with goals set for carers. Carers can contact the Carers Assessment Worker at any time, either by email or mobile phone.

**Caseload**

Carers Assessment Workers have a varied caseload of about 35 carers each (300 in total in the team) at any one time depending on need but as carers can re-refer this is not a finite number and there is also ongoing telephone work which is encouraged.

During 2009/10 there were 1121 Carers Assessments completed by Somerset Partnership Foundation NHS Trust, of which 1057 were carried out by the Carers Assessment Worker Team which is 94% of all assessments. If the carer has support needs then a Carer Recovery Plan is also completed by the Carer’s Assessment Worker as well as providing emotional and practical support to the carer.

Until recently Carers Assessment Workers were carrying out annual carer reviews but now only are able to do this if the carer requests this. A carer can usually be seen within a month if requesting a reassessment and often the Carers Assessment Workers are working with carers in crisis.

Somerset Partnership NHS Foundation Trust use the RiO electronic case record and carers have their own section which can be highlighted as a hyperlink on the cared for person’s record making it possible to cross reference between the two (a facility which Somerset County Council SWIFT System does not allow).

Carers Assessment Workers have access to all Somerset Partnership NHS Foundation Trust training and are supervised by the Carer’s Assessment Team Manager who is the Users & Carers Development Manager. Team meetings are held monthly and are well attended and well structured. There is also a peer support meeting monthly which it has been agreed with commissioners that managers do not attend.

**Carers Support Groups**

The Carers Assessment Workers have a role in supporting three mental health Carers Support Groups – one in Mendip, one in Yeovil and one in Bridgwater. The Carers Assessment Workers are encouraged to support these groups and are seen as a good way to meet a large number of carers together yet offer the opportunity for one to ones with carers before or after the meetings as required. Carers also do not have the time or energy to run groups themselves.
There are two Carers Support Groups in Taunton which are run by Rethink and other groups across the county run by carers for carers or other Trust staff. These groups are highly valued by the carers who attend. There are also 10 Autistic spectrum disorder carers groups run by carers.
6. Stakeholder perspectives

This section of the report outlines the feedback obtained during the consultation and engagement process with the carers and other stakeholders as outlined from Section 3: Methodology.

From the consultation feedback it was clear that there are a number of generic issues common to all carers plus a unique perspective from each of the different types of carers in Somerset who have their own specific needs.

6.1 Carers views

Questionnaire feedback

A questionnaire, designed by the Carers Advisory Group, was distributed to 1,000 adult carers in Somerset with a 32.3% response rate of 323 and 13 duplicated.

Figs. 6-1, 6-2 and 6-3 show the breakdown of responses by area, gender and ethnic origin.

Fig. 6-1: Breakdown of responses by area

![Graph showing percentage of carers living in different areas of Somerset](image)

Fig. 6-1 shows that there were responses of between 8% and 28% across each of the five localities with the least number from West Somerset (8%), the highest number from South Somerset (28%) and 4% who did not answer to this question.
Fig. 6-2: Breakdown of responses by gender

![Graph showing gender breakdown]

Fig. 6-2 shows that a higher proportion of carers who responded were female which equates with the national findings that more carers tend to be female:

- 23% (73) respondents were male
- 74% (234) respondents were female
- 4% (11) unanswered

Fig. 6-3: Breakdown of questionnaire responses by ethnic origin

![Graph showing ethnic origin breakdown]

Fig. 6-3 shows that the highest proportion of responses were from carers who are of White British origin which reflects the Somerset population of 97% White British. 2.7% of respondents to this questionnaire were from Black or Minority Ethnic populations, but this is not surprising as the questionnaire was not circulated widely or translated for Black or Minority Ethnic groups. Instead
Somerset County Council chose to set up four separate focus groups as outlined in Section 6.3.

### 6.2 Generic issues / common experiences

Irrespective of the type of condition of the cared for, questionnaire and face to face respondents described a number of common experiences and generic issues which broadly fit under the priorities of the Somerset Multi-agency Carers Strategy:

- Identification of carers
- Information
- Assessment
- Practical support (including short breaks)
- Emotional Support
- Health and well being
- Finance
- Work, leisure and learning
- Recognition

#### Identification of carers

Most carer groups identified problems with not knowing about Carer Registers, GPs not completing them or being recognised as carers by agencies. The results of the questionnaire showed that only 48.6% of respondents thought they would be known about by the statutory agencies.

- 48.6% (161) of questionnaire respondents thought they were known to NHS, Social Services or other agencies
- 18.7% of responses to the questionnaire were from unknown carers
- 10.3% said “don’t know”
- 19.3% stated “some but not all”

#### Information

Information was frequently cited as one the key priority areas for improvement by all types of carers either due to a lack of information, not knowing where to go to find it, or too much information at the wrong time.
• 73.4% (243) carers who responded to the questionnaire said they knew how and where to ask for help for themselves but in face to face meetings most carers described either a lack of information or too much information at the wrong time

“There is far too much information from too many sources and choice paralysis…Carers do not want to read another strategy document that ticks all the boxes on paper but does not deliver …” (Somerset Carer)

Carers spoke of the need for time to digest information and would prefer to be fed it gradually or know where to go for information as and when it is needed. There were often complaints of information being full of jargon and the need for it to be regularly updated and localised.

The questionnaire highlighted other aspects about information requirements:

• 64% (202) of respondents were given enough information about the condition of the person they are caring for

• 42% (134) of respondents were given enough information about the impact of the condition on them as a carer and their family

• 43% (137) of respondents were given enough information about support and financial benefits for carers

• 51% (168) of respondents said they would like more information on support to carers

There were 46 responses regarding information and advice in the qualitative section of the questionnaire asking for comments or suggestions for improvement and this was the largest theme.

It should be noted that nearly half of the carers, 48.6% (161), who responded to the questionnaire said they were known by NHS or statutory services so it would be expected that this number at least would have been given sufficient information.

Communication with carers needs to be simple and to the point, but don’t assume we also have a disability (Somerset carer of person with learning disability).
The questionnaire also asked carers where they most frequently obtained their information; this is shown in Fig. 6-4:

- 59.8% (141) of respondents (highest score) received their information via Somerset County Council or NHS staff, which would include Carers Support Workers or Carers Assessment Workers
- 37.5% (124) was word of mouth or carers groups
- 32.6% (108) from meetings or events
- 19% (63) other organisations
- 13.9% (46) information leaflets
- 13% (43) Somerset Direct
- 7.3% (24) Local papers
- 6.3% (21) Your Somerset - Somerset County Council newspaper
- 3.9% (13) Local radio
- 2.1% (7) Patient Liaison Service
- 1.2% (4) Somerset County Council website

**Assessment**

The Carers Advisory Group suggested that the term “assessment” is not always known about by carers so it is not specifically referred to in the carers questionnaire; instead carers were asked whether they know they are entitled to talk to someone about their needs as a carer and if so had this happened:
• 73.4% (243) carers said they knew they were entitled to talk to someone about their needs as a carer

• 3.6% (12) carers said they had been asked about their needs

Of the few carers who had had an assessment some were frustrated by the lack of positive outcomes following the assessment with comments such as "what was the point?" or "what a waste of money".

**Practical support**

Less than 30.2% of carers who responded in most areas said they know how and where to ask for help and the questionnaire responses showed a very similar pattern for all areas as shown in Fig. 6-5.

**Fig. 6-5: Do you know how and where to ask for help**

**Q1 and Q23 Where to ask for help by area**

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**Short breaks**

Breaks can mean a sitting service in someone’s home, an overnight stay away from home or an opportunity for the carers to have time on their own in whatever way they choose.

Apart from information, the need for a break was the biggest common issue raised by carers:

• 55.3% (183) of respondents to the questionnaire had been given information about taking a break from caring
• 64.8% (206) of carers said they carry out a caring role for more than 40 hours per week

• 37.9% (78) of carers who care for over 40 hours per week said they had not received information and advice about opportunities to take a break

• 33.3% (16) of carers who care for 21-40 hours a week said they had not received information and advice about opportunities to take a break

• 41.4% (12) of carers who care for 10-20 hours a week said they had not received information and advice about opportunities to take a break

• Carers of people with mental health issues showed the highest % of having been given information about taking a break from caring

• When asked what help or support are you currently receiving the highest proportion of responses stated respite, short breaks or sitting service

There were frequent complaints by carers in the questionnaire responses and in face to face meetings about the difficulty in booking short breaks; particularly for self funders who often had to rely on the private sector, with beds frequently full and none specifically allocated for short breaks. Carers repeatedly had to use different care homes with no continuity of care which added to the stress for both the carers and cared for.

It was considered by both staff and carers that respite should be an entitlement which needs to be much more flexible such as vouchers or direct payments to be used as and when required. However, some carers reported that it is rare that money from direct payments is spent directly on carers having the break with a feeling they had to “use it or lose it” and that respite systems are not designed to meet carer needs.

Without regular breaks there is undoubtedly an increased risk of carers being unable to cope with continued caring and 60 carers identified this as the number one priority in the voting at the Carers Rights Day.

**Contingency plans**

The lack of an emergency or contingency plan was registered both with carers and also health and social care practitioners and was identified as an area for improvement as this too has an impact on the carer in times of crisis.

• The need for a contingency plan for crisis or emergencies was voted as 7/10 in order of priority by 60 carers at the Carers Rights Day.
Support groups

Support groups were rated as highly valuable by those who attended them with mixed views about who should run these. Most valued the presence of a Carers Support Worker or Carers Assessment Worker at the support group and found it a lot to ask carers to run their own groups with so many other pressures, although if Carers Support Workers had left, often carers did continue the groups themselves or volunteers took over.

- The age group showing the greatest proportion of carers receiving information on local support groups was age group 66-80 years with 72.9% who had received information versus 18.7% who had not
- Of carers within age group 18-30 years, a higher proportion had NOT received details of local support groups with 42.9% (3) answering No and 28.6% (2) answering Yes
- Neither of the two under age 18 carers who responded to the adult questionnaire had received information on local support groups
- Taunton was the area where the greatest % of carers had received information on local support groups with 79.7% answering Yes versus 16.2% answering No
- West Somerset carers had the highest number of carers NOT receiving information about support groups (37%) against 44.4% in the area who had

Transport

Transport was raised as an issue, either as part of getting to appointments or linked to respite. Even if respite is available transport is not always provided and was seen as an additional cost to the carer with a plea for transport to be part of the overall cost of respite and arranged at the same time.

- Transport was mentioned five times in the questionnaire responses and several times in face to face contacts
- Transport was voted 10th in order of priority at the Carers Rights Day by 60 carers

Commissioners state that transport is now being offered as part of a respite package; if local residential short breaks are offered and the carer or service user chooses an alternative then they would have to pay for the transport themselves.

Health and wellbeing

Health checks were often mentioned in the face to face meetings as of high importance and ranked as a higher priority than Carers’ Assessments. Carers
also suggested that they should be given priority appointments with GPs to ensure their own health needs are not overlooked.

The constant long-term pressures of caring can take a huge toll on a carer’s health and at least eight parent carers of children with Asperger’s Syndrome reported that they were taking antidepressants to help them cope because there is nothing else the GP could offer and suggested that may other carers had the same response.

“How can carers hope to have good health, both mental and physical, and a life of their own when there are no services to relieve the pressure of caring?” (Somerset Carer).

Employment support

Carers expressed concern that they often had to give up their jobs because of caring responsibilities, which also resulted in loss of income and inability to keep up pension contributions.

- 13.3% (44) of respondents to the questionnaire said they had received support for employment
- 8.2% (27) of respondents to the questionnaire said they had received support with education
- 16.9% (56) of respondents to the questionnaire said they had received support with training
- 5% (17 people) said don’t know for each of above

Finance

Lack of finance and loss of pension contribution was a common theme which ran throughout the consultation. The lack of Carers Allowance after 65 caused some resentment but acknowledged that this is out of the remit of this review.

The questionnaire asked about information regarding finance and benefits and Fig. 6-6 shows the percentage of carers who felt they had received enough information about support and financial benefits.
Fig. 6-6: Percentage of carers who felt they receive enough information about support and financial benefits.

Do you think that you receive enough information about support and financial benefits offered to carers?

- 42.6% (141) of questionnaire respondents said they do receive enough information about support and financial benefits
- 40.2% (133) of questionnaire respondents said they do not receive enough information about support and financial benefits
- More carers of people with learning disability responded that they did not receive enough information about this (54.5%), as opposed to saying that they did (34.5%)
- Carers for older people gave the highest response to receiving enough information on support and financial benefits at 55.1% Yes, 31.5% No
- All age groups under 66 responded more highly that they do NOT receive enough information about support and financial benefits – with the highest rate from 31-45 year old where 61.3% responded as NO
- West Somerset results showed that 63% of responders felt they had received enough information about support and financial benefits (33.3% said they had not) which was the highest positive response
- Mendip results showed that 35.3% responders felt they receive enough information about support and financial benefits (47.1% said they had not) – the lowest positive response
**Emotional support**

All carers groups highlighted that face to face contact with a known person is very important. The support provided by Carers Support Workers and Carers Assessment Workers is highly valued by those who receive it, but this is only a small proportion of carers in Somerset.

- In the questionnaire feedback when asked what help or support you currently get (Question 2), the number of carers who said they received support from a Carers Support Worker was 3.1%. (10)

- In the Carers Rights Day support offered by Carers Support Workers or Carers Assessment Workers was ranked as the third highest priority, equally with support provided by Social Workers in Adult Social Care teams and practical support

For those who did not receive face to face support, contact via the phone was suggested to be of value by many carers in the face to face discussions and the Carers Panel members suggested that this should be part of the universal offer for carers.

The Care First counselling service for carers was not well known by many of the carers we consulted with, including a County Councillor who is also a carer and was surprised to hear about its existence. Those that had heard of it thought it was only provided over the phone and were unaware that carers are entitled to six free face to face counselling sessions with a counsellor in the local area.

- Only 2 out of 318 respondents said they were receiving counselling when asked about the support they were receiving

**Giving Carers a Voice**

Regardless of the type of carer, lack of recognition was a common aspect with carers saying they often felt overlooked by professionals, were not asked their opinion about the person cared for, or given sufficient information about how to manage the cared for person.

- 44.4% (147) of questionnaire respondents thought they were listened to and asked their opinion about the person they are caring for

- 29.9% (99) of questionnaire respondents said they were listened to and asked their opinion about themselves as a carer, with those caring for people with a physical disability showing the greatest rate of responding no to a) and b), with 10.7% and 17.8% answering that they were not listened to or asked their opinion

- 18.2% (58) of respondents felt that they were not recognised as a carer
Those carers who had been caring for 10 years or more showed a higher rate of being recognised as a carer (64%), as opposed to the carers who had responded as caring for 3-4 years with 28.6% who felt recognised and carers of people with learning disabilities gave the highest response that they did feel recognised at 58.2%

There was a marked difference in responses between male and females with 10.4% (33) of males who responded as recognised and 36.2% (115) of females.

South Somerset showed the highest percentage of carers indicating that they did not feel recognised as a carer at 23.9% (22) and only 37% (34) of carers saying “they feel recognised”.

Taunton showed the highest percentage of carers responding that they “did feel recognised” at 58.1% (43), with 16.2% (12) responding that they “sometimes felt recognised”.

Mendip showed the greatest rate of carers indicating inconsistency with 29.4% (15) saying that “some but not all services recognised them as carers”.

There was a strong feeling expressed by the Carers Panel representatives (25 carers) that there is a need to ensure that carers who provide input to consultation or training for statutory or voluntary agencies are given some payment in recognition of their services. Somerset Partnership NHS Foundation Trust currently offers £32 per session, but there is no consistent approach in the Somerset Multi-agency Strategy, although travelling and care expenses are generally reimbursed.

Employment of carers and former carers in training and support roles was also seen as a lost opportunity by many carers, some of whom had offered to do this for various professional groups including GPs, with no positive response and suggested a lack of recognition of carer expertise and added value.

Recognition was ranked as 7th in order of priority at the Carers Rights day by 60 carers.

6.3 Unique carer experiences

In addition to the generic experiences identified by all types of carers there were a number of issues specific to certain groups of carers. Detail is provided in the table in Appendix 1 but key issues are summarised here:
**Parent Carers**

Parents of children with mental or physical disabilities or special needs are often disregarded as carers with an expectation that the caring role is part of their normal role as a parent; however the stresses and added pressures which a disabled child may have upon the family as a whole should not be underestimated.

The Somerset Direct: Finding your way book was described as very useful but parent carers frequently said it is difficult to find any information in one place. Even a parent carer who runs a training group described not being able to find out anything having written to 20 special schools without response.

Parent carers described a system which does not readily support funding for the kind of support they feel would best meet their needs. Often services are only obtained by fighting for them, which most parent carers are too exhausted to do, and therefore find it easier to give up, especially where there is no diagnosis.

The theme of parent carers having to battle at every stage of child development was recurrent particularly at pre-school, during school and then at transition to adult services which are stages with different needs and no cross over of support about where to go next. Some parents described receiving much better services at adulthood e.g. assessment and respite with a sudden change of attitude and opportunity to access support.

Many parent carers did not realise that they were entitled to flexible working; financial benefits; support for siblings etc. They also expressed an interest in learning more about medication, treatment and holistic therapies which they felt should be available without paying.

Difficulty in obtaining a diagnosis or a statement of needs was also a recurrent issue for parent carers with stories of parents having to appeal and then decisions being reversed, which many parents see as a waste of public money.

There is huge variation described in the type of support offered across areas, with differences in the way eligibility criteria are applied so that one family may meet the eligibility criteria in one area of Somerset and not in another.

There was positive feedback about post adoption support from Somerset County Council for children with special needs with foster carers and adopters feeling better supported, such as being offered specific training which parent carers were not.

Parent carers described NHS services as variable depending on where you live:

“I changed surgery and had to fight to do this – it was a battle to get an appointment for myself as the receptionist wouldn’t accept I could only go at certain times” (Somerset parent carer).
Some parents had had to access speech and language therapy via Barnados and paid privately with long waiting lists to see a psychologist and parents were rarely referred to a social worker.

There was a plea for a more Multi-agency approach and although voluntary organisations were described as often giving good support they need to work better with statutory bodies with a central knowledge of all services around the person.

The Special Educational Needs co-ordinator, known as SENCO, in schools was considered very variable with a suggestion that they should be better trained. Respite care is also a need for parent carers yet not given sufficient importance despite the fact that parents are often at breaking point.

Quotes from parent carers in Somerset

“We were quite precise that we wanted respite care but the social worker was reluctant - all we need is 3 hours a week or even a month break”;

“I went into school everyday to PEG feed her daily as there was no one else to do this”;

“the biggest problem is getting the people to do the care with the right skills – e.g. sitting in on a Saturday night. We need a web page of who is available to do the services – otherwise it’s a cop out’.

(Somerset carers)

Other specialist support required which was identified by parent carers:

- Holiday play schemes
- Support in schools for specialist medical intervention or PEG feeding: Health and education not properly integrated with the need for specialist paediatric support
- Direct payments
- Access to leisure activities
- Short term breaks or respite
- Services for 16-18 year olds

Young Carers

During the consultation process Peter Fletcher Associates consultants attended two evening support group meetings and met 25 young carers. During the first
meeting young carers present were involved in designing a questionnaire to reach the views of hidden young carers and also discussed the issues important to them in terms of types of services or support required now and in the future. The questionnaire was distributed via the Young Carers Project Workers to 100 young carers with 15 returned (see Appendix 2 for summary of results)

- 62.5% (10) of young carer respondents said they would know where to find help
- 53.6% (9) said they were listened to
- 43.8% (7) said they needed someone to talk to

Peter Fletcher Associates also ran a competition for young carers inviting them to submit diaries of “a day in the life of a young carer” which consisted of 15 detailed stories describing the pressures of caring for a range of different types of people including disabled parents, parents who misuse drugs or alcohol, parents with mental health issues and siblings with learning disability or physical disabilities.

During the second meeting a different group of young carers took part in a pool competition but were also given the opportunity to give their views about information and advice, communication and support. A further meeting took place in April 2010 which enabled young carers to discuss how they would like to have a stronger voice and what the governance arrangements might be.

The young carers described the Young Carers Project as giving children and teenagers a chance to have fun, have someone to talk to and be accepted by others in the same position as themselves. Feelings which young carers expressed about caring were:

- Sad
- Worried
- Lonely
- Nervous
- Pressure

Young carers said the Young Carers Project and made them feel:

- Happier
- Supported
- Respected
- Relieved
- Listened to
Young carers views of their service in Somerset

- The service is fantastic, and they even give us advice on how to explain why dad is ill as he has a mental illness
- Meeting others in the same situation does help and we are glad of what you do for us
- The service is perfect
- Could do the odd talk in schools which would let children know of this service as sometimes you do not talk of being a carer or helping a relative so you do not know about the Young Carers Organisation
- Even though I haven't been for a while I still manage to get information about events so I think it is quite good already

Source: Somerset Young Carers Support Group meetings and questionnaire responses

Suggestions for improvements by Young Carers included:

- Newsletter, posters and leaflets for information, to share ideas, how to cope and that help is available through schools and clubs
- Fortnightly information not a term programme
- Make letters more interesting
- More trips such as cinema, shows, theme parks, craft day, swimming, meeting at a cafe for a chat together, day out on a farm; places where we might not be able to visit due to the person we care for or learning new things such as first aid
- Counselling; help in caring; help for parents; help with homework
- Listen to our ideas; do not treat us older ones as little kids; make it more accessible to all age groups
- Letters do not always come on time and sometimes one member gets invited to carers trips but not the others even though they are in the same group
- To have a break from caring; residential trip away from home and normal caring chores, and to have a blast with friends
- Support – someone to turn to, a helping hand, someone to listen and help us get things sorted for ourselves and family
- Funding and finance – to help us and our families deal with the disabled
- Meet others in similar circumstances and make new friends
Views of Young Carer Project Workers

Key issues identified by Young Carer Project workers were the need to change attitudes and culture within schools. Very few referrals are received from teachers or attendance officers and better awareness amongst these staff is required, particularly for young carers of parents with mental health or drug and alcohol problems. Schools and GPs need to be more aware of the issues and refer to the Young Carers Project e.g. none of the Young Carer Project Workers could remember the last time they received a referral from a GP.

The Young Carer Project Workers also work with families and the Pathfinder project whose main objective is to shift the culture of other workers to think about the whole family.

Suggestions for improvements by the Young Carer Project Workers:

- Encourage children and young families teams not to close cases so quickly
- Link a project worker to schools
- Introduce a do it yourself toolkit for hidden carers - where you go, what help there is locally with a help line
- Make better links with GPs and raise their awareness

Carers of people with learning disability

Peter Fletcher Associates consultants attended two learning disability support group meetings and met with approximately 15 carers. The co-coordinators of each of the six carers support groups were contacted to distribute questionnaires and to communicate with their groups about the wider consultation exercise to ensure maximum engagement and 60 questionnaires were returned by carers of people with learning disability. There was also a proforma sent to Mencap members with a group response highlighting gaps and suggestions for improvement. We also received information from a consultation exercise carried out by the NHS South West Carers Learning Disability lead.

It was recognised that the services which are set up to meet the needs of people with learning disability such as day opportunities are not classified as respite for carers and yet this does have an impact upon carers who expressed concern about the lack of meaningful, day time activity for the person they are caring for and which creates additional pressures and tensions within the family. Although not set up to do this, day opportunities are being used as a form of respite for the carer as well as benefitting the cared for person.

With the move towards personalisation and more tailormade activities some carers have concerns that this could put additional pressures onto them by
having to sort out transport and a range of different activities for often shorter periods which could mean less time for themselves. Carers of people with learning disability welcomed the personalisation agenda but wanted choices to be realistic. They also wanted more day services for people in residential care and training relevant to circumstances about specific treatment and conditions.

Transition planning for young people with a learning disability and those with older parents was also an issue with often very different services available for adults and children, whilst moving from one department to another can be confusing. Somerset County Council is aware that there is a gap in supplying services for older carers in transition and they are assessing how this can be addressed.

It was suggested that people with multiple disabilities appear to miss out as they have a number of needs and a named worker is not always possible which could help with this.

**Staff views**

Peter Fletcher Associates consultants met with five staff team managers from the learning disability teams, Mencap Community Development Manager, Commissioning Manager from Somerset County Council and two social workers and a senior social worker from Community Learning Disability Teams.

Some staff from Learning Disability Teams felt the transition carers meetings, the Learning Disability Partnership Board and Carers Assessments carried out by learning disability staff all worked well.

However, carers did not always agree with this and there was concern that often carers of people with learning disability do not get offered an assessment at all, or the support of a Carers Support Worker.

There are six support groups for carers of people with learning disability supported by the Community Learning Disability Teams and these are seen as very valuable by the carers and staff. Other issues for concern:

- Resources and assistive technology for older carers is needed to reduce labour intensive supervision
- Learning disability carers have suggested that groups need to be run externally and Somerset County Council have recruited someone to work with carers to address these issues
- Raised expectation of transition carers
- Ensuring the voice of transition families is represented within the Learning Disability Partnership Board so services can be planned ahead of time
• Better relationship needed between carers and services
• Better partnership working such as invitations for carers on all decision making groups
• Better efforts to support carers in transition
• More investment in the Getting a Life project – looking at the carers future as well as the child. Somerset County Council has stated that it will not provide more investment for this but it will look at how it can incorporate the transition with Job Centre Plus

**Carers of people with Autism and Asperger’s Syndrome**

There are clearly some unique needs of carers of people with Asperger’s and Autism and needs will differ according to where the cared for person is on the Autistic spectrum. A commissioning strategy for this group has been developed for 2010-2011 by Somerset County Council and NHS Somerset.

There were frequent comments about being left in crisis with nowhere to turn and a lack of services, information or knowledge about what could be offered.

The unique nature of Autism and Asperger’s Syndrome means that behaviour can often be quite different at home from when seen by professionals in offices for a short space of time. With often no visible signs of physical or mental disability parent carers are often blamed for difficult or challenging behaviour and reported being given far less help than when the child reaches adulthood at 18 years.

“Things changed dramatically when he reached 18 - suddenly I saw a psychologist , got respite care and was asked why I hadn’t had anything all these years” (parent carer).

There was a plea for more services for people with Asperger’s Syndrome and Autism and their carers. Transition planning at various stages; not just at age 16 but also in the mid-twenties, when moving on should also be planned for. Most adults with Asperger’s Syndrome are still living at home with elderly parents so carers have most of their life planned out ahead of them likely to be caring for decades to come. There is also the constant worry of what will happen to the person they are caring for when they become too old to care.

By recognising that people have many different needs and not grouping them altogether as mental health, carers of people with Asperger’s Syndrome felt services could be improved. The need for pooled budgets and a breaking down of silos between different departments was identified as particularly important for this specific group. However Somerset County Council states that the Autism Strategy and Autism Bill will address these issues.

“We need advocacy that works so that the authority listens and a budget that is spent on clients” (Somerset carer).
There was also concern about assuming that everybody wants independent living in the community. It must be recognised that this does not work for everyone and can sometimes mean social isolation for many hours, with only a short input from a paid carer who may spend a few minutes and then rush off again. This can place additional stresses on the family/unpaid carer in situations where vulnerable people have been left lonely and isolated with minimal support.

“People get lost in the system waiting for help, it goes on for years. Only when there is a crisis does anything happen, if you are lucky! But it could be so much better if the was treatment earlier! Why wait for a crisis?” (Somerset carer).

“There is a lack of ability to contact other families with direct payments, so we could share costs and do activities together” (Somerset carer).

**Carers of people with mental health needs**

Unique aspects of the carers of people with mental health needs are in some ways similar to those of carers of people who abuse drug and alcohol due to the sporadic nature of the caring role, shame, guilt and stigma which means that sympathy and the opportunity to offload onto friends and family is made even more difficult. There was concern that GPs rarely offer any advice or support for the carer and physical aspects of health checks are often overlooked. The level of support and services provided is also often dependent upon the effectiveness of the individual care co-ordinator.

“If you’re living in a chaotic environment you haven’t got the time or energy to phone. Lots of carers get depressed yet we are not asking for a huge amount - a lot of time it is generic things – acknowledge the fear we are facing on a daily basis at times of emergency. So much of the treatment is medically led and professionals never listen to the users and carers” (Somerset carer).

“GPs don’t have much time – our GP went over her head and we were not taken seriously, particularly if it’s mental health – it would be easier if our son was in a wheelchair “(Somerset carer).

Mental health carers from the Carers Participation Group say they have offered to provide GP training but this has never been taken up. Carers believe there is much work to do around changing attitudes of professionals which they are keen to help with. This is already happening in the Somerset Partnership NHS Foundation Trust will carers sitting on interview panels and talking part in staff induction training.

The lack of availability of talking therapies is also an issue for mental health carers with those cared for often having to wait for several months and carers left to deal with the situation in the meantime.
Dual diagnosis is also an issue if someone has mental health problems and drug and alcohol issues. Several carers suggested the need for a clear pathway for carers of someone with a dual diagnosis of mental illness and drug or alcoholism as it is not clear where to go for help and often no agency will take responsibility.

Issues of confidentiality being a barrier to getting help was raised by this group (and the Asperger’s Group) with GPs reluctant to include the carer and debts often mounting up due to banks not being able to divulge information.

Somerset Carer views

“In the case of my long-term unemployed son, who has been suffering with depression for many years, doctors have refused to talk to me or refer me to a psychiatrist as they claim that only the patient can be treated. In the case of my 85 year old mother who recently fell, it would have been helpful to have been copied in to medical diagnoses/advice etc as she gets confused and forgets what she has been told” (carer).

“I would have wanted to know why my partner was behaving in the way he was, how I should have been dealing with it, and the possible outcomes based on the knowledge of the medical people dealing with him. Instead, we had to try to work out for ourselves that he was swinging from depression into a bipolar high - about which we knew nothing - which ultimately resulted in him leaving home and destroying his relationships with everyone he knew” (Somerset carer).

“My daughter has a dual diagnosis but because she has a drug habit, mental health issues are ignored” (Somerset carer).

Carers welcomed the services provided by Rethink, Mind, and Intouch voluntary organisations. This was largely due to the fact that they feel fully involved in the whole process of support for the person they care for such as at interview stage, moving to accommodation and when the person exits the service where ongoing support is still available.

Rethink report that they frequently signpost carers to a carer assessment and are surprised at how many carers are not aware of this.

The other group who would come under ‘carer’ are friends who whilst not family are often the only carer involved and Rethink also support these individuals as appropriate by ensuring consent of the service is obtained.

An example of a service from Rethink

‘All my clients currently live alone, with a few having next of kin and relatives living some distance away. With two of my clients, in particular, I keep in regular contact with their next of kin, via email and if necessary act as their advocate for reviews with Social Services, communicating with Care Providers etc.,
In the past I have signposted carers to counselling services, Crossroads Care and obviously, supporting with listening sympathetically.’

Source: Rethink worker

**Carers of people with dementia**

For people with dementia the carer may be a husband or wife or a family member not living with the cared for person but all observing the gradual onset process, lack of diagnosis, the fear and anxiety and lack of information about how to cope or react.

The fact that the carer is not always listened to when often they know the person best, is particularly important when the person is manifesting the first signs of dementia, as by ignoring the views of the carer, treatment and help may be delayed.

In the South West Dementia Review when consulting with carers of people with dementia 11 of the 50 attendees said they thought they had had a Carer Assessment and of these two people received more support as a result.

Other unique aspects for carers of people with dementia included specific service requirements for the cared for person which could alleviate the pressure on the carer such as:

- **Home Carer skills** – many carers express the view that the home help or sitter that came to their house was of little value because they could not understand how to help the person with dementia. Language is also frequently sited as a problem with care workers who do not have English as their first language along with lack of consistent staff coming to the home; the dementia advisor pilot is intending to address these issues

- **Night Care** – carers for people with dementia often feel exhausted and the time that is most difficult for them is through the night. Sometimes they just need someone who can look after the cared for person so that the carer can get some sleep. Frequently the need is for a relatively short period of nights while the dementia sufferer is going through a bad patch, or has an infection when behaviours and wandering are temporarily worse. Otherwise, for when the carer is not available for a short period and the cared for person would not be safe to leave alone overnight

- **The need for specialist dementia intermediate care** so that the person cared for is able to have a good transition from hospital to home and regain some skills to alleviate the pressure on the carer

- **Intensive short term community support** for people with dementia to support hospital discharges or to see through a crisis period,
with help coming from staff experienced in how to manage dementia

**Carers of people who misuse drug and alcohol**

The definition of carers included in the Somerset Multi-agency Carers Strategy 2008-2010 does not explicitly include looking after someone with substance misuse problems and this needs addressing.

With mixed experiences of support services, there is a need for staff to be aware of the specific issues affecting this group of carers and the knowledge to provide relevant information, signposting, support and advice which would enable more effective carer assessment.

National guidance acknowledges the need for dedicated support services because of the significant negative impact that drug misuse can have on the carer’s mental and physical health and wellbeing.

Somerset Drugs and Alcohol Team commissioned a study\(^{26}\) to look into carers needs and reported in January 2009. The study consulted with 41 carers and findings highlighted some key aspects unique to this group of carers.

During the consultation for this review Peter Fletcher Associates attended the Turning Point Yeovil Carers Support Group and also received feedback from carers involved with the In Touch service.

In the Somerset survey and during our consultation carers found it difficult to access relevant information and details on support services in their area. Information is scattered and produced in different formats by different agencies. Carers suggested that due to the stigma attached to drug and alcohol addiction carers are more likely to seek help from third sector, self help organisations such as AL Anon and Alcoholics Anonymous, so targeting these organisations with information about carers support may be more useful.

Common barriers to carers accessing services were reported as due to lack of:

- Awareness of support services available in the local area
- Confidence about contacting or attending a group
- Finances

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\(^{26}\) Supporting Carers and Family Members affected by the Substance Misuse of Others-A Somerset Study on Behalf of Somerset Drug and Alcohol Action Team, Dr Sharon Collins and Helen Begum, January 2009.
Carers suggested a need for Somerset agencies to work closely to provide a joined up, seamless service.

Carers of people with substance misuse would value:

- Information, advice and support on a range of subjects
- Coping strategies on setting boundaries, understanding about addiction and its effects and the treatment options for the person using drugs or alcohol through informal meetings with others in a similar position
- Support/self help group meetings
- One to one and family counselling
- Workshops; telephone help lines; leaflets; and websites

Carers suggest that the best way to raise awareness was through GP surgeries, health centres and adverts in the local papers. Other popular methods are via family groups, drug and alcohol services and websites.

Turning Point support group members suggest that the most important need is for someone to talk to who has been in the same situation. This could be in the form of a buddy or telephone support during a crisis, delivered by a volunteer but must be someone who the carers can trust as it is very difficult to confide in family or friends or even other support group members.

Current carer training is not suitable for carers of people with substance misuse as experience is so different to other carers. Training needs to include:

- Stress management
- Break away training
- De-escalation
- Boundary setting
- Looking after yourself

One of the biggest barriers is the carer admitting the circumstances as they often feel stigmatised and ashamed of the issues. Most do not see themselves as a carer and there is a reluctance to become involved with mainstream carer organisations. Respite is not as others see it and carers would prefer a course or chance to mix socially as the best form of respite.

Somerset Partnership NHS Foundation Trust has a course specifically for carers with drugs and alcohol but a similar group for carers of people with dual diagnosis has also been suggested as needed.
Carers of people with a sensory loss

Carers of people with a sensory loss described the key difficulty as the lack of awareness by the general public and professionals about the needs of people with sensory loss. The people they care for are often described as being awkward due to the fact that the disability is often not evident which adds to the pressure on the carer and consequent lack of support. Carers said they would value an annual telephone call to ask if they were okay and to know where to go when they need help. The impact of the rural geography of Somerset was described as difficult for the carer group due to lack of transport and local services for sensory loss. The length of time to wait for equipment was an issue and carers often resorted to buying these themselves. Other difficulties were persuading the cared for person to use the equipment or to ask for help. Access to hearing aid tests, and the fact that the condition is progressive are not taken into account and carers feel they are left to cope alone. There was concern that professionals offer no information at the clinics or guidance but give you leaflets with no explanation. Somerset Sight and Deaf Plus were valued resources and the support groups for carers (both specialist and generic) are welcomed as a great source of emotional and practical support. Somerset Sight also arranges holidays for the cared for and the carer which are valued. Experience of Somerset Direct was mixed with a suggestion that staff should be trained to be better aware about the impact of sensory loss and relevant services.

Some carers have a sensory loss themselves and described the added difficulty this presents: “I'm a carer 24 hours a day for my wife who is blind and my learning disabled son but no account is taken of my deafness”.

The key message is that there is not enough support for carers of people with a sensory loss, with a lack of awareness, training and specialist support required. There is an added difficulty of many carers not being viewed as carers by themselves or others.

Equalities

Carers from Black and Minority Ethnic Groups

The number of carers from Black and Minority Ethnic groups in Somerset who responded to the questionnaire was 2.7% (9 people) of the total number of people contacted with the questionnaire, and reflected a reasonable response percentage.

Peter Fletcher Associates consultants contacted two community groups from the Midwest European Communities Association, and saw a total of 18 people face to face.

Feedback from the Midwest European Communities Association highlighted the general lack of awareness and understanding in the current system compounded by cultural and language problems. The thought of being paid benefits or
receiving services for caring for family members was alien to them and not supported in their country of origin. Of the small number of people contacted it appeared that the majority of carers access support via their own community and via mainstream services but felt more support was needed in order to better understand their rights to access mainstream services.

Information and advice could be improved if channelled through existing associations and most of the carers indicated that they would not join existing carer groups due to perceived resistance and prejudice. A significant number of carers indicated that the greatest obstacle to accessing mainstream services, including GPs, was a lack of sensitivity over cultural issues; lack of advocacy and interpretation / translation support.

People felt that response times generally were poor with people often left for weeks if not months not knowing the outcome of applications etc. An example given was the provision of aid and adaptations in relation to the cared for person. In terms of assessment the majority of those contacted would prefer face to face contact with the assessor, although the idea of self assessment or facilitated assessment via their own association was broadly supported.

Financial support and help to gain employment were seen as high priorities. People identified the need for more short breaks but having the choice of by whom, when and where these should be provided. Most indicated that they would wish to have this delivered by friends, family or members of their local community. The collection of information about ethnic origin of carers is very patchy. The figures for take up of St John Ambulance carers training for example does not show a breakdown of carers from ethnic minority groups whilst the Expert Patient carers training does.

**Carers from Gypsy and Travellers Groups**

It has been difficult to make direct contact with Gypsy and Travellers carers in Somerset. The Somerset County Council Gypsy and Traveller lead circulated 100 questionnaires without success and other methods of making contact were explored through the local Adult Social Care Teams; Learning Disability Teams and Somerset Partnership NHS Foundation Trust, in order to try and ascertain some of the unique characteristics of this carer group but with little success. We have therefore drawn on findings from various other studies in the south west.

In the Bristol Mind study27 most people were registered with a GP and GPs were the main health service that they used. Some people had experienced prejudice and discrimination from GPs and psychiatrists. Some people had been refused treatment, and staff had used insulting language. Some people did not want to be

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27 Do Gypsies, Travellers and Show People get the support they need with stress, depression and nerves? - Bristol Mind.
referred on to different people to help them; they did not want to have to repeat their story and wanted to build up a relationship and trust with one person. Staff also noted that diversity training had not covered issues around Gypsies, Travellers or Show People – a question for Somerset trainers and the Somerset Carer Assessment tool.

In the Council for Racial Equality Report\textsuperscript{28} in Scotland there were repeated assertions that GPs are not allowing Gypsy and Travellers to register forcing many to seek primary care through Accident and Emergency clinics. There was also a suggestion that hand-held records for Gypsy and Traveller patients should make the provision of primary care and the screening and treatment of patients more streamlined which could also apply to carers.

In a Department of health report in 2004 \textsuperscript{29}there was some evidence of an inverse relationship between health needs and use of health and related services by Gypsy and Travellers, with fewer services and therapies used by a community which demonstrated greater health needs. Gypsy and Traveller’s attitudes to health services demonstrated a cultural pride in self-reliance; illness was often seen as inevitable and medical treatment seen as unlikely to make a difference with more trust in family carers rather than in professional care.

In talking to a Somerset learning disability social worker who is in contact with a Gypsy family she reports that services to carers are often required on an episodic basis, frequently at times of crisis and then with loss of contact again.

**Lesbian, Gay, Bisexual and Transgender Carers**

Peter Fletcher Associates have worked with Equality South West, Somerset Gay Health and Want 2BU in an attempt to contact carers. A request for feedback was made in the March 2010 Newsletter targeting some 211 contacts, but with no response. It has therefore not been possible to determine any unique perspective from this potential group of carers or to ascertain what the numbers involved might be.

**Other Views**

Other key stakeholders were interviewed and their perspective was recorded using a series of semi-structured interviews (see Appendix 3). The areas discussed focused on the priorities outlined in the Multi-agency Carers Strategy with particular emphasis on:

- Partnerships


\textsuperscript{29} The University of Sheffield School of Health and Related Research: Summary of a report to the Department of Health, 2004.
• Information
• Assessment
• Support – all aspects
• Funding
• Other areas impacting on the delivery of the strategy

Somerset County Council

Senior Managers views

In total six strategic senior managers at director level were interviewed across all of the main service user groups of adult social care and children and young people. Identified below are the key points from these discussions:

• There was a perception that Somerset provided good support for carers but this perception needed to be tested out. There was concern that statutory agencies assess people too much. The aim of any future service design should be about recovery and re-ablement, supporting self help, community and family support with minimal intervention from statutory services.

• Partnership with other statutory agencies (NHS Somerset and Somerset Partnership NHS Foundation Trust) was considered good as were the relationships with carers representatives although it was felt that carers role in governance could be developed further.

• There was an appreciation that a single point of contact for carers was important and some feedback to suggest the current arrangements were not effective and did not meet the needs of all groups.

• The severity of the current financial position was emphasised particularly over the next three years. Remodelling of services may indirectly impact on carers though priority would be given to people where the carers were considered at risk.

• Personalisation offers an opportunity to make significant changes since it is becoming more obvious that the current levels of funding / services are not sustainable given demographic and other pressures. Some issues regarding provision for respite and personalisation changes may free up the market and offer greater choice. It was considered that additional support for carers would be needed to make this work.

• It was acknowledged that the current charging policy needs to be examined as this was often a factor in the tension between carers support and the support provided for the cared for person.
Previous research suggested that Somerset was under performing in relation to benefit uptake for carers

- Respite services were less than ideal with too few slots and not local enough. There was also a tension between planned respite and the need to provide crisis support

- The role of Carers Support Workers needs to be validated against best practice to justify the investment. A Carers Support Worker is being advertised for the Learning Disability Teams but they will not be used to undertake assessment. Some concerns were expressed over the quality of Carer Assessments by core staff and the need for more training on this

- Children and Young People services have good information for tracking the needs of people as they move through the education system. The Young Carer Project Team is highly valued and respected

- It has been identified that the Active Living Network potentially has a greater role to support carers of 50+ years, by identifying and supporting them, especially in rural locations

**Carers Support Worker views**

Carers Support Workers were given an opportunity to meet with Peter Fletcher Associates consultants at a specially arranged meeting with them all as a group; attendance at the local Carer Panels; at the Carers Rights Day in Taunton and at stakeholder workshops.

Carers Support Workers were all very passionate about their roles, highly committed to their jobs and felt strongly that there is a danger of diluting this service and losing the best practice learning and development which has been built up in Somerset over the past 15 years.

Most felt that the move out of GP surgeries was a retrograde step, although some saw this as very positive. Most considered their roles in facilitating Carers Support Groups was important and that the educational role could be extended such as to primary and secondary care and staff in other agencies to access more hidden carers. However there was fear expressed by many Carers Support Workers that they may open the flood gates if they concentrated on this aspect of their role and would not have the capacity to cope so did not pursue this aspect of their role.

**Social workers and occupational therapist views**

Social workers and occupational therapist representatives who carry out care management within the local Adult Social Care teams from each of the five
district areas attended the Carer Panels. They described wanting to be better informed about carers needs when completing the Single Assessment Process. The opportunity to refer to a Carers Support Worker to carry out the Carers Assessment was seen as useful especially when there can sometimes be a conflict of interest between the cared for person and the carer.

**Adult Social Care operational manager's views**

There were issues raised by operational managers about having Carers Support Workers in place and working on the assessment function which can be summarised as:

- Financial implications
- SWIFT system does not link up the carer with the cared for
- Conflicting issues with two different workers
- Conflict of interest if care manager is working with both carer and cared for
- Lack of process to allow Carers Support Worker to set up services and therefore having to come to a care manager
- Lack of knowledge about percentage of carers who are not known to care managers that Carers Support Workers are working with
- Opportunity to raise awareness about carers and their needs in Adult Social Care teams by having Carers Support Workers based with them
- Lack of formal training for care management staff about carers needs and rights

**NHS Somerset**

Two senior managers from NHS Somerset were interviewed, one as part of the strategic Carers Panel and the other at her office at NHS Somerset. NHS Somerset is working to achieve the standards set in the World Class Commissioning Competences as outlined in Section 3 and to ensure that the views of carers are taken into account wherever possible with a view to supporting carers to maintain optimum health.

NHS Somerset is committed to raising awareness of carers needs amongst its staff and service providers and providing services closer to home. It has identified a number of sites such as Community Hospitals where they have been developed with local communities which could potentially be used for more carer information, support etc. (see Section 3)
NHS Somerset intends to continue to develop closer partnership working with the Active Living Centres across Somerset.

**Primary Care**

Discussions took place with ten GPs at the Wyvern Health Cooperative Board; four Practice Managers at the Local Medical Committee and with one Community Matron for Long Term conditions.

GPs reported that they would welcome more of an awareness raising and educational role from Carers Support Workers and Carers Assessment Workers who they say they rarely see unless linked to a practice. When Carers Support Workers were based with them GPs suggested that this was of benefit as a reminder to ask about carers needs and to enable easy referral of carers onto training programmes or other support to give carers the opportunity to learn how to manage those they care for and their own health and stress related problems.

The main issue for most practices is capacity / resources against a number of competing priorities. There is currently an overload of initiatives and with limited resources to do more work with carers this would mean displacing something else.

Most new patients are asked by the GP if they are a carer but there is no follow up. Age profile of carers would suggest older carers may look to the GP for information and advice but younger carers would not. The current arrangement to link Carers Support Workers with GP surgeries, rather than be based with them, is seen as less effective.

Registration of carers by coding is not straightforward - each practice operates a different protocol for maintaining the system. Sometimes carers and the cared for person are not registered with the same practice. The details are often not updated or removed when the person is no longer a carer.

Although there was a desire to support carers in staying well, the immediate benefits appear to be to the social care system not to GPs, although it was recognised that there could be some impact on acute hospitals and use of urgent care.

Questions raised by practice managers and GPs:

- What does the carers register lead onto?
- What support is accessed by a Carer Assessment?

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30 Four practice managers one from each area of Somerset representing approximately 25000 people
Where can GPs refer people on to?

Should there be some form of benefits for being registered as a Carer?

Concerns including stimulating demand and raising people’s expectations

**Somerset Partnership NHS Foundation Trust**

In total three senior managers were interviews as part of the review. Identified below are the key points from these discussions:

- Working relationships with commissioners were considered good as were links with primary care
- There was a perception that commissioners were too focused on assessing performance against the number of assessment completed as opposed to improving outcomes for carers
- Feedback from carers suggested the website for carers was well used and valued. However, more generic information and advice needs to be improved so that it is tailored to the needs of the individual both in terms of access, content and geography
- Existing carer services had developed a good reputation and had benefited from being under a single manager. The employment aspect of the services was award winning and integral to the success of the team
- There was an acknowledgment of the importance of supporting carers via investment in mainstream preventative services but these needed to be linked in well to specialist provision. The organisation is very committed to the personalisation programme but this needs to reflect concerns over mental capacity

**Carers Assessment Workers views**

A team meeting of all Carers Assessment Workers was attended by a Peter Fletcher Associates consultant with their manager present and one or two attended each of their local Carers Panels. It was clear that this is a very committed and passionate group of staff which feels strongly that their role is highly valued and should not be changed following this review. The assessment function is also seen as a highly important part of their role and they would not want this to be lost in the future having developed specialist skills in assessment and support for carers of people with mental health needs.
Voluntary and community sector feedback

A meeting\textsuperscript{31} was held with 15 voluntary and community sector organisations as listed in Appendix 5 to discuss their role in providing care and support to carers who had taken part in the Carers Panels. The following is a list of gaps identified at the meeting regarding services which the voluntary and community sector might fill:

- Emotional support
- Regular and flexible breaks of high quality to include a professional style sitting service
- Transport – volunteer drivers
- Bereavement follow up in rebuilding life after caring responsibility ceases
- Employment support
- Carer identification
- Gaps in knowledge about statutory providers and of other organisations
- Extend advocacy
- Befriending
- Community support for existing and new local carers groups, with access to professional support and used to disseminate information
- Holiday play schemes

In Phase 2 of this review the role of the voluntary and community sector in providing services to carers was further considered in the stakeholder workshops.

Carers UK

General concerns which have been raised by Carers UK locally are:

- The need to maintain the specialty of Carers Assessment Workers and to develop the role of the Carers Support Workers into more specialist areas
- Concern about the move of Carers Support Workers away from GP Practices and being incorporated into Adult Social Care teams

\textsuperscript{31} A consultation workshop was held on 14\textsuperscript{th} Jan 2010 and was attended by Carers and a range of representatives from voluntary sector organisations in Somerset as listed in Appendix 5
• Need for preventative services to prevent carer breakdown
• Concern about number of Carers Support Workers leaving their posts and being replaced by a more generic role

Independent providers

Key providers of services which impacted upon carers either directly or indirectly were invited to the Carer Panel discussions. Three operational managers from the providers below attended:

• Somerset Care
• Way ahead
• Brunel care

Issues which they raised were:

• A large number of domiciliary care providers provide services to the cared for person and by doing support a large number of carers
• Acknowledgment that improvements could be made to provider services by listening to carer as experts
• Providers of domiciliary care recognise that that continuity of carers is important and are always striving for this
• Providers would value one central place to signpost carers to for information
• Many new carers do not know about Somerset Direct
• Provider staff should be asked about hidden carers as they are seeing many people with carers who are unidentified
• Service user consultation events are carried out but more emphasis will be placed on open honest dialogue about what works well with carers
7. What do carers want?

Following the initial consultation five stakeholder events were held in February and March 2010. The purpose of these events was to:

- Provide feedback from the initial consultation phase
- Consider best practice from other areas
- Identify key areas for service improvement and rank these in order of priority

There were also two young carer meetings held to feedback the initial findings from the questionnaires and to ask young carers about the types of services that should be developed in the future and the governance arrangements for these.

This section outlines the outcomes from these stakeholder events with the recommendations and priority ratings which attendees gave for the future development of carers’ services and model of service delivery required in Somerset.

At the adult carer stakeholder events 51 carers attended with an average of 10 carers at each event. The aim was to ensure that carers were in the majority in order to have the loudest voice so other stakeholders consisted of one Carers Support Worker, one Carers Assessment Worker, and one representative from organisations providing services to carers including the voluntary and community sector (for full list see Appendix 5).

At the two young carer meetings held in February and April 2010 approximately 12 young carers attended each meeting with ages ranging from 9 -18 years.

7.1 Key requirements

The main priorities which had been identified from the consultation during Phase One were:

- Information and advice
- Assessment
- Practical and emotional support including short breaks
- Health and wellbeing

These areas were discussed at the stakeholder events which were held in Phase Two and attendees were asked for suggestions about how services could be delivered and shaped to improve these aspects. At the adult carer events
stakeholders worked in small groups to formulate three recommendations. These were then shared with the whole group and each person attending was then given three votes to prioritise them in order of importance. The carers votes were recorded separately from other stakeholders and the results are listed in the Fig. 7-1 in order of priority. Section 7.2 shows the summary and conclusions made as a result of these votes.

**Fig. 7-1: Suggestions for improving Somerset Adult Carers Services in order of priority by stakeholders**

<table>
<thead>
<tr>
<th>Priority rating</th>
<th>Priority Feed back</th>
<th>Number of votes by Carers</th>
<th>Number of votes by other stakeholders</th>
</tr>
</thead>
</table>
| 1               | • Maintain specialist services that recognise the continuing and changing needs of carers including planned, suitable short breaks  
• Practical, reliable, flexible support, including respite  
• Decent stress management – linked to 24/7 support  
• Help Line with Support 24/7 linked to emergency respite incl. weekends  
• Planning to prevent crisis for carers or cared for person                                                                                       | 19                        | 4                                     |
| 2               | • GP’s to automatically forward information on services to carers  
• Carers Champion in every surgery – signposting to high quality services                                                                                                                                       | 18                        | 5                                     |
| 3               | • Centralised, easily accessible, relevant information system including listing of all “registered carers”, web site  
• One stop shop – including out-of-hours service. One number – one                                                                                | 13                        | 14                                    |
<table>
<thead>
<tr>
<th>Priority rating</th>
<th>Priority Feedback</th>
<th>Number of votes by Carers</th>
<th>Number of votes by other stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>• More information about respite criteria, availability, costs etc</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>• Independent Carer driven assessments with access to advocacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Redefine “Carers Assessment” so that purpose and outcomes are clearer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>• Senior management need to meet with carers to better understand their support needs</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>• Independent, but well funded, monitoring of services by carers and including influencing strategic decisions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>• Continuity / regular support by trained staff taking an holistic approach with good communication</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>• Someone to “shout” in my corner- advocate for me</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>• Providers that treat us like customers</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>• Joined up services that are user orientated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>• Carers Support groups – “professionally” run</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>• Openness re entitlement to service – clarity about eligibility</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
7.2 Summary of stakeholder views and perspectives

Feedback from carers and other stakeholders suggested that improvements need to be made if the current model of service delivery system is to improve the outcomes for carers outlined in the Somerset Multi-agency Carers Strategy and support a greater number of carers in the medium to long term.

Using the feedback from the consultation in Phase One of this appraisal and the outcomes from the stakeholder events in Phase Two, as shown in Fig 7-1, the priority ratings have been analysed and collated in the list below. This shows in order of priority, the key aspects of any new Carers Service Model in Somerset:

**Fig 7-2 Carer priorities from stakeholder events**

- **Carer priorities from stakeholder events**

  1. Practical, flexible and reliable support. This must include continuity and regular support from trained staff, contingency plans and planned short breaks which are easily accessible and flexible so the carer can have more choice and control over when, where and how this support is provided.

  2. A helpline with access to practical, emotional support and short breaks to both prevent crises occurring and in times of emergencies. This must include opportunities for carers to be involved in activities outside of their caring role.

  3. Information and advice available at a local community level including from GPs, supermarkets, etc.

  4. Single access point for information and advice with the right information for all different types of carers.

  5. Streamlined, simplified assessment process including on-line and self assessment with an outcome of a support plan for the carer.

  6. Access to independent advocacy for carers.

  7. Greater say in the decision-making process and carers to be recognised as an “expert” by staff both at a strategic and family level.

  8. Carer Support groups professionally run.

  9. Treat carers like customers.

  10. Clear eligibility criteria and charging.
7.3 Young carers feedback

Young carers’ feedback during Phase Two was in two parts – one meeting focused on what services should be in place for young carers in the future and the other on governance arrangements. The results are listed in Fig. 7-2.

**Fig. 7-3: Suggestions for improving services for young carers**

<table>
<thead>
<tr>
<th>Suggestions for improving services for young carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Newsletter, posters and leaflets for information, to share ideas, how to cope and that help is available through schools and clubs</td>
</tr>
<tr>
<td>✓ Letters do not always come on time and sometimes one member gets invited to carers trips but not the others even though they are in the same group</td>
</tr>
<tr>
<td>✓ Information on back of buses, school notice boards, train stations</td>
</tr>
<tr>
<td>✓ Adverts on TV, on line, BBC i player</td>
</tr>
<tr>
<td>✓ Write a song</td>
</tr>
<tr>
<td>✓ To have a break from caring</td>
</tr>
<tr>
<td>✓ Residential trip away from home and normal caring chores, and to have a blast with friends</td>
</tr>
<tr>
<td>✓ More trips such as cinema, shows, theme parks, craft day, swimming, meeting at a café for a chat together, day out on a farm; places where we might not be able to visit due to the person we care for or learning new things such as first aid</td>
</tr>
<tr>
<td>✓ Meet others in similar circumstances and make new friends.</td>
</tr>
<tr>
<td>✓ Support - someone to turn to, a helping hand, someone to listen and help us get things sorted for ourselves and family</td>
</tr>
<tr>
<td>✓ Funding and finance – to help us and our families deal with the disabled</td>
</tr>
<tr>
<td>✓ Assemblies for young carers</td>
</tr>
<tr>
<td>✓ Counselling</td>
</tr>
<tr>
<td>✓ Help in caring</td>
</tr>
<tr>
<td>✓ Help for parents</td>
</tr>
<tr>
<td>✓ Help with homework</td>
</tr>
<tr>
<td>✓ Listen to our ideas</td>
</tr>
<tr>
<td>✓ Do not treat us older ones as little kids</td>
</tr>
<tr>
<td>✓ Make it more accessible to all age groups</td>
</tr>
</tbody>
</table>
7.4 Summary of young carer feedback

From the consultation with young carers it was evident that the young carers valued highly the Young Carers Project.

Key aspects of support required included:

- better information via schools
- opportunity for time way from home including recreational activities and residential breaks
- counselling
- peer support
- support for parents
8. Demographics & Rural Issues

8.1 Demographics

_Carer Population and population projections_

The population in Somerset is 530,000 and will increase by 87,000 (16.4%) as a whole from 2004-2029. Approximately 58.2% of the population is of working age compared with a national average of 62.2%. In 2006 48.6% were male and 51.4% female.

In 2001 there were 492,451 carers living in the South West. The Somerset Multi-agency Carers Strategy indicates that based on the 2001 census there are over 50,000 carers within Somerset providing varying levels of care. This represents 10.1% of the total carers' population in the region and makes up approximately 9.43% of the population of Somerset. In March 2008 it was estimated only 14.6% of carers were known to statutory agencies in Somerset, which leaves a possible 43,000 unknown carers.

Fig. 8-1 shows the number of carers in Somerset who provide unpaid care broken down by number of care hours undertaken. South Somerset has the largest proportion of carers providing unpaid care and West Somerset the least. However, issues of rurality, social housing, employment and transport are significant contributing factors for carers living in West Somerset.

**Fig. 8-1: Number of carers in Somerset providing unpaid care**

<table>
<thead>
<tr>
<th>Somerset Districts</th>
<th>Total number of people who provide unpaid care</th>
<th>People who provide unpaid care: 1-19 hours</th>
<th>People who provide unpaid care: 20-49 hours</th>
<th>People who provide unpaid care: 50+ hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somerset</td>
<td>50,034</td>
<td>36,254</td>
<td>4582</td>
<td>9,468</td>
</tr>
<tr>
<td>Mendip</td>
<td>10,029 (20.04%)</td>
<td>7,377</td>
<td>902</td>
<td>1,750</td>
</tr>
<tr>
<td>Sedgemoor</td>
<td>10,902 (21.8%)</td>
<td>7,476</td>
<td>1054</td>
<td>2,372</td>
</tr>
<tr>
<td>South Somerset</td>
<td>15,303 (30.6%)</td>
<td>11,244</td>
<td>1335</td>
<td>2,724</td>
</tr>
</tbody>
</table>

---

33 POPPI information system Dept. Health
Older age is a very significant demographic characteristic of the Somerset population profile and has an impact upon carers, both due to the fact that older people are more likely to need caring for and that many carers are also older people themselves.

Fig. 8-2 demonstrates that the south west has a significantly higher proportion of its population as older people in all four of the age bands than the position in the country as a whole. Somerset also has a higher proportion of its population as older people in all four of the age bands than the whole of the south west.

**Fig. 8-2: Proportion of population aged 55 plus in 2004- Somerset, South west and England**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Somerset</th>
<th>South West</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Numbers</td>
<td>% Total Population</td>
<td>Numbers</td>
</tr>
<tr>
<td>55-64</td>
<td>5,300</td>
<td>14.2</td>
<td>688,900</td>
</tr>
<tr>
<td>65-74</td>
<td>4,300</td>
<td>10.2</td>
<td>500,100</td>
</tr>
<tr>
<td>75-84</td>
<td>8,000</td>
<td>7.2</td>
<td>349,700</td>
</tr>
<tr>
<td>85+</td>
<td>5,500</td>
<td>2.9</td>
<td>144,800</td>
</tr>
</tbody>
</table>


Fig. 8-3 shows a more detailed breakdown of population projections in Somerset over the next 30 years with 28.5% over 65 and 5.4% over 85 by 2030.

**Fig. 8-3: Somerset total population, population aged 65 and over & aged 85 and over as a number and as a percentage of the total population, projected to 2030**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>534,100</td>
<td>567,200</td>
<td>596,500</td>
<td>626,200</td>
<td>652,800</td>
</tr>
<tr>
<td>Population aged 65 and over</td>
<td>110,200</td>
<td>132,900</td>
<td>148,900</td>
<td>165,700</td>
<td>186,200</td>
</tr>
<tr>
<td>Population aged 85 and over</td>
<td>16,200</td>
<td>19,500</td>
<td>22,900</td>
<td>28,100</td>
<td>35,500</td>
</tr>
</tbody>
</table>
Fig. 8-3 above demonstrates that the older people’s population in Somerset is set to grow markedly in the future. In absolute terms, the 65+ population increases from 110,200 in 2009, to 148,900 in 2020 (35% increase), to 186,200 in 2030 (69% increase).

In comparative terms, Somerset’s increasing numbers of over 65s by 35% in 2020 and by 69% in 2030 compares to increases in the south west of 27% and 53%, and 22% and 46% for the country as a whole for 2020 and 2030. The proportion of over 85s of the Somerset population increases from 3.03% in 2009 to 5.44% in 2030.

The number of older carers aged 65 yrs plus will increase by 35% over the next ten years. Over the same timescale the number of 85 year olds providing unpaid care will rise by 42%. Fig. 8-4 shows the number of unpaid carers in Somerset which may impact upon services required if an adequate amount of preventive support is not provided. Figs. 8-4 and 8-5 below show a more detailed breakdown of the numbers of unpaid carers by age group many of whom may not be known to statutory agencies.

**Fig. 8-4: People aged 65 and over in Somerset providing unpaid care to a partner, family member or other person, by age, projected to 2030:**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People aged 65-74 providing unpaid care to a partner, family member or other person</strong></td>
<td>7,995</td>
<td>10,179</td>
<td>10,879</td>
<td>10,793</td>
<td>12,078</td>
</tr>
<tr>
<td><strong>People aged 75-84 providing unpaid care to a partner, family member</strong></td>
<td>3,764</td>
<td>4,170</td>
<td>4,932</td>
<td>6,140</td>
<td>6,547</td>
</tr>
</tbody>
</table>

Source: POPPI information system Dept. Heath
Similarly the numbers of carers aged 85 plus providing unpaid care will increase by on average 41% across each of the three groups highlighted above between 2009 and 2020 as shown in Fig. 8-5 below.

**Fig. 8-5: People aged 85 and over in Somerset providing unpaid care to a partner, family member or other person, by age and by hours of care provided, projected to 2030**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>or other person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People aged 85 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>providing unpaid care to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a partner, family member</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>or other person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total population aged</td>
<td>12,484</td>
<td>15,222</td>
<td>16,836</td>
<td>18,192</td>
<td>20,214</td>
</tr>
<tr>
<td>65 and over providing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>unpaid care to a partner,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family member or other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: POPPI information system Dept. Health
Fig. 8-6 shows the projected population increase of people with dementia in Somerset amounting to an approximate 35% increase in the incidence of dementia in the county over the next 10 years to 2020. This will have a major impact upon carers as this condition places a huge strain often on older carers who are often required to provide care on a 24 hour basis.

*Dementia*

**Fig. 8-6: Projected population increase of people with dementia in Somerset**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>People aged 85 and over predicted to have dementia</td>
<td>3,796</td>
<td>4,535</td>
<td>5,287</td>
<td>6,474</td>
<td>8,112</td>
</tr>
<tr>
<td>Total population aged 65 and over predicted to have dementia</td>
<td>8,125</td>
<td>9,437</td>
<td>10,973</td>
<td>13,088</td>
<td>15,541</td>
</tr>
</tbody>
</table>

*Source: POPPI information system Dept. Health*

**Carers receiving services**

During 2007 / 2008 Somerset assessed or reviewed 9,950 carers of which 3,005 (30%) where receiving a carer specific service and 6,940 were receiving information only. (Source: CASSR-RAP data). Fig. 8-7 shows the number of carers receiving services provided as an outcome of an assessment or review aged 65 and over, projected to 2030 which highlights the likely demand for carer’s services in the future.

**Fig. 8-7: Number of carers in Somerset receiving services provided as an outcome of an assessment or review, aged 65 and over, projected to 2030**

<table>
<thead>
<tr>
<th>Year</th>
<th>2009</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of carers aged 65 and over receiving services</td>
<td>6,685</td>
<td>8,062</td>
<td>9,032</td>
<td>10,051</td>
<td>11,295</td>
</tr>
</tbody>
</table>

*Source: POPPI information system Dept. Health*

**Long-term limiting illness**

Within the county 18% of people have a long-term limiting illness health problem or disability that limits their daily or work activities. This is in line with the wider South West region and slightly higher than the national average. Fig. 8-8 shows the population breakdown of people with and without a limiting long term illness
**Fig. 8-8: Long term limiting illness**

<table>
<thead>
<tr>
<th></th>
<th>Total Population</th>
<th>With a Limiting Long-term Illness</th>
<th>Without a Limiting Long-term Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somerset</td>
<td>498,093</td>
<td>90,130 (18.1%)</td>
<td>407,963 (81.9%)</td>
</tr>
<tr>
<td>South West</td>
<td>4,928,434</td>
<td>892,034 (18.1%)</td>
<td>4,036,400 (81.9%)</td>
</tr>
<tr>
<td>England</td>
<td>49,138,831</td>
<td>8,809,194 (17.9%)</td>
<td>40,329,637 (82.1%)</td>
</tr>
</tbody>
</table>

Source: ONS, 2001 Census

More recent data on long term limiting illness demonstrates a general correlation between long term limiting illness and older age and a high proportion of people with limiting long term illness are likely to have carers.

**Learning disability**

Approximately 1,650\(^{34}\) adults with learning disabilities are supported by the Somerset Adult Learning Disability Service of which approximately 32% people remain at home with parents or carers. These figures are likely to increase especially with an ageing carer population for many people with learning disabilities but it has not been possible to obtain any population projections for this group.

**Young carers**

In 2001 there were approximately 15,656 young carers under the age of 20 living in the South West.\(^{35}\) There are approximately 111,000 children aged under 18 living in Somerset and at any point in time 3% (3,330) are assessed as being “in need”. Whilst no Somerset specific figures are available it is estimated that there may be 1,565 young carers in Somerset aged less than 20 years.

**Black and minority ethnic groups**

It is estimated that approximately 17,605 carers in the South West are from ethnic minority groups. Somerset specific data is not available but using the regional figures it is estimated that there could be 1,760 carers from ethnic minority groups living in Somerset.

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\(^{34}\) PANSI- Projecting adult needs and service information – Dept Health

\(^{35}\)Centre for International Research In Care, Labour and Equalities– Dept Health
• According to the latest estimates over 97% of the population of Somerset gave their ethnic origin as White British
• The majority (over 27%) of Somerset Black and Minority Ethnic population is aged 30-49
• Somerset Black and Minority Ethnic population has more than doubled since 1991
• More than half of Somerset Black and Minority Ethnic population live in the Districts of South Somerset and Taunton Deane

(NB: Awaiting updated figures from Somerset County Council)

Summary

This brief outline of relevant demographic projections for Somerset clearly demonstrates the existing high numbers of older people and those with limiting long term illness, dementia, and learning disability and the significant increases in all these areas that the county will experience in the years ahead. These increases are proportionately greater than the South West overall position and much greater than the country as a whole.

It is likely that these projected increases will have an impact on unpaid/family carers across Somerset. The likely increase in the number of carers will increase demand for support as more and more carers become aware of their rights and entitlement. Without the relevant support and preventative measures in place to enable carers to sustain their caring role there will be a significant increase in demand for Adult Social Care and NHS services.

8.2 Rural Issues

The demographic changes in Somerset as well as rural issues will have a major impact over the next five years on the effectiveness and sustainability of carers’ services.

Somerset average population density is 146 persons per sq km, compared with a south west average of 207 persons and national average of 244 persons\(^36\). The population is very dispersed with only about a third of the population living in the four largest towns of Taunton, Yeovil, Bridgwater and Frome. Particularly sparse population densities are identified on Exmoor, other upland areas and parts of the Somerset Levels.

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\(^{36}\) Office for National Statistics Regional Trends data
It is in the mostly rural areas where there is a high proportion of people aged over 65 and in particular, some areas of West Somerset, Sedgemoor, and South Somerset and also on the outskirts of Taunton. It is interesting to note that although more rural areas have the highest proportion of older people overall, it is in urban areas where many older people live alone.

**Transport links**

The impact of the rural nature of Somerset on carers is highlighted by the following statistics:

- 28% of rural residents have either a minimum 30 minute travel time to their nearest GP or no service at all by public transport, compared with only 1% of urban residents
- 43% of residents have either over one hour travel time to their nearest general hospital or no service at all by public transport (51% from rural areas and 37% from urban areas)
- 24% of rural residents have at least one hour travel time to their nearest Community Hospital or no service at all by public transport
- 1:5 people have either a minimum 30 minute travel time to their nearest supermarket or no service at all by public transport

(Source: Office of National Statistics and Joint Strategic Needs Assessment)

Rurality and low population density present challenges for carers due to difficulties with transport, accessibility of local services, and employment opportunities all of which will need to be taken into account when developing the best model to meet the future needs of carers in Somerset.

**Housing and accommodation needs**

Housing and accommodation are also a key factor and play a part in supporting carers and enabling people to remain more independent. In particular Extra Care housing enables couples, where one person is caring for their partner, to remain living together in the same accommodation rather than being split up, as in a move to a care home. In 2008 a review by Peter Fletcher Associates of Extra Care Housing was carried out in Somerset and findings suggested that the major towns, particularly Taunton, appeared to have a current undersupply, whilst the over 85s are predominantly concentrated in urban rather than rural areas with more potential for demand for this type of housing.

Most people say that they want to remain in their own home, even in preference to Extra Care Housing schemes, so the idea of a virtual Extra Care Housing scheme where the benefits of housing with care and housing support on site could be transferred to people in their own homes has been suggested which could also provide additional support for carers. One of the great challenges for
housing with care will be the growth of the number of people with dementia who will have increasingly complex housing and care needs.

There is an emerging Somerset Assistive Technology strategy and policy which has close links to benefit carers. Somerset Extra Care Housing schemes have only made limited use of assistive technology at present, mainly through community alarms. The use of a hub for meals, activities, and health promotion, with more housing support and care staff visiting people in their own homes with a more enabling approach, could offer great potential for a new type of Extra Care Housing in the future.

The Extra Care Housing Schemes have also not been utilised as a local community resource, for example by Active Living Centres, which could also incorporate a carer resource, providing information and support for carers aged over 50 in a local community.
9. Researching best practice

This section outlines the methodology used and outcomes of the research into best practice across other parts of the UK in order to evaluate how well Somerset is delivering services to meet carers’ needs.

9.1 Methodology

There were two stages to the research into best practice nationally which was carried out by Peter Fletcher Associates:

Stage 1

A desk top exercise using the internet to identify other areas where specific services for carers have been recognised either with a beacon status award or other aspects of best practice. A paper was produced and circulated which has been built on during the course of this appraisal and some of the examples were extracted and displayed at the stakeholder events.

Stage 2

A number of other localities were identified to make comparison using two criteria:

- Population density measured by the number of citizens per square kilometre
- Sites recognised as either Beacon Councils or sites of good practice

Somerset’s current population density is 146 (citizens per square kilometre). The five south west authorities to which Somerset is compared range between 108 – 214 population densities. The other sites were areas of best practice, some of which were of similar population density to Somerset such as Lincolnshire but others were of larger population density but with useful learning and models of service delivery which could also be applied to a more rural area. Figure 9.1 lists the other areas contacted with their population densities:
* denotes Beacon Council status or other award for best practice for carers

### 9.2 Alternative models of delivery

In looking at other authorities, including beacon sites, there is no single commissioning model which can be used as an exemplar to benchmark against. However each area which was examined had some aspect of good practice and learning which could be applied to Somerset. These have been taken into consideration when making recommendations about a suggested model for the development of carer services against the key priority headings which have been identified by Somerset carers as most important and used throughout this report:

- Information
- Assessment
- Practical and emotional support, including short breaks
- Health and wellbeing
- Other factors

The research into best practice identified examples of innovative and cost effective services which can be found in Appendix 4. Peter Fletcher Associates were also asked to identify three different models and identify the advantages / disadvantages of each. Initial research indicated that there are not three clearly distinguishable models; instead we have examined the key elements of carer services in each area.
9.2.1 Information & Advice

All localities contacted operate customer contact centres and support generic web sites which include some information for carers. Of the areas contacted 9/10 had developed a Carers Hub model. Of these seven had developed this in conjunction with the third sector whilst two other areas (Essex and Lincolnshire) have developed this in-house. All provide a wide range of information specifically for carers accessed by telephone and via a website.

Lincolnshire and Essex operate an in-house Carers Team who provided a similar service for the whole of the county and act as the first point of contact for carers enquires. In Lincolnshire this team is based in the corporate customer contact centre. In the vast majority of areas the information and advice element is provided for all carer groups, irrespective of age or type of impairment. In 3/10 areas people with mental health needs were directed to the specialist mental health trust.

The majority of Carers Centres are funded using a Service Level Agreement from Carers Grants supplemented by additional monies from Adult Social Care and Primary Care Trusts. Discussion with both Gloucestershire and Sunderland indicate that their funding is incentivised to encourage the identification of new carers and most are pro-active in working with local services GPs, libraries, supermarkets etc. Carers Centres have started to develop web based technology which combines mapping with information, thereby delivering a much more tailored delivery of relevant information to individuals. For an example of how this technology can work click see:

www.swdc.org.uk/system-development/carers/service-map/

Most areas reported that it was not the lack of information that was the greatest concern but the need for a central place for both local and national advice, either written or web based that is available in various formats with a single agency responsible for updating this information. In respect of information and advice there appear to be three options within this element:

Option 1: Customer contact centre providing information with onward referral (Somerset & Cornwall)

Option 2: In house centralised Carers Team (3/10 localities)

Option 3: Independent Carers Centre (7/10 localities)
9.2.2 Assessment

In 7/10 areas Carer Assessments were undertaken as a core task of community teams and carried out by both health and social care professionals. Hertfordshire in particular felt strongly that it is important to adopt a whole family approach, a sentiment echoed by a number of other authorities. In Dorset assessments are undertaken by specialist Carers Assessment Workers located in community teams, but managed as a specialist team with their own county-wide manager. This is unlike Somerset Adult Social Care where Carers Support Workers are now based in Community Adult Social Care Teams and managed by the Adult Social Care Team Manager. However it is a similar model to Somerset Partnership NHS Foundation Trust where Carers Assessment Workers are in a specialist county-wide team with their own manager.

Essex operates a specialist in-house team that undertakes assessment, but this is also a core task for other staff. Lincolnshire still has a centrally based team, but this is located as part of the customer contact centre and has developed a system where “trusted assessors” from other agencies, including the third sector, can undertake assessments which are then collated by the central team and signed off. There was evidence both from Somerset and other areas that specialist workers were used to undertake carer specific assessments with other professionals retaining control of more complex cases.

Several areas including Devon, Sunderland, Hertfordshire, Oxfordshire and Lincolnshire had either developed or were in the process of developing self assessment. Lincolnshire has a good example of online self assessment. Essex has developed a self assessment tool which is sent by free post to the team who screen and sign off each assessment. In both Essex and Lincolnshire assessments and reviews are undertaken by this dedicated team using telephone contact.
In Devon, as part of the Department of Health demonstrator site, 40 of the 75 GP practices receive a financial incentive for completing a Carers Health and Wellbeing Check which is completed by the carers and signed off by the practice. This triggers a payment to GPs and at the same time supports an improvement in the number of carers registered.

In two areas consideration was being given to developing Carer’s Resource Allocation System (RAS) linked to a self assessment tool. In both Wiltshire and Oxfordshire there were limited specialist staff but these were used to either support carers to undertake self assessment, to work with community teams to improve performance and occasionally to provide a separate assessment where there is potential for dispute between the needs of the carers and the cared for person. In all cases the responsibility for Carer Assessments remained a core function.

In a number of areas mental health trusts still deploy specialist workers to undertake assessment as part of a wider multi-agency team approach.

Several areas felt there was too much emphasis on Carer Assessments as a performance target. Instead it was considered that greater emphasis should be placed on achieving the right outcomes for carers. In respect of assessment there appear to be three options within this element:

Option 1:  7/10 areas, including two award winning areas, see Carers Assessment as a core task undertaken by all social and health care professionals and not by specialist assessment workers.

Option 2:  Only Dorset uses a similar model to Somerset in that they deploy specialist assessment workers located in community teams. These are managed by a single manager similar to Somerest Partnership NHS Foundation Trust which has a specialist county-wide team with its own manager.

Option 3:  Essex and Lincolnshire are perhaps the most advanced in terms of providing greater choice in how carer assessments can be completed, offering face to face meetings with generic staff, telephone or self assessment on-line or hard copy.

<table>
<thead>
<tr>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>The characteristics of what constitutes best practice appeared to be:</td>
</tr>
<tr>
<td>A choice of assessment opportunities which should include self assessment and the use of telephone and on-line assessment</td>
</tr>
<tr>
<td>• The responsibility for carer assessments should be a core function undertaken by mainstream social and health care professions. The development of a “trusted assessor” could widen choice to include staff working in third sector and NHS staff</td>
</tr>
<tr>
<td>• In the majority of areas mental health and learning disability teams make their own arrangements for carer’s assessment but work closely with a carers centre to prevent inappropriate referrals</td>
</tr>
</tbody>
</table>
9.2.3 Practical Support including Short Breaks

Looking at other areas there was a very diverse picture across the areas sampled. Each area had different partners, each at different stages of development and therefore it was only possible to draw general conclusions. There was not particular preference for the use of in-house or directly commissioned independent sector services. Most authorities are moving to being a purely commissioning organisation, but those who still retain some in-house care home and other specialist accommodation provision utilise the voids to offer generous short breaks based on a full carer assessment. By far the greatest investment goes into:

- Emotional support and counselling
- Crisis intervention and short breaks

Short breaks take many shapes and forms in each of the areas and mean different things to different carer groups. Short breaks can vary from a residential respite unit, day centre support, holiday away from home or a sitting service. In the majority of areas this was a service that could only be accessed following a formal assessment and the entitlement differed depending on the needs of the cared for person.

In a number of areas accessing respite in a fair and equitable way was a challenge which no one area had appeared to have resolved satisfactorily. Some authorities had developed points or voucher systems or more streamlined booking systems to facilitate easier access. Feedback from carers in other areas had driven certain developments including the ability to save or flex short breaks over a period of time or swap between different types of short breaks (residential, sitting or holidays away).

Whilst some areas have devised systems of entitlement based on the Resource Allocation System (RAS) of the cared for person, it appears that this did not necessarily reflect the carer’s ability to cope; the ideal system would be some correlation between both elements. Resource Allocation Systems (RAS) are still in the early stages of development nationally. Each area tends to set its own value within the system and therefore for these reasons no useful comparative data is available.

In Sunderland, the Carers Centre administers a percentage of the NHS Short Breaks Budget in the form of small grants based on the number of hours someone is caring. In a small number of areas Carer Centres also support self assessment and in at least two areas host Carers Support within the centres themselves. In comparison with Somerset perhaps one significant difference is the way in which the different forms of breaks are marketed to people and the degree of flexibility and choice. The earlier research identified many innovative services which had been developed, including:

- Preference appointments with GPs
• Emergency or contingency plans
• Health checks for carers
• Discount cards with local employers
• Discount on transport
• Short breaks funding either in cash or as a voucher

### Practical Support & Short Breaks

The characteristics of what constitutes best practice appeared to be:

- Access to short breaks on a planned basis needs to be fair and equitable across the various carers groups. Carers should have an understanding of their entitlement and the choice of how, when and by whom this support should be delivered.

- The development of a Carer Centre model (outsourced or in-house) which focuses on carer issues, better communication with existing carers and marketing to unknown carers, as well the development of community based services across rural locations.

### Example of best practice

**Sefton Carers Emergency Respite Team and Flexible Accessible Breaks**

This team provides short-term, home-based respite support to carers in crisis or emergency situations. Following a home visit to register with the service, carers are provided with the contact details to enable them to access support which is available 24 hours a day and all year round, including weekends and bank holidays. The team is supported by a coordinator, having regular team meetings and supervision. The team remit is to take over the carer role, which would include all caring tasks, excluding nursing procedures, which would be carried out by the Primary Health care team, and whatever domestic tasks are required to sustain the situation.

There are now over 7,000 carers registered with the carers centre and 1,236 carers registered with Carers Emergency Respite Team. The service has expanded to include flexible accessible breaks.

Beacon Council Contact: cert@sefton-carers.org.uk

Established by third sector organisations such as Carers UK, Crossroads whilst others were supported by the Carers Centres or members of the community teams.
Ongoing opportunities for face to face contact beyond the Carer Assessment were provided by all Carers Centres, including the two in-house centres. Not all areas provided face to face contact with paid workers. In 4/10 areas this was provided by a combination of volunteers and paid staff.

**Emotional support and counselling**

The characteristics of what constitutes best practice appeared to be:

- Easy access to emotional support with a choice of how this should be provided. This could be via face to face contact, websites, telephone support or local groups. This does not necessarily need to be paid staff, but if buddies or volunteers are used then there needs to be good training and support structures

- An independent counselling service should be in place which is easy to access and widely publicised.

Discussions with commissioning leads from other areas revealed no single system that could be compared easily. Often support in a crisis was a combination of an emergency help line and a duty team, with access to short breaks or a sitting service or by access to domiciliary care providers for a limited number of hours. In some areas such as Devon, carers were able to access spare capacity of in-house services at very short notice. In several areas time had been invested in developing emergency or contingency plans for carers so that should anything happened to the carer then a pre determined set of preferences were triggered.

**Support in a Crisis**

The characteristics of what constitutes best practice appeared to be:

- Support in a crisis needs to be well promoted and monitored to ensure follow up and reassessment if necessary

- Contingency plans must be in place for the carer and the person cared for to cover different eventualities and periods of time

**Example of best practice - North Wiltshire**

**Emotional and Social Support - Working with libraries**

Carers Support North Wiltshire has built a relationship with its ten local libraries, delivering ‘Well Being Days’ which offer alternative therapies to carers alongside a chance to meet others, and Drop in sessions with workers such as Financial Advisors. The County Librarian is now planning story-telling sessions for children and siblings of
9.2.6 Health and Well-being

The majority of areas contacted had initiated some form of wellbeing checks for carers often linked to improving the accuracy of Caree's Registers. Devon is a Department of Health demonstrator site and has developed a wellbeing check which carers complete and then take to their GP to be signed off. There is a financial incentive (£75 per each wellbeing check completed) linked to targets for each participating practice. In Devon the average profile of the carer population is approximately 10% compared with an average 2.5% of carers registered with GPs. A target of 4% of carers on the GP Carers Register has been set which will then be reviewed annually. However feedback from one Devon carer who had experienced this check suggested this could be a waste of resources which might be better spent on giving the carer £75 to spend on a break instead.

Manchester and Liverpool have undertaken a number of GP based initiatives including training for practice staff, the appointment of carer champions within each surgery or the use of information points supported by volunteers.

In Wiltshire it was recognised that carer issues in GP Practices varied considerably in response to a model of Carers' Health Clinics which was created by Carers Support West Wiltshire. This involved offering carers a ten minute appointment with the Practice Nurse, a ten minute appointment with a representative from the Financial Assessments and Benefits Team and a ten minute appointment with a representative from Carers Support West Wilts. The purpose of this was three fold:

- To ensure Carers give time to their own health and wellbeing
- To ensure all state entitlements/benefits have been claimed to maximise income
- To advise carers about the services which carer support organisations can offer

Wiltshire is shortly to implement a Carers-Mark (Gold, Silver or Bronze) to be awarded to GP practices who work proactively to support carers. This will add an element of “consumer” pressure to the system as well as rewarding best practice.
The Financial Assessment and Benefits Team reported a total annual increase of revenue of £19,379.88 to four carers who attended the first clinic in Wiltshire.

**Health and Well-being**

The characteristics of what constitutes best practice appeared to be:

- Health and wellbeing checks completed on all carers
- Option of carers completing these themselves and signed off by GP
- Financial incentive linked to targets for each participating practice to ensure GPs carry these out

**Other factors:**

Discussions with the ten other areas identified a number of other differences in the way services for carers are commissioned:

**9.2.7 Carers Centre Development**

Of the ten areas contacted 9 had developed a Carers Centre model as a way of providing a greater focus on carer issues. This enabled a more performance driven, responsive service for carers with a more efficient use of resources. In seven areas the Carers Centre was commissioned from the Community and Voluntary Sector such as Crossroads, Princess Royal Trust or local voluntary organisations. Not all are operated as a User Led Organisation (ULO) and in Essex and Lincolnshire these remain an in-house function provided by the council. Whilst there was no evidence of any areas asking for a membership fee to be part of the Carers Centre there were a number of centres which asked for voluntary donations but we were unable to determine the level of fundraising obtained from this source.

Evidence from the ten areas contacted suggests that the Carers Centre element of the model does deliver better outcomes for carers. However the National Indicator NI 135 is considered by many not to be a good indicator of better outcomes for carers and there was no discernable trend in each of the areas contacted using this measure. There were also reported variations in the quality of NI 135 data which makes it an unreliable indicator of performance.

Other evidence of improved outcomes from a Carers Centre includes:

- Improved levels of carers satisfaction
- Improvement in the quality and waiting time for Carers Assessments
• Higher levels of identification of previously unknown carers
• Improved levels of carer engagement
• More equitable service across rural areas
• Value for money in that the centre reaches more carers at the same or reduced cost than the previous system
• It provides better co-ordination of carer volunteers

Fig. 9-2 outlines the benefits of a Carers Centre and gives examples of other areas that have this model

Fig. 9-2: Description of a Carers Centre

**What is a Carer Centre?**

Carers Centres provide a range of services, including:

• Information, advice and in some cases advocacy
• Counselling and emotional support
• Supporting carers groups
• Benefit checks
• Variety of health and well-being courses
• Supporting carers engagement and governance arrangements
• Administration of grants for short breaks

**Characteristics of a Carers Centre**

The Carer Centre does not have to be in one building or location and in many areas local contact points are used. For example Sunderland is developing 28 local centres as part of a “People First” network; it will comprise 28 centres with a variety of services available and in many cases these centres will have video link or conferencing facilities. Sunderland Carers Centre will be able to use technology to enable it to connect to the full customer service centre network to widen the accessibility of their services. Aside from the technological innovations, information prepared by Sunderland Carers Centre will be available on the Council Customer Relationship Management (CRM) system, which will enable customer service staff to provide quality information to carers. Carer Centres are also commissioned to target hard to reach groups, unknown carers and work with GPs.
9.2.8 Strategic planning

Without exception each authority had developed a detailed Carers Strategy which built on the National Carers Strategy but few made reference to implementation plans with little evidence of relating strategy to available funds. Most were multi-agency strategies produced in conjunction with health, voluntary organisations and to lesser extent, carers themselves. Many strategies identify as a priority those carers who undertake either 20 hours or 50 hours caring per week.

The majority of authorities based their strategy on the combination of Carers Grant and Carers Breaks funding from Primary Care Trusts with an acknowledgement of the relationship between funding for the cared for person. In a significant number of areas, Carers Grant funding is allocated on traditional lines, being top sliced for generic services and then allocated across various service user groups.

Many areas referred to the inadequacies of the National Indicator 135 as a true measure of performance or improved outcomes for carers. The majority of areas had a separate carer lead but underpinned by close co-operation with NHS counterparts. Only in Devon was the carers lead a jointly funded post.

In all areas consulted there was a link between the generic carer service and specialist teams such as mental health and learning disabilities, as part of the desire to mainstream services. Although assessment remained part of the professional team responsibility, the promotion and co-ordination of information and advice, carers groups etc, was part of the generic Carers Centre to a greater or lesser degree.

9.2.9 Personalisation

Very few areas have made significant progress with the personalisation agenda in respect of carers. It is therefore not possible to determine a best practice model or to suggest how this could dramatically impact on the way funding is currently allocated. At least two areas were developing Carers Resource Allocation Systems and several were looking to develop self assessment in order that carers could have access to limited funding for short breaks or sitting services. Nowhere is the tension between the carer’s needs and those of the other person.

Many areas still make use of their Council contact centres as the single point of access but which then refer on to the Carers Centre to keep carers out of the system and provide a much more carer focused, independent service to carers which is well received. In several areas there is an element of performance related funding related to annual targets. Carers Centres provide a wealth of information and support and most have their own websites with examples here:

http://www.prtcarerscentre.org.uk/
http://www.carersgloucestershire.org.uk/
http://www.herefordshirecarerssupport.org/index.php
cared for person so greatly demonstrated as when looking at the implementation of self directed support and individual budgets.

In Lincolnshire any carer who has completed a self assessment and provides more than 19 hours per week support is entitled to £272 per annum to use flexibly for short breaks. In Devon any person providing more than 50 hours caring per week is entitled to a break of three hours per week. In each case this entitlement could be saved up or used flexibly across a range of short breaks.
10. Comparison with existing carers services in Somerset

10.1 Information and advice

The Somerset Carers Strategy states that Somerset Direct is the single access point for carers. Whilst the service provides a single number and access point for all people requiring council services only 13% (43) of carers who responded to our questionnaire said they received information from Somerset Direct and the majority of carers who were consulted with had not heard of Somerset Direct. For those carers who had experience of using this there were suggestions that staff needed more training in carers’ needs and better knowledge about where to refer people.

The route for carers into Adult Social Care and/or a Carers Support Worker is via Somerset Direct or identification via the Adult Social Care team undertaking assessments of the person cared for. What is evident is that very quickly a referral becomes part of the Adult Social Care team case load if the reason for referral cannot be dealt with by Somerset Direct.

Somerset Direct has a relatively low number of contacts from carers and is not currently available 24/7. However it has the potential to be developed further as an initial single point of contact for carers, as identified in the Somerset Multi-agency Carers Strategy.

Characteristics of Somerset’s service:

- Somerset Direct provides a single point for carers’ enquires but feedback suggests this is not specific enough or tailored to carers’ needs. There is no single information point specifically for carers and each agency providing separate information routes
- Carers very quickly gravitate to formal assessment and support from statutory services
- The majority of information and advice is provided during or post assessment
- There is no co-ordinated information across local communities

10.2 Assessment

The responsibility for Carer Assessment is split between specialist workers and other social and health care professionals. In Adult Social Care approximately 72% of assessments are undertaken by Carers Support Workers and in Somerset Partnership NHS Foundation Trust 94% by Carers Assessment
Workers. This means that quite often a family may have more than one worker visiting to carry out two separate assessments. This has pros and cons – whilst it may offer carers an independent advocate and opportunity to be assessed alone, this option is also available by the Adult Social Care worker. During the consultation process several carers have raised the issue of being confused by different workers visiting them when unclear about their roles and duplication of resources.

Within the Community Learning Disability Teams Carer Assessments are undertaken as a core task by the cared for worker although they are currently advertising for a Carer’s Support Worker which will carry out more of a provider role.

Somerset has limited choice for people wishing to opt for other routes for Carer Assessment such as self-assessment screening on-line or assessments carried out by Somerset Direct over the phone, which are not currently an option.

In the questionnaire only 3.6% (12) carers said they had been asked about their needs and in most face to face meetings carers stated that having a Carer Assessment is rare with lack of outcomes if they do have one (except for Somerset Partnership NHS Foundation Trust who provide carer recovery plans). There is also a lack of resources to enable carers to be followed up or reviewed.

Characteristics of Somerset’s service:

- All Carer Assessments in Somerset are undertaken either by specialist Carers Support Workers or Carers Assessment Workers or core staff in statutory agencies
- There is no self assessment, supported assessment or opportunity to complete an assessment online or through another agency (particularly relevant for BME community)
- Specialist workers spend a significant proportion of their time on assessment as opposed to providing practical and emotional support. Within both mental health and Adult Social Care there are pressures to limit this type of intervention with carers

10.3 Practical support including short breaks

Somerset has invested in Carers Support Workers and Carers Assessment Workers over the past 15 years with positive outcomes for many carers who highly value their support. However they have contact with a relatively small number of carers in the context of Somerset’s overall total. There is a need to re-focus this service to ensure best use of resources and tailor it to providing what carers value most from it.

The feedback from carers suggested that in Somerset services are fragmented, difficult to access, with no clear entitlement and confusion between the vast
arrays of information sources. Carers’ greatest concerns are related to accessing services in rural areas, booking short breaks and associated transport issues.

10.4 Support in a crisis

Support in a crisis is also required by carers and by having good contingency plans in place which cover a range of eventualities and time periods and ensure the crisis is more easily dealt with. Evidence gathered during the consultation suggests that current services in Somerset, such as Help in a Crisis are under-used often because they are not known about, or not available at the times required (e.g. Carers Assessment Workers have tried to access this service without success)

Characteristics of Somerset’s service:

- The entitlement of carers to short breaks is unclear and varies across each carers group; it does not appear to be based on any sound rationale
- There are difficulties in accessing short breaks and associated transport difficulties particularly in rural parts of the county
- Carers do not routinely have contingency plans developed

10.5 Emotional support & counselling

The Care First Counselling Service is well established in Somerset with 20% of its contacts taking place with carers. However this service still appears to be relatively unknown even by carers who are in touch with statutory agencies and by some staff and county councillors who were unaware of its existence.

The model adopted appears to be the right one for Somerset and each of the ten areas contacted had developed a similar system in the form of ether a contracted service similar to Care First (4/10 areas) or a local service provided by the Carers Centres. The need in Somerset is to build on this service, advertise it more widely and ensure that carers are aware of its existence and how to use it. In addition, other resources which are available via NHS Somerset and Somerset Partnership NHS Foundation Trust should be better publicised.

10.6 Health and well-being

The majority of Somerset carers who participated in the consultation exercise identified their local GP practices as the most convenient place to access information and advice and to recognise the impact of caring upon their own health and wellbeing. The need to access regular health checks and priority
appointments with GPs was frequently raised and given higher importance than Carers Assessments by the carers we consulted with.

A positive development in Somerset is the pilot between Carers UK, St John Ambulance and WyvernHealth.com which has already recognised the need to raise awareness amongst primary care staff with a project underway to identify carer champions in each GP surgery and undertake awareness training.

**Characteristics of Somerset’s service:**

- There are no routine health checks for carers
- The Carers Counselling Service is not widely known about
- Carers registers do not reflect the number of carers in the local community
- The quality of emotional support via local support groups or Carers workers is patchy and does not extend to many of the hard to reach groups

**10.7 Strategic Planning**

- The current Somerset Multi-agency Carers Strategy and action plan are not fully resourced nor are funding decisions made in keeping with the identified strategic priorities
- The systems assessing how investment impacts on better outcomes is not robust

**10.8 Giving carers a voice**

Somerset Partnership NHS Foundation Trust has put in place significant measures to ensure carers are consulted and involved in decision making. Somerset County Council has also made similar progress, particularly around carers’ involvement in interviews and the voice of employees. However, the Carers Strategy group only has two carer representatives and needs strengthening
11. Gap analysis

Fig. 11-1 is a summary of stakeholder perceptions of the current service following the consultation in Phase 1 and Phase 2 of this appraisal. It identifies any positive practice and whether services are meeting carers’ needs, using a red, amber, green rating for each particular strategic priority:

- Green suggests the service fully meets the needs of carers
- Amber indicates a risk of not meeting the needs of carers
- Red suggests that this element of the service is not meeting the needs of carer
- The final columns identify where the gaps are and recommended solutions

Fig: 11-1: Gap analysis of current service delivery in Somerset

<table>
<thead>
<tr>
<th>Strategic priority</th>
<th>Rating</th>
<th>Positive practice in Somerset</th>
<th>Gaps</th>
<th>Possible solutions</th>
</tr>
</thead>
</table>
| Information and Advice | AMBER | Carers Champions now being set up in 43 GP surgeries Somerset Direct is in place and has been identified in the Somerset Carers Strategy as the single point of contact for carers | • The current information was described as patchy and variable in quality.  
• The majority of carers have not heard of Somerset Direct.  
• Somerset Direct do not have dedicated specialist carer staff  
• No specialist carer information, advice and support service for Somerset Direct to refer carers onto  
• Not all GP practices signed up to Carers UK/St John Ambulance pilot. | • Carers training programme for Somerset Direct staff  
• Carers Centre/local resource to refer carers onto for specialist carers information and advice  
• Carers Champions to be extended to all GPs  
• Most people wanted information to be local, specific and accessed via local GP or other local outlet |
<table>
<thead>
<tr>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMBER</td>
</tr>
<tr>
<td>• Current Carer Assessments are either undertaken by the worker of the cared for person or by Carers Support Workers or Carers Assessment Workers</td>
</tr>
<tr>
<td>• Carers that have contact with a specialist carer worker value them highly.</td>
</tr>
<tr>
<td>• Positive benefits of an independent advocate for the carer by having a separate worker</td>
</tr>
<tr>
<td>• Majority of carers consulted with had not had a Carers Assessment and were unaware of a specialist carers support service</td>
</tr>
<tr>
<td>• Danger of cared for person’s worker becoming de-skilled in carer aspects and not considering wider family</td>
</tr>
<tr>
<td>• Confusion for the carer about two different professionals with duplication of assessment function</td>
</tr>
<tr>
<td>• Make more efficient use of resources by equipping the worker of the cared for person to also focus on the carers needs; offer Carers Assessments separately and in private if required</td>
</tr>
<tr>
<td>• Ensure the worker develops a professional relationship with carer and cared for person so carer is clear about role</td>
</tr>
<tr>
<td>• Offer independent advocacy from the voluntary and community sector/Carers Hub if required</td>
</tr>
<tr>
<td>• Stream line the carer assessment process and make it proportionate to need e.g. screening tool/self assessment or via telephone at Somerset Direct to be followed by a detailed Carer Assessment if need indicated.</td>
</tr>
</tbody>
</table>
| **Practical Support including short breaks** | **AMBER** | • This was identified as one of the most important aspects of the service  
• Some carers are receiving regular respite and support | • Lack of consistency in what is offered to different groups of carers and no rationale behind decisions about entitlement  
• Lack of eligibility criteria for carers services  
• Lack of respite beds  
• Difficult booking procedure  
• Lack of creative alternatives or options of breaks in own home  
• Carers reported lack of flexibility and difficulty in accessing current arrangements  
• The majority of carers wanted more breaks and greater choice both in terms of booking and also how the break could be provided | • Introduce a carers eligibility criteria  
• Introduce a universal offer for respite sitting service  
• Negotiate with independent sector re bed availability for respite care  
• Stimulate market to offer more creative options for short breaks  
• Introduce personal budget and a voucher scheme for carer to organise their own breaks |

| **Emotional Support** | **AMBER** | • Some carers are benefiting from Care First Counselling service  
• Carers valued carer support groups and Carers Support Workers and Carers Assessment Workers | • Low level of awareness about counselling service  
• Low level of awareness about NHS emotional support services | • Introduce a publicity campaign about the Care First Counselling service and other services |
<table>
<thead>
<tr>
<th>Category</th>
<th>Issues and Solutions</th>
</tr>
</thead>
</table>
| Health and well being    | - Face to face contact was highlighted as a priority  
- The Wyvern health.com, /Carers UK/St John Ambulance pilot is a positive step in improving GP awareness of carers issues  
- Lack of health checks for carers  
- There was reported a great variation across the county in how GPs recognised and supported carers. There is little evidence as to the number of people registered as carers with their GP  
- Carers UK/St John Ambulance awareness raising may address this – use evaluation findings to develop action plan  
- Analyse findings from Devon demonstrator site  
- Encourage widespread use of Expert Patent programme – Looking after your self and Caring with Confidence courses  
- NHS Somerset to monitor GP carer registers |
| Employment & Finance     | - A small number of carers who support people with mental health needs are receiving a bespoke employment service that has developed an excellent reputation and is highly valued  
- FAB team offers financial and benefits advice and has  
- Lack of awareness about the Job Centre Plus carers resource  
- The majority of carers find lack of employment opportunities and lack of flexibility by employers frustrating. This creates financial disadvantages both in the short and long term  
- Lack of awareness  
- Widen awareness about Job Centre Plus support for carers  
- Widen awareness about FAB team and Care First support availability  
- Ensure an information role about finance and benefits for |
<table>
<thead>
<tr>
<th>Recognition</th>
<th>AMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>provided an educational element - eg talks at carer support groups but this may not continue</td>
<td>about financial and benefit advice services</td>
</tr>
<tr>
<td>• Care First Counselling service has an information service providing financial and benefit advice</td>
<td>carers is available either at Somerset Direct or a Carers Centre</td>
</tr>
<tr>
<td>• Ensure an education role is available on benefits and advice to local carer support groups and other community groups which carers may attend</td>
<td></td>
</tr>
<tr>
<td>• Some carers have a voice in Somerset County Council, NHS Somerset and Somerset Partnership NHS Foundation Trust on various boards and implementation groups but opportunities are mainly for carers to influence decisions as opposed to make decisions, drive priorities and monitor progress</td>
<td>• Limited voice for carers in Somerset</td>
</tr>
<tr>
<td>• Small number of carers involved in planning an decision making</td>
<td>• Lack of Carers Partnership Board</td>
</tr>
<tr>
<td>• Carers Strategy Group is having limited impact on planning, decision making and monitoring carers services in Somerset</td>
<td>• Agree formal governance process for carers services and Carers Grant</td>
</tr>
<tr>
<td>• Limited voice for carers in Somerset</td>
<td>• Set up Carers Partnership Board with majority carer representation and carer as chair</td>
</tr>
<tr>
<td>• Lack of Carers Partnership Board</td>
<td>• Ensure Somerset Carers Strategy is updated with action plan and monitored by the Carers Partnership Board</td>
</tr>
</tbody>
</table>
12. The suggested model for Somerset

As part of this review we were asked to examine the advantages and disadvantages of some of the broader factors influencing how services may be commissioned and to provide a suggested model of future service delivery which would best meet Somerset’s needs.

The gap analysis has identified the positive practice being carried out in Somerset and the gaps in service provision against best practice elsewhere in the UK with suggestions for improvement. As a result we have a suggested model for Somerset as shown in Fig. 12-1 which outlines the key elements of a comprehensive carer service based on best practice.

**Fig. 12-1: Suggested best practice model for Somerset**

The key elements of the suggested model in Somerset will ensure that carers have access to high quality carer specific information and possibly low level services, regardless of type of carer. A carer can self refer to Somerset Direct or the Carers Hub where specialist carer information and advice would be provided and a simple screening tool completed over the phone to identify the carer’s eligibility.
The benefits of a Carers Hub provided by a third sector organisation would enable an independent service and prevent the need for carers to access statutory services unless absolutely necessary.

The Carers Hub would work proactively to reach and maintain contact with carers and provide a comprehensive range of information, advice and support via a variety of different outlets in local communities. This could include GP surgeries, libraries, post offices, Active Living Centres, extra care housing units, community centres, etc.

This service is intended to complement Somerset Direct by providing more specialist information, advice and support for its “membership” specifically focused on the needs of carers and would be the first step in developing an ongoing relationship with carers and thereby preventing them entering the Adult Social Care or NHS systems.

Somerset Direct will still play an important role in signposting carers to the Carers Hub but also in providing a gateway to statutory services. To ensure ease of access Somerest Direct will need a direct line and facility to transfer calls to the Carers Hub without the need for carers to have to make another phone call.

There will need to be a Carer Assessment process and Carers Eligibility Criteria for carers to access Adult Social Care support such as short breaks. The eligibility criteria will need to take into account the amount and type of care being provided by a carer, number of people being cared for, transport needs, other commitments and sources of support.

Carers should have choice in the type of break, who provides it and where it is provided and be able to book this in a simple and flexible manner. Carers should be able to access emergency support during a crisis with the agency contacted taking responsibility for co-ordinating this support.

Fig. 12-2 shows the key elements of the suggested model for Somerset.

**Fig. 12-2: Key elements of suggested best practice model for Somerset**

<table>
<thead>
<tr>
<th>Information and Advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>A single focus for all carer enquires and which provides a range of support and which prevents inappropriate onward referrals</td>
</tr>
<tr>
<td>Accessible by telephone, web and in person; not over-dependent on technology</td>
</tr>
<tr>
<td>A service which is outward looking, proactive in recruiting new carers</td>
</tr>
<tr>
<td>A service which supports all carers irrespective of age or impairment</td>
</tr>
</tbody>
</table>
- Comprehensive information and advice for carers to be provided close to their local community, particularly given the rural nature of Somerset. This should include GP surgeries, but also elsewhere such as libraries, post offices, etc.

### Assessment

- Assessment should be the core function of all social and health care staff and not by specialist carer workers
- Assessment should be proportionate to needs which must include a simple screening tool which a carer can complete themselves and more detailed Carer Assessment to be completed by a Somerset County Council or NHS employee or trusted assessor.
- Choice should also be extended to how assessments are completed and should include face to face; telephone contact, postal and online.

### Practical support including Short breaks

- Clear eligibility criteria for short breaks need to be developed across all carer groups which are fair and equitable and which includes transport when needed
- Carers should have choice in the type of break, who provides it and where it is provided
- Carers should be able to book simply and be able to flex their entitlement
- Carers should be able to access emergency support during a crisis with the agency contacted taking responsibility for co-ordinating this support
- Carers who are assessed should be encouraged to develop an emergency or contingency plan

### Support in a Crisis

- Support in a crisis needs to be well promoted and monitored to ensure follow up and reassessment if necessary
- Contingency plans must be in place for the carer and the person cared for to cover different eventualities and periods of time

### Emotional support & counselling

- Easy access to emotional support with a choice of how this should be
provided. This could be via face to face contact, websites, telephone support or local groups. This does not necessary need to be paid staff, but if buddies or volunteers are used then there needs to be good training and support structures

- An independent counselling service should be in place which is easy to access and widely publicised

**Health and Wellbeing**

- Health and wellbeing checks completed on all carers
- Option of carers completing these themselves and signed off by GP
- Consideration to financial incentive linked to targets for each participating practice to ensure GPs carry these out

**Carers Hub Development**

- Somerset will adopt the Carers Centre model in the form of a hub as a way of delivering better services to carers (see Fig 9-2 for a detailed description)

**Strategic Planning**

- The Multi-agency Carers Strategy should be realistically costed and underpinned by deliverable action plans
- Significant changes in services for the cared for person should be subject to a carers impact assessment
- Strategy development and monitoring should be co-ordinated by a jointly funded/apPOINTed carers lead

**Governance**

- Carers should lead the decision making and monitoring process. There should be a Carers Partnership Board or similar that formalises and gives structure to this commitment which includes a development, planning and monitoring role with an agreed set of performance indicators, quality standards, process and pathway to measure against and regular satisfaction feedback from carers.

**Personalisation**

- Carers should have an individual short breaks entitlement based around an assessment of need and clearly defined carer eligibility criteria. This entitlement could be used flexibly across a variety of services over a 12 month period.
13. Making Best Use of Resources

13.1 Existing Investment

Current funding for carers’ services in Somerset is complex and comes from a number of sources:

- Funding of defined services using Carers Grants or other dedicated funding sources;
- By far the largest contribution is from the packages funded for the cared for person, by both NHS Somerset and Adult Social Care, in the form of day care, short breaks or other services;
- Equally significant is the contribution of mainstream services funded corporately by statutory agencies such as Somerset Direct; Health Promotion; Communications;
- There is also significant inward investment by national voluntary organisations particularly around specific conditions such as Parkinson’s, Alzheimer’s, Stroke, etc.;
- There is anecdotal evidence to suggest expenditure on services such as short breaks and sitting services is funded by people using their own resources.

Because of the nature of investment highlighted above it is not possible to quantify the full extent of funding for carers’ services. Fig. 13-1 shows the known levels of investment in carers’ services for 2009/10. It is estimated that during 2009/10 approximately £6.47m will be invested to support carers. Of this funding £3.36m is estimated to benefit carers by providing respite and sitting services (all client groups) via the support packages of the cared for person.

Fig. 13-1: Levels of investment in carers’ services for 2009/10 in Somerset

<table>
<thead>
<tr>
<th>Overall Carers Funding</th>
<th>2009/10 budget figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers Grant (adults &amp; children)</td>
<td>£2,340,000</td>
</tr>
<tr>
<td>Additional Adult Social Care (Carer Support Workers salaries, GP rents)</td>
<td>£301,516</td>
</tr>
<tr>
<td>Additional Adult Social Care (Respite &amp; Sitting services all user groups)</td>
<td>£3,366,400</td>
</tr>
<tr>
<td>NHS Somerset Funding</td>
<td>£470,000</td>
</tr>
<tr>
<td>Total</td>
<td>6.47m</td>
</tr>
</tbody>
</table>
Of the £6.47m identified it is estimated that £4.93m is used directly to benefit carers via providing emotional and practical support as well as short breaks.

National funding provided by NHS Somerset is set to increase in 2010/11 from £470K to £943K. However, a significant proportion of this funding is already committed to priorities identified within the Somerset Carers Strategy.

Fig. 13-2 shows the breakdown of funding against the strategic priorities listed in the Multi-agency Carers Strategy for 2009/10.

Fig. 13-2: Breakdown of investment in carers’ services in Somerset 2009/10

13.2 Modelling of proposed changes

Outlined below are costs associated with developing the suggested model for Somerset based on stated assumptions.

The model is driven by the number of carers in the wider community and the number of hours of unpaid care each provides. However, trying to model the cost of new services has limitations due to uncertainty about:

- The accuracy of the 2001 census data
- The number of carers in touch with statutory agencies, with an element of double counting suspected
- The cost and activity associated with existing funding streams
- Lack of agreed eligibility criteria for carer related services
**Assumptions**

The following assumptions have been made in carrying out the financial modelling:

- No account is taken about the type of breaks taken and those which may be supplemented by additional funding from the cared for person’s support package.

- The number of carers represent 9.44% of the population in Somerset in 2009/10 based on the number of carers identified in the Somerset Carers Strategy and the Somerset Joint Strategic Needs Assessment.

- Overall eligibility needs to take account of both the carers’ needs and the needs of the cared for person. However, to support the modelling of the recommended option the following criteria is used:
  - Carers who provided 0-19 hrs unpaid care per week (low)
  - Carers who provided 20 – 49 hrs unpaid care per week (medium)
  - Carers who provided Over 50 hours per week (high)

- For modelling purposes only we have ignored the number of carers known to statutory agencies as this figure is unreliable due to the fact that it may include an element of double counting by Somerset County Council and Somerset Partnership NHS Foundation Trust. Instead we have assumed that all carers in the medium and high group are eligible for a service.

- Using the above criteria we have assumed that people known to statutory agencies are in the medium and high two categories only. Figures are based on extracts from the Somerset Multi-agency Carers Strategy which states that 70% of carers provide unpaid care 1-19 hours (low); 10% provide 20-49 hours (medium) and 20% provide 50 hours plus (high).

- The cost of a Carers Hub for a population similar to Somerset is estimated between £275,000 and £425,000. Costs may differ if developed in-house or if commissioned from the community or voluntary sector and would need to be established through a competitive tendering exercise. Ultimately overall costs are determined by the level of services specified. A figure of £350,000 is taken as a working assumption which is approximately a cost of £7 per carer per year based on 50,000 carers. This cost is referred to as the cost of membership but it is not necessarily suggested that this cost is recovered from carers themselves.

- The value of existing services in Somerset relating to information, advice, training and support, which elsewhere would be provided by a
Carers Hub is estimated to be £131,700. This is based on the amount allocated for information and advice in the Carers Grant in 2009/10.

- The current cost to Adult Social Care of Carers Support Workers is £301,516, which also includes cost of renting space in GP practices. It is reasonable to assume that a proportion of these costs should be retained within community teams to support core assessment, but also the percentage which relates to information, advice, practical and emotional support is costed into the Carers Centre.
- 66% of the Carers Support Worker function would be provided via the Carers Hub producing a contribution of £199,001. This does not include any TUPE related costs.

13.3 Commissioning improvements to existing service

13.3.1 Carers Hub

The report recommends the development of a Carers Hub as a focal point for carers across the county. A Carers Hub would:

- Act as a specialist point of contact for all carers enquiries via face to face contact, literature, websites and telephone support
- Provide an information network across all communities with appropriate signposting to relevant agencies
- Undertake screening assessments, including opportunities to self assess, with onward referral where appropriate
- Co-ordinate and support the future development of carer services
- Be responsible for the development and support of carers groups
- Be responsible for marketing and raising the profile of carers as well as accessing hitherto unknown carers
- Provide access to a range of services including counselling line, face to face support, benefits checks, crisis support and booking system for short breaks
- Promote, facilitate and develop the engagement and participation of carers
- Support the Carers Partnership Board and wider governance arrangements
- Provide co-ordination and evaluation of training for carers
Funding & efficiency savings

As previously mentioned, research indicates that the average annual running costs of a Carers Centre, with a population profile similar to Somerset, is £350,000 per annum.

It may not be possible to fund the entire costs of the Carers Hub element by simply redirecting existing funding. The specification would need to be very clearly defined and may result in other savings identified. One of the attractions of outsourcing this service is that community and voluntary sector organisations may be able to attract additional funding sources not normally available to the statutory sector. It has not been possible to estimate the extent of this funding and therefore no assumptions are made about this.

In 2009/10 the value of existing services (predominantly information and advice) which could be expected to be provided by a Carers Hub is £131,700.

The cost of providing Carers Support Workers for those people eligible to Adult Social Care is £301,516. This report also recommends that other assessment routes are developed and that “Core” staff undertake Carers Assessment supplemented by “trusted assessors” from other agencies. Using these assumptions then 66% of this funding (£200,000) could be invested in the Carers Centre.

The cost of Carers Assessment Workers from the 09/10 Carers Grant Allocations is £165,500. This has not been included for modelling purposes at this stage as it is not clear what savings could be made due to the high level of assessment work currently being undertaken by Carers Assessment Workers. If the assessment function could be undertaken elsewhere then the same approach be adopted for Carers Assessment Workers, but phased over a two year period once the model has been established and proven effective.

The better co-ordination and a realignment of existing services under the control of the Carers Hub should also generate some efficiency savings in terms of administrative costs. There could also be some efficiency savings by greater integration of any new information network into local community support such as Active Living Centres, extra care housing schemes etc.

It is assumed that 15,000 carers would meet the medium or high eligibility criteria with a further 35,000 carers to benefit from access to the Carers Centre. Whilst not evidenced in the research into other areas (see Section 9) it is conceivable that carers may be prepared to pay a nominal membership fee (e.g. £10 per annum) in return for a range of benefits. Charging a membership fee for all carers could produce in the region of an additional £150,000 – £350,000. Equally for every 1% increase in the number of people with “moderate” needs, an additional £3,500 of income would be produced for the Carers Centre. This approach would have a number of benefits:
• Release Carers Grant for additional investment in short breaks
• Incentivise the enrolment of new members
• Create independence from statutory funding and thereby improve overall sustainability
• Increase the likelihood of carers becoming engaged or participating in an organisation in which they have an interest
• Allow the Carers Hub to offer differential pricing with discount to members
• Greater uptake in carer related benefits

It is also recommended that the Carers Hub provides a “booking” service to support the information and advice provided in respect of short breaks. The short breaks market in Somerset is predominately provided by the independent sector both in terms of residential beds and breaks at home. The Carers Hub could charge approved providers a booking fee based on a % of the value of the referral. Whilst the costs of providing this service and the response of the market would need to be explored in greater detail it would not be unreasonable to suggest that this could prove a valuable source of additional income (see below).

Sustainability

It is anticipated that the general population in Somerset will increase by 87,000 by 2029 from 2001 base. An increase in general population of 3,000 people per year would generate another 280 carers, 84 of whom would have either medium or high needs. As previously mentioned the cost of developing a Carers Hub network is approximately £7 per carer per year which would require an additional £588 per year funding to support the Carers Hub should a membership fee not be introduced.

Analysis of costs does suggest that, based on levels of activity in 2009/10, and the numbers of carers supported; a Carers Hub could be afforded from existing funding and is sustainable in the medium to long term.

There may also be initial start up costs, particularly around infrastructure and website development that could be funded from the unallocated elements of the NHS Somerset Carers Breaks funding.

13.3.2 Assessment

The face to face contact and emotional support provided by Carers Support Workers is both valued and trusted by those small numbers of carers who benefit from this service.

The report recommends that Carer Assessments becomes a core function of all staff within Adult Social Care and the NHS, following the wider deployment of a
more robust single assessment process. It is also recommended that this be developed further by using trusted assessors, on-line assessment and self assessment as alternative routes to assessment. “Trusted assessors” could be developed with partner agencies within both statutory and voluntary sectors.37

The timescale for the development of these initiatives may be a factor that would influence the sequencing of any changes. There may also be a need for additional training to support staff from other agencies to take on the “trusted assessor” role.

In order to allow time to evaluate the benefits of these proposed changes, to minimise potential disruption and to ensure continuity, it is not recommended that the assessment arrangements for mental health and young carers be changed until the Carers Hub has been established, and work is carried out with core team staff to identify the potential for them to take more of the carer assessment role. This would then free up the Carers Assessment Workers to be able to devote more time to providing emotional support and specialist training for carers which they can only provide on a limited basis at present due to the fact that they are carrying out 94% of Carer Assessments. Young carers project workers will need to continue with their assessment role for young carers as the Adult Social Care worker would not be appropriately skilled for this task. Within the Learning Disability service “core” staff already carry out the Carer Assessment.

There is significant duplication and overlap, not only within assessment, but also between the approaches adopted by agencies working with different types of carers. The review questions the need for two “Carers Charters”, one developed by Somerset County Council and the other by Somerset Partnership NHS Foundation Trust. Whist applauding the initiative shown by Somerset Partnership NHS Foundation Trust in developing a carers’ website, many stakeholders consulted with viewed this as a lost opportunity not to have a more generic approach. This duplication applies equally to information packs and is both confusing and inefficient. Agencies working with young carers, carers of people with mental health issues and learning disability will need to work proactively and develop a partnership with the Carers Hub to ensure carers can be supported, where appropriate, outside complex, expensive health and social care systems.

**Funding & efficiency savings**

It is recommended that current funding (£100,000) of posts from Carers Support Workers is reallocated to support core staff within Adult Social Care Teams. Additional efficiencies may be created by:

- The development of screening assessment to be undertaken by Somerset Direct, Carers Centre, on-line and via GP Practices etc
- Core staff undertaking the Carer Assessment function

37 Gloucestershire County Council are currently developing this model with their “circle of support”
• Reassignment of 33% Carers Support Worker funding / posts to Adult Social Care Teams or alternatively extracting an element of this funding as efficiency savings

• The development of “trusted assessors” within other statutory agencies and voluntary organisation

• Efficiency from time currently involved in arranging short breaks

This change may be accomplished without the need for any additional resources. However, the take up of the new types of assessment will need to be carefully monitored to avoid community teams being under resourced and to ensure quality and performance is maintained during the transition.

Sustainability

It is anticipated that the proposed changes in funding outlined above will be sufficient to cope with an anticipated 280 extra carers per year of which 70% will not require a full Carers Assessment. It is envisaged that once the model has been evaluated and proven to be effective in delivering better outcomes for carers, then support for young carers and people with mental illness will be incorporated into the Carers Hub in the third year of operation with consequent efficiency savings. Figure 13-3 shows a summary of the suggested carer service improvement schedule for years 1, 2 and 3:

**Fig.13-3 Summary of suggested carer service improvement schedule for years 1, 2 and 3**

<table>
<thead>
<tr>
<th>Service Redesign</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish Carers Hub</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re-configure Carers Support for adults</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluate Carers Hub Service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re configure Carers Support for people with mental illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re configure Carers Support for Younger People</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**13.3.3 Short breaks**

Evidence from carers in Somerset suggests that the single most beneficial service which is prioritised across all groups is the need for a break. Equally, there was significant feedback as to the disparity across various carers groups re
the allocation of short breaks and significant difficulties accessing short breaks services, as configured at present.

Currently £2.24m is earmarked from the Carers Grant (09/10) for providing practical and emotional support for carers including short breaks covering all carers groups. This does not include the NHS carers’ breaks grant of £470,000.

- Of the total spend on carers’ support services, including NHS Continuing Health care, it is estimated that £1.2m is invested in non-emergency short breaks
- A further £184,000 is invested in emergency short breaks for adults. It is not clear if people had their own entitlement and made their own arrangements for this service whether the need for emergency support would diminish
- A further £3.37m is estimated as the level of funding linked to respite and sitting services for the cared for person

As previously mentioned for the purpose of this appraisal we have used “number of hours of unpaid care” as the criterion to determine a carer’s eligibility for short breaks. We have made no adjustment for the differences between carers groups i.e. mental health, learning disabilities, older people, since one of the messages which emerged from the consultation was the current inequity between various groups.

This report recommends that each carer who meets the eligibility criteria, irrespective of the agency involved or the needs of the cared for person, be provided with an annual entitlement to fund a break. Converting the existing investment into an entitlement for carers could enable carers to exercise greater choice and control over this important aspect of support. Carers would use this entitlement flexibly to determine where, when and in what form the break should be taken and who should provide the service. Support in managing short breaks would be provided via the Carers Centre.

**Funding**

Existing data suggests that 15,000 carers provide 19 hours or more of unpaid support per week. However, the data also indicates that only 44% of these carers are known to statutory services. (This assumes that all carers currently known to statutory services are either in the medium or high categories as suggested in the Somerest Multi-agency Carers Strategy, which when expressed as a percentage of the total numbers of carers projected to be in these categories equates to 44%).

For the modelling purposes we have assumed that all carers meeting themedium and high criteria would be entitled to funding for a break in their own right and have assumed a current 44% take up rate. We have sought to test out the
affordability and sustainability of providing each eligible carer with a defined entitlement.

- The cost of providing each carer who meets the “medium” criteria and provides between 20-49 hours per week with an annual entitlement of £400 (equivalent of 2.5 hours per month @£12.00 per hour) is approximately £0.9m per annum.

- The cost of providing each carer who meets the “high” criteria and provides over 49 plus hours per week with an annual entitlement of £800 (equivalent of 5.5 hours per month @£12.00 per hour) is approximately £3.6m.

- The total cost of the above two elements would be £4.5m set against an existing investment of £4.58m.

- Alternatively, by only supporting people who meet the “high” criteria then an annual entitlement of £1000 could be afforded within the same financial envelope but this would mean no entitlement for people who meet the “medium” criteria.

- However, for every 1% increase in the number of carers taking up their entitlement it would cost an additional £102k per annum.

- Assuming that 100% of carers who meet the “medium” and “high” criteria take up their entitlement, as opposed to the 44% known at present, then an annual entitlement of £440 could be afforded for those people meeting the “high” criteria only.

- The numbers of people aged over 85 years of age and those with dementia is set to increase over the next 10 years. It is therefore reasonable to assume that the % of carers as a proportion of the overall population will increase above the current rate of 9.44%. We have assumed a 1.5 % increase in the proportion of carers in the wider population over the current rate and modelled the affordability of the concept of an annual entitlement. Based on a carer population of 1.5% above the current rate and a 100% uptake by carers who meet the “high” criteria, then an annual entitlement of £380 could be afforded within current resources.

- However, if the take up rate remains at the current level of 44%, but the overall number of carers increases by 1.5%, then an annual entitlement of £872 could be afforded within current resources for those carers who meet the “high” criteria only with no entitlement for anyone below these criteria.
Summary of the costs and projected costs of suggested service improvements for carers in Somerset

<table>
<thead>
<tr>
<th>Summary</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cost of investment in Somerset carers services 2009/10</td>
<td>4.58m</td>
</tr>
<tr>
<td>2. Cost of providing each carer who meets the suggested “medium” criteria (20-49 hours per week) with a £400 pa entitlement (equivalent of 2.5 hours per month @£12.00 per hour)</td>
<td>0.9M</td>
</tr>
<tr>
<td>3. Cost of providing each carer who meets the suggested “high” criteria (over 49 plus hours per week) with a £800 per annum entitlement (equivalent of 5.5 hours per month @£12.00 per hour)</td>
<td>£3.6m</td>
</tr>
<tr>
<td>4. Only supporting people who meet the “high” criteria with an annual entitlement of £1000 per annum. This would mean no entitlement for people who meet the “medium” criteria. (based on budget in 1 above)</td>
<td>£1000 per annum</td>
</tr>
<tr>
<td>5. Cost of 1% increase in the number of carers taking up their entitlement</td>
<td>£102,000 per annum</td>
</tr>
<tr>
<td>6. Maximum affordable entitlement paid to those people meeting the “high” criteria, assuming a 100% take up rate</td>
<td>£440 per annum</td>
</tr>
<tr>
<td>7. Maximum affordable entitlement paid to carers who meet the “high” criteria assuming an increase in carer population of 1.5% above current estimates and with a 100% uptake by carers</td>
<td>£380 per annum</td>
</tr>
<tr>
<td>8. Maximum affordable entitlement paid to carers who meet the “high” criteria with no increase in take up rate but assuming an increase in carer population of 1.5%. No entitlement for anyone below these criteria.</td>
<td>£872 per annum</td>
</tr>
</tbody>
</table>

**Sustainability**

Any increase in percentage uptake could be offset considerably by the introduction of a membership fee (e.g. £10 a year per carer) to fund the Carers Hub element and thus increase the funds available for short breaks. This could provide short breaks support to approximately 750 additional carers.

The above figures suggest that all funding, including that currently channelled through the cared for person support packages, would be available to create an annual entitlement which would be more equitable and sustainable. Many carers who support people with a learning disability would see these proposals as a significant reduction to their current level of support.
The cost of an annual entitlement for all carers carries perhaps the highest risk both in terms of affordability and sustainability. The suggested approach is based on providing a basic entitlement for all carers - but is the sum involved meaningful? A more targeted approach, based on clear criteria, would perhaps be more realistic and sustainable.

13.3.4 Decommissioning Services

Information and Advice

Initially some of the existing services / relationships for services would be continued under the auspices of the Carers Hub with carers given the responsibility to monitor and evaluate the effectiveness of these services. Whilst carer training would continue, such as provided by the Expert Patient Programme and St John Ambulance, the role of promoting these courses, administering bookings and evaluation would be via the Carers Hub and, as a consequence, some efficiency savings could be achieved. Volunteer development and prevention would form part of the core function of the Carers Hub with existing arrangements coming to an end in March 2011.

A Carers newsletter, website and other communication would be the core function of the Carers Centre, as would support to carers groups.

These services which include training, counselling, support for carers groups etc would continue to be provided by existing providers to minimise any disruption. However, it would be for the new Carers Hub to determine how these services are deployed, monitored and developed in the future.

Assessment

The proposed model recommends that all assessments are undertaken by core staff. It also recommends that “trusted assessors” are developed with other agencies and that screening self assessment is developed both in hard copy and on-line. The responsibility to sign off these assessments would remain with the statutory agencies in keeping with current legislation.

Perhaps the most significant change would initially affect Carers Support Workers. The review recommends that the funding for the assessment part of their role or a proportion of posts remain with the Adult Social Care teams, but further consideration should be given as to whether this additional function (i.e. carer assessments) could be undertaken within existing resources, consequently providing more efficiency savings.

The Carers Support Workers role in delivering practical and emotional support is highly valued by carers and as such would become an integral part of the Carers Hub resource. There may be some TUPE related costs associated with this move or alternatively staff could be seconded. However, what is important to stress is that these roles will change and the provider of the Carers Hub should be able to
deploy these resources flexibly and in such a way as to best meet needs of carers both now and in the future.

The investment in Carers Assessment Workers is £165,000. It is suggested that they complete 94% of all Carer Assessments within Somerset Partnership NHS Foundation Trust. If the recommendation is accepted that “core” staff undertake these assessments, then a proportion of this investment could be extracted to fund the Carers Hub with the remaining funding re-invested in Community Mental Health Teams. There would be the possibility of an efficiency saving in relation to the existing management structure of approximately £35k.

As previously mentioned it would not be envisaged that carers support for young carers, and carers of people with learning disabilities would be affected. However, it is suggested that once the various recommendations have been implemented these services be reviewed to examine how outcomes for carers can be improved. In the interim the agencies that operate specialist support for carers need to explore ways they can work effectively within generic support structures for carers.

Practical, emotional support include short breaks

Much of the existing support is provided through generic services or using specialist providers for the various service user groups. Undoubtedly, bringing together all the elements of current funding so that carers can access a standard entitlement would be an organisational challenge, but not necessarily disruptive to people who use the service.

There would need to be a significant awareness campaign both with carers and service providers in order to orientate them to a more personalised approach.

Equally, the Carers Hub would have a role in providing advice and support for carers on how to best use their entitlement as well as possibly operating a booking system with local providers. The county council would need to develop appropriate monitoring procedures in keeping with the wider personalisation agenda currently being developed.

13.3.5 Other Costs

The proposals in respect of Strategic Planning would be cost neutral and form part of the brief for the existing carers lead.

The governance proposal discussed in the next section of this report would need to be further developed but it is envisaged that costs of the Carers Partnership Board to meet six times a year would be minimal and funded from existing commitments to carer engagement. There would be an additional cost of a paid chair for the Carers Partnership Board estimated at £9,000 which is optional.
The entitlement aspect of short breaks has only been implemented in two areas and is still embryonic and not well evidenced. However without additional funding the sustainability of the short breaks entitlement carries perhaps the highest risk as the number of carers increase.

**13.3.6 The Role of Community and Voluntary Sector**

The role of the community and voluntary sector is significant both in terms of information and advice as well as support. However, this valuable resource is largely uncoordinated and could be focused better to provide a more comprehensive and accessible range of services for carers. Should the recommendation to establish a Carers Hub be agreed then this could provide a significant opportunity for the Community and Voluntary Sector to play a more active role in the co-ordination, monitoring and service delivery, particularly in respect of information and advice and practical and emotional support.

Evidence from other areas suggests that the community and voluntary sector is better placed to deliver more responsive services and improved communication as well as developing social capital and greater innovation. The review also recommends the development of screening assessment for carers and the development of “trusted assessors” both of which could be delivered by the community and voluntary sector.

Finally, the review recommends no change in the existing services to young carers. However, this service does, at some future date, lend itself to being further developed under a social enterprise model or by the not-for-profit sector.

**13.3.7 Benefits and Risks**

Outlined in Fig 13-5 is a summary of the benefits and risks associated with the proposed changes. The aim throughout this review has been to build on existing good practice and where appropriate suggest ways of improving the current system to deliver better outcomes for carers.

**Fig: 13-5 Summary of benefits and risks associated with proposed new model of carer services in Somerset**

<table>
<thead>
<tr>
<th>Benefits associated with proposed model</th>
<th>Risks associated with proposed model</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Proven track record of improving outcomes for carers in other areas</td>
<td>1. Potential to destabilise existing providers / networks</td>
</tr>
<tr>
<td>2. Key aspects identified from the Somerset carers consultation</td>
<td>2. Potential to lose local knowledge of specialist carer workers</td>
</tr>
<tr>
<td>Benefits associated with proposed model</td>
<td>Risks associated with proposed model</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>3. Provides carers with a single information point which is up to date and responsive</td>
<td>3. Carers Hub needs to be incentivised to identify previously unknown carers</td>
</tr>
<tr>
<td>4. More customer focused with better access for carers and avoids stigmatisation of using statutory services</td>
<td>4. Short breaks “entitlement” element of model could be unsustainable over time.</td>
</tr>
<tr>
<td>5. Greater engagement with Black and Minority Ethnic Communities</td>
<td>5. Carers Hub needs to link with and be provided at Active Living Centres, Extra care housing units, Mobile Libraries etc to meet the needs of carers in rural communities</td>
</tr>
<tr>
<td>6. Greater flexibility and efficiency regarding use of resources- e.g increased value for money by better co-ordination, reduced duplication and potential to raise funds independently.</td>
<td>6. Needs to link with and be supported by specialist teams such as mental health, learning disabilities etc.</td>
</tr>
<tr>
<td>7. Improved communication and information particularly across rural areas</td>
<td>7. Deterioration in performance (numbers and quality) of Carer Assessments due to proposed changes</td>
</tr>
<tr>
<td>8. Greater choice regarding accessing services in a non institutionalised way</td>
<td>8. Carer annual entitlement possibly not sustainable in the long term without additional investment.</td>
</tr>
<tr>
<td>9. Performance driven - an element of funding would be linked to performance criteria around access to unknown carers</td>
<td></td>
</tr>
<tr>
<td>10. Greater levels of participation, scrutiny and recognition for carers</td>
<td></td>
</tr>
<tr>
<td>11. Enhanced role for Community and Voluntary Sector</td>
<td></td>
</tr>
</tbody>
</table>
13.3.8 Communication and Coordination

The development of a Carers Hub does offer an opportunity to improve communication. However, if the Carers Hub is given the lead responsibility to communicate with carers, carers groups and the variety of community outlets then the quality, consistency and dissemination of information would be improved. The Carers Hub should also be charged with holding and updating relevant information via the website and carer information packs. Currently the ownership for this function is unclear with Somerset County Council, NHS Somerset and Somerset Partnership NHS Foundation Trust all offering different information. GP practices, service providers and local voluntary organisation often supply supplementary information which adds to the confusion and dilution a coherent message to carers. Equally the proposed Carers Partnership Board may have a role in ensuring better communication with carers, including reaching more hidden carers and monitoring communication.
14. Universal offer to carers

One of the four themes in Putting People First is about universal services and ensuring that people have fair access to a wide range of services avoiding the need to become dependent upon statutory services. During our discussions with local stakeholders and other areas we also explored what the minimum or universal offer to carers should include.

Listed below are the most common services which carers said they wanted and which could be offered and which could be accessed via a Carers Hub without undertaking a full Carer Assessment. With the exception of crisis support, which may require further work to establish access and eligibility, the support identified is already available but lacks co-ordination and communication across all communities and carer groups. The services included:

- Information & Signposting
- Support to register with GP
- Counselling line
- Face to face support
- Support Groups
- Benefits checks
- Crisis Support
- Other generic advice re housing, transport etc
- Engagement / participation
- Training
- Screening Carer Assessment (including self assessment)
15. Representation and governance

In order to ensure that carers’ services are effectively implemented and monitored in Somerset it is proposed that the governance arrangements are strengthened to enable wider representation and a stronger voice for carers.

15.1 Current arrangements in Somerset

The Somerset Carers Strategy Group is a Multi-agency network of commissioners, providers and carer representatives with broad priorities and objectives to ensure that the Somerset Multi-agency Carers Strategy is delivered and that services for carers meet their needs.

The Somerset Carers Strategy Group identified the need for widespread consultation with carers and stakeholders of all service groups and this appraisal of the current service provision for carers against the Somerset Carers Multi-agency Strategy priorities.

Somerset Carers Strategy Group has seven broad objectives:

- To review evolving legislation, guidance and national policies relating to carers
- To provide the strategic direction for services for all carers across the county
- To co-ordinate effective and structured carers consultation
- To make recommendations regarding the use of the Carers Grant
- To develop and implement the Somerset Multi-agency Carers Strategy
- To monitor and evaluate the implementation of the Somerset Multi-agency Carer’s Strategy

15.2 Other areas

When researching best practice in other areas, aspects of governance were examined and it was found that supporting carer engagement and governance arrangements were often facilitated by the same organisation which operated a local Carers Centre.

Most areas have a formal Carers Partnership Board with a mixture of stakeholders but a majority membership of carers. In many cases there is a direct link between the governance structures for planning, delivering and
monitoring of carer services, local support groups, the Carers Partnership Board and other Partnership Boards.

Several authorities have given the Carers Partnership Board the lead role to scrutinise and hold agencies to account for the delivery of the Carers Strategy and the Carers Grant. In Wiltshire for example four area based carers organisations are underpinned by local and specialist groups for carers. These areas nominate representatives to form part of the Carers Partnership Board. To facilitate speedy and comprehensive consultation, there is a network of 600 carers on-line who are regularly consulted with by a variety of agencies.

Other areas such as Enfield, Cambridgeshire, Peterborough, Haringey and Buckinghamshire all have clear terms of reference for their Carers Partnership Board and a strong governance process linking to other Partnership Boards, often reporting to an overall Health and Wellbeing Board. In a small minority of areas countywide forums are still dominated by statutory agencies and voluntary organisations. In at least two areas the process of consultation with carers is formalised to such an extent that major changes to services for the cared for person are subject to a Carer’s Impact Assessment.

15.3 What are stakeholder views about governance in Somerset?

During the final stakeholder events aspects of governance were discussed and there was unanimous agreement from carers that they wanted to have more say in how services are planned, delivered and monitored. Experience of running the six carers panels during the course of the appraisal highlighted the added value carers can provide in a dialogue with staff and providers of services. This model, based on the learning from other areas, could be easily adopted in Somerset as part of a wider governance process which links in with other decision-making bodies and monitoring mechanisms within Somerset County Council and NHS Somerset.

Several members of the Somerset Carers Strategy Group, which includes the commissioners and carer representatives, do not consider the current arrangements are working well due to the following reasons:

- Only two carers are represented on Somerset Carers Strategy group (chairs of the Carers UK local branches) and there is domination by professionals and voluntary organisations
- Not all types of carers are represented
- Lack of influence by carers
- Insufficient linkage/recognition by other Council and NHS boards
15.4 Proposed governance arrangements for Somerset Carers Strategy /Services

It is recommended that a strengthened Somerset Carers Partnership Board be introduced with a clear remit to ensure the Somerset Multi-agency Carers Strategy is implemented with a robust action plan and monitoring framework in place with the following characteristics:

- Somerset Carers Partnership Board to link into a formal governance process with other Somerset Partnership Boards – e.g. Learning Disability, Health and Wellbeing etc
- To influence carer service developments, monitor carers services, ensure cost effectiveness and services tailored to what carers want and need
- Majority representation by elected carers who are equal partners with recognition and respect as experts in their caring role
- A monitoring role to ensure the Somerset Carers Strategy is effectively implemented
- An elected chair who is a carer who could be paid
- Election process via carers register and carers stakeholder event
- Training and mentoring for carer representatives
- Carer membership which represents the wide range of different caring situations and geographical split across the county

15.4.1 Governance structure

Fig. 15-1 shows the proposed governance structure for Somerset Multi-agency Carers Strategy and services. This is based on a Somerset Carers Partnership Board.

Fig. 15-1: Proposed governance structure for Somerset Carers Services

![Diagram of proposed governance structure](image-url)
Representation

A Somerset Carers Partnership Board must include representatives from each type of carer:

1. Learning disability
2. Dementia
3. Older people
4. Physical disability
5. Sensory loss
6. Drug and alcohol
7. BME
8. Mental health
9. Parent carers
10. Young carers
11. Autistic spectrum

Other stakeholders would include

- Commissioning managers-NHS and Somerset County Council
- Children and young people services
- Job Centre Plus
- Drug and Alcohol Action Team
- Service providers – two representatives with one vote from a Carers Services network/forum which includes voluntary and community sector and independent providers (see below)
- County Councillor
- Somerset Carers Lead

Recommended maximum membership 20 people.

In view of the large numbers of service providers and potential conflict of interest it is suggested that a separate Carers Services Network is set up to provide a forum to discuss carer issues. It will important that this network has good links with the Carers Partnership Board by nominating two representatives (with one vote) to attend the meetings – either on a co-opted basis or to every meeting.
Terms of reference

There must clear terms of reference in place for the Carers Partnership Board and carers themselves have suggested the following:

- Involvement and dialogue is a key aspect
- The Carers Partnership Board must have a development function as well as influencing planning and monitoring of current services
- Each member of the Board should have made a difference by the time they leave
- Build in the opportunity to network at the Carers Partnership Board meetings –which would be time well spent sharing information
- Carers expenses must be paid and included in the terms of reference
- State the obvious i.e. “What is the purpose of the Somerset Carers Partnership Board?” and ensure objectives are set and outcomes are met
- The Carers Partnership Board’s primary purpose will be to ensure an action plan is in place for the implementation of the Somerset Multi-agency Carers Strategy and to monitor its progress.

Election process

- It is suggested that the carer representatives on the Carers Partnership Board are elected by carers themselves. This could be carried out by writing to all carers on the carers register and inviting then to an open stakeholder meeting and then carers invited to nominate themselves or another carer to sit on the board. A voting and/or interview process would then take place to select the carer representatives who would sit on the Carers Partnership Board for a maximum of three years.

- Consideration should also be given to electing members to sit on other boards – such as the Learning Disability Partnership Board etc. This will ensure carers have a strong presence on other boards and that good links are made between them.

Chair

A job description and person specification would be needed and an interview or other type of selection process put in place. It is suggested that the chair of the Carers Partnership Board should be a current carer with strong leadership skills and ideally experience of sitting on boards and chairing meetings who has the ability to gain respect and credibility by carers, officers and county councillors and to be treated as an equal partner.
Training and mentoring would be available for other carer representatives to enable them to develop these skills.

**Carer forums/support groups**

It is suggested that each of the carer representatives on the Carers Partnership Board is elected by a local carer forum/support group to enable local representation and a two way process of information, communication and influence over planning, decision making and monitoring of carers services. This would involve some infrastructure time and costs but it is proposed that this would be a requirement of the Carers Hub and outlined in its service specification.

The young carers have already set up a county wide forum which is keen to feed into the Carers Partnership Board (see below). Other existing forums such as the Somerset Partnership NHS Foundation Trust User and Carers Participation Group and the Somerset Parent Partnership could also ensure links in this way.

**Young carers**

The governance arrangements to ensure services for young carers are monitored and developed were seen as important by young carers.

Suggestions from the consultation meetings with young carers included

- Regular meetings with County Council
- Councillors and managers to spend a day with a young carer
- Facebook page/use of internet to enable on-line voting, having a say, information etc.
- Young carers to contribute to the Carers Partnership Board via one or two representatives from a Young Carers Forum which has already been set in place.
- Young carers to be involved in having a say in how documents are written and decisions made. The ability to contribute should not be underestimated whatever the age of the young person.

**15.4.2 Ensuring Quality**

The review recommends the establishment of a Carers Partnership Board to monitor more effectively the implementation of the Carers Strategy and specific services for carers. In order for statutory agencies to effectively
commission carers services there is a need to agree a set of outcome measures and standards with underpinning data which will help to determine if better outcomes are being delivered to carers.

Staff and carers will need to know the pathway through the system with a set of processes and standards for staff to follow to ensure carers a quality service. It is therefore suggested that a Carers Pathway be developed with processes and standards.

Services should also be subject to a performance monitoring framework for which the Carers Partnership Board is responsible and there should be a monitoring function built into their terms of reference with the ability to hold statutory and third sector bodies to account for services delivered to carers or the people they care for.

There will be an agreed set of key performance indicators and other outcome measures available to the Somerset Carers Partnership Board with reliable data about local activities within agreed timescales. If services are not meeting quality standards then the Carers Partnership Board must be able to influence this.

The review has identified a number of gaps in information which needed to be addressed in order to ensure more effective monitoring and strategic planning. These include:

- Percentage of carers on GP Registers to be monitored by NHS Somerset and reported to Carers Partnership Board
- Outcomes of Carer Assessments to be more clearly defined, recorded and reported
- Number of assessments undertaken by generic workers, specialist staff and other contact points
- The number of carers in touch with statutory agencies appears to involve an element of double counting. The RiO and Swift systems need to reconciled or alternatively use the “membership” of the Carers Hub as the primary source of data
- Response time from initial contact to assessment completed
- Somerset Direct – information on the number and type of carers referrals
- Care First counselling services – information on the number and type of carer referrals
- Greater transparency over investment in both carers and the services for people they care for

- Improved ethnicity data from training providers
### Governance

The characteristics of what constitutes best practice suggest the following:

- There should be a structured approach to decision making so that people who actively care are involved in decisions about their individual circumstances and also the wider development of carers services.

- Carers should be in the majority in any body which holds statutory agencies to account for the delivery of the local carers strategy.

- Funding streams should be linked to the implementation of the local carers strategy with clear measures on how such investment delivers improved outcomes for carers.

- Links with specialist teams and generic carers services need to be integral to the development of any new service and these links closely monitored.

- All Partnership Boards should ensure they link together and that carers are represented on all decision making forums.
16. Conclusion

According to research undertaken by Carers UK, carers save the UK economy over £15,000 per carer each year. The cost of not supporting carers in Somerset would equate to over £750m per year to the wider economy. The cost of replacement residential care for those carers in Somerset who provide more than 50 hours per week (20%) is estimated to be approximately £312m set against an investment in 09/10 of approximately £6.47m in all carer services. Investing in carer services, even in the current financial climate makes sound financial sense and supports the “Putting People First”\textsuperscript{38} prevention agenda.

The review has sought to undertake a widespread consultation and appraisal of carer services against the priorities set out in the Somerset Multi-agency Carers Strategy. The review has consulted with nearly 1,500 carers as well as voluntary and community organisations and staff involved in the provision of services to carers. Carers have been at the centre of structuring and planning the review as well as leading on key elements through a series of carers panels.

Attempts have been made to also consult widely with all equalities and diversity groups but unfortunately this has been with limited success due to coinciding with the tender process for a new contract in Somerset. Whilst face to face contact has been made with the Mid West European Communities and a small percentage of questionnaires returned by carers from black and minority ethnic groups it was envisaged at the outset of this review that a larger number of people from these communities would have contributed. After discussion with the Gypsy and Traveller officer it was agreed that he would circulate questionnaires to Gypsy and Travellers; questionnaires were also circulated to a number of Canal Users following a meeting with their representative and contact was made with the Lesbian, Gay, Bisexual and Transgender Community via an article in their newsletter but this failed to yield any response.

Services for carers in Somerset should be available to all equalities and diversity groups. However, Peter Fletcher Associates suggest that further work may be required to ensure that services are tailored appropriately and that if recommendations are to be taken forward they would need to be subject to Equalities Impact Assessments\textsuperscript{39} prior to implementation.

\textsuperscript{38} Putting People First - A shared vision and commitment to the transformation of Adult Social Care - Department of Health. 2007

\textsuperscript{39} Carrying out Equalities Impact Assessments prior to implementation of service developments and changes is the agreed approach at Somerset County Council
The demographic changes in Somerset as well as rural issues will have a major impact over the next five years on the effectiveness and sustainability of carers’ services. Rurality and low population density present challenges for carers due to difficulties with transport, accessibility of local services, and employment opportunities all of which will need to be taken into account when developing the best model to meet the future needs of carers in Somerset.

Somerset should be commended for developing a range of high quality carers support services over the past fifteen years. These services have often been cited as innovative and leading in best practice. Examples include:

- Carers Support Workers
- Carers Assessment Workers
- Network of support groups
- Carers Assessment process
- Recent GP pilot
- Full time carers lead
- Somerset Multi-agency Carers Strategy

However, services for carers across the county were often described as patchy with variations in the level and quality of service depending on where someone lived. The review noted a lack of a single specialised reference point for carer information in Somerset that was easily accessible by all communities.

The majority of carers wanted to access information and advice more locally e.g. via their GP practice and without necessarily being assessed. The need for formal assessment to access many services was off putting to many carers. When researching other areas greater choice regarding assessment routes had proved valuable with a more proportionate approach which prevents carers coming into contact with the statutory sector unnecessarily.

For the small number of carers who are supported by specialist carer workers there was a high level of satisfaction. The face to face contact and emotional support provided by a trusted professional was highly valued by many. However, the majority of carers were unaware of specialist carer support or Assessment Workers and found difficulty in accessing relevant, local information when they needed it.

Carers valued practical and emotional support and sited this as one of their highest priorities both on a planned basis and also in crisis. Many carers valued the support of other carers and wanted to be able to contact a known person to talk to at times of crisis. Financial support and the difficulties with maintaining employment featured highly in carers day to day concerns.
A break from caring was voted the most valued service. Some carers felt breaks could be provided more flexibly and carers themselves should have more control over the type of break and the booking arrangements.

Training for carers was considered useful and very relevant. However, not all groups within the community were able to access training. There were some gaps for carers of some specialist conditions, although it should be noted that these deficits are already being addressed.

The role of the community and voluntary sector is significant both in terms of information and advice as well as support. However, this valuable resource is largely uncoordinated and could be focused better to provide a more comprehensive and accessible range of services for carers. Support for young carers, parent carers and carers of people with learning disabilities and mental health needs to be better linked to mainstream carer provision.

The title “carer” does not adequately describe the role and many people do not see themselves as a carer. Carers often feel undervalued, lacking influence, recognition and excluded from decision making at a strategic and individual level.

We were also asked to make an assessment on how robust the strategy was and the likelihood that it would deliver better outcomes for carers within the defined timescales. The gap analysis has identified where services are at the moment, compared with what the strategy says, and sets out any shortfalls. It is recommended that the current strategy be revised to take account of the outcome of this review with particular reference to:

- The need for consistent, good quality information which is easily accessible by all communities
- Clarification of the role of “core” staff in undertaking Carers Assessments
- Clarity on eligibility criteria particularly for short breaks
- The need to provide a range of preventative services that can be accessed without the need of formal Carers Assessments
- How GP carers register can be improved so that the numbers registered reflects the number of carers in the local community.
- The role and contribution of independent sector providers
- How the needs of the following groups will be met:
  - Parent carers
  - Carers of people with Autism and Asperger’s Syndrome
  - People who misuse drugs or alcohol
  - Other hard to reach groups such as Lesbian, Gay, Bisexual and Transgender carers
As a result of this review it is suggested that the Somerset Multi-agency Carer Strategy (2008-2011) should be revised in order to ensure a higher probability that it will deliver the better outcomes for carers within a reasonable time-frame.
17. Recommendations

Access

Recommendation 1

Improve the single point of access for carers by ensuring Somerset Direct staff receive training in carer awareness and provide a dedicated carers line which can refer on to a local carer resource such as a Carers Hub.

Information and advice

Recommendation 2

Comprehensive information and advice for carers to be provided close to their local community. This should include GP surgeries but also elsewhere such as libraries, post offices, etc. Web based information systems should combine mapping and information to provide geographical specific data tailored to enquirer’s location. This should include:

- A single carers website
- Common information adopted by all agencies
- A single carers charter

Recommendation 3

Build on the Carers UK GP awareness project to ensure that all GP practices take part.
Carers Hub Development

Recommendation 4

A Carers Hub to be developed as a focal point for carers across the county. This would:

- Act as a specialist point of contact for all carer enquiries via face to face contact, literature, websites and telephone support.
- Provide an information network across all communities with appropriate signposting to relevant agencies.
- Undertake screening assessment, including opportunities to self assess, with onward referral where appropriate.
- Co-ordinate and support the future development of carers’ services.
- Be responsible for the development and support of carers groups.
- Lead on marketing and raising the profile of carers as well as accessing hitherto unknown carers.
- Provide access to a range of services including a counselling line, face to face support, benefits checks, crisis support and booking system for short breaks.
- Promote, facilitate and develop the engagement and participation of carers.
- Actively support the Carers Partnership Board and wider governance arrangements.
- Co-ordinate and evaluate training for carers.

Recommendation 5

66% of the current investment in Carers Support Workers should be allocated to the Carers Hub to retain the Carers Support Worker role as a provider function to offer emotional and practical support including information and advice, awareness raising etc.
Recommendation 6

There should be greater integration with Active Living Centres, local support groups with any new information network developed by the Carers Centre.

Assessment

Recommendation 7

Assessment should be proportionate to the needs of carers and must include a simple screening tool which a carer can complete themselves with a more detailed Carer Assessment to be completed by the Adult Social Care Team or NHS staff as part of the single assessment process.

Recommendation 8

It is also recommended that assessment routes be developed further to provide choice by using trusted assessors, on-line assessment and facilitated self assessment as alternative routes to assessment with the option of face to face; telephone contact, postal and on-line. Trusted assessors could be developed with partner agencies in both statutory and voluntary sectors.
Recommendation 9
Develop clear eligibility criteria for non-universal carers based on the following criteria:

- Carers who provided 0-19 hrs unpaid care per week (low)
- Carers who provided 20 – 49 hrs unpaid care per week (medium)
- Carers who provided Over 50 hours per week (high)
- Level of other support, age and ability of carer
- Number of hours and type of care being provided by the carers
- Number of people being cared for
- Transport issues

Carer Support Workers and Carer Assessment Workers

Recommendation 10
The role of Carers Support Workers in Adult Social Care to be split between “assessment” function and “practical and emotional support”. The funding for the assessment role of approximately £100k is retained with the community teams or an element is extracted as efficiency savings. The same approach be adopted for Carers Assessment Workers, but phased over a two year period once the model has been established and proven effective.

Recommendation 11
The learning disability service already follows the proposed model but needs to work proactively to support the Carers Hub network and thereby reduce the likelihood of carers gravitating into an expensive health / care management system.
Recommendation 12
The Young Carers Project should continue. In the future, consideration to be given, to how this service fits with existing statutory children’s services and the emerging development of the carer hub.  

Practical support (including short breaks)

Recommendation 13
It is recommended that each carer who meets the eligibility criteria, irrespective of the agency involved or the needs of the cared for person, be provided with an annual entitlement to fund a break. Support in managing short breaks would be provided via the Carers Centre.

Recommendation 14
Carers should have choice in the type of break, who provides it and where it is provided. The booking system should be simple and sufficiently flexible to allow carers the ability to “flex” their entitlement.

Support in a Crisis

Recommendation 15
A universal range of services should be available to provide support to any carer in a crisis. The responsibility for co-ordinating this support will be with the presenting agency and must be seamless and not subject to funding disputes.

40 Delivery of the Young Carers Project will need to come through the CYPD governance structure, initially to CYPD Directors management board, to ensure developments are considered in the light of service developments generally.
Recommendation 16

Ensure all care / support plans include a contingency plan for the person cared for and their carer(s) to cover a range of eventualities and time periods with staff trained in how to complete these.

Emotional support

Recommendation 17

The Care First Counselling service should be extended to include young carers and advertised more widely to ensure all carers are aware of its existence and how to access it.

Other resources for emotional support which are available via NHS Somerset and Somerset Partnership NHS Foundation Trust should also be better publicised.

Advocacy

Recommendation 18

Somerset County Council must ensure that Advocacy Services include meeting the needs of carers and this should figure more prominently in the specification. The Carers Hub must raise awareness of the availability and benefits of advocacy and how to access this.

Employment support

Recommendation 19

It is recommended that the employment advisor role currently developed within Somerset Partnership NHS Foundation Trust be reassigned to work from the new Carers Hub to provide better support to all carers in respect of employment opportunities, and to develop relations with relevant Department of Work and Pension staff.
Health and well-being

**Recommendation 20**
Carers should be identified by their GP and offered an annual health check with priority appointments.

**Recommendation 21**
Carers to be consulted prior to hospital discharge to ensure that support services are in place.

**Recommendation 22**
NHS Somerset should outline plans to ensure how the number of carers registered with GPs should reflect the number of carers in the local community.

**Recommendation 23**
Carers UK be encouraged to develop a Carers-Mark (Gold, Silver or Bronze) to be awarded to GP practices who are working proactively to support carers.

Wiltshire is shortly to implement a similar system which adds an element of “consumer” pressure to the system as well as rewarding best practice.

**Giving carers a voice**

**Recommendation 24**
Organisations which the commissioners contract with should be asked to evidence, monitor and report how carers are given a voice within their organisation.
## Governance

**Recommendation 25**

A Somerset Carers Partnership Board should be set up to replace the Somerset Carers Strategy Group with a carer as chair and majority carer membership, representing all carer types and linking in to local carer forums and panels. This should take responsibility for ensuring all carers on a carer register are communicated with, and asked for feedback at least annually about the services they receive.

**Recommendation 26**

The investment in carers services should be published annually and the effectiveness of this investment reported to the Carers Partnership Board.

## Training

**Recommendation 27**

Where there is a gap in training for certain types of carers then this needs to be addressed by existing training providers or by commissioning more specific support through relevant community organisations accompanied by appropriate data collection including ethnicity.

## Strategic planning

**Recommendation 26**

As a result of this appraisal it is suggested that the Somerset Multi-agency Carers Strategy (2008-2011) needs to be revised in order to ensure a higher probability that it will deliver better outcomes for carers within a reasonable time-frame.
Recommendation 28

Consideration should be given to developing alternative funding sources which could include voluntary contributions or a nominal annual membership fee. It will be important to retain an element of incentivisation to identify unknown carers. However, the ability to pay or make contributions should not be a barrier to accessing this service and the funding released should be invested in short breaks.

It is also suggested that the Carers Hub provides a “booking” service in respect of short breaks which is funded by a booking fee paid by providers, based on a percentage of the value of the referral.

Equalities

Recommendation 29

The Somerset Multi-agency Carers Strategy should be revised to ensure all equalities groupings are included.

Recommendation 30

All recommendations in this report must be subject to an Equalities Impact Assessment.

Recommendation 31

Significant changes in services for the cared for person should be subject to a Carer’s Impact Assessment.
18. References

2. Somerset Multi Agency Strategy 2009
3. POPPI information system Dept. Health
4. Source: Somerset County County Council
5. Source: Somerset County County Council
6. World Class Commissioning: Competency 3 - Proactively build continuous and meaningful engagement with the public and patients to shape services and improve health.
8. There are Local Implementation Teams for Mental Health; Long Term Conditions; Older People; Stroke, Coronary Heart Disease, Diabetes; Respiratory Disease; and Cancer.
9. Number recorded on Somerset County Council Swift IT system March 2010
10. Number recorded by Somerset Partnership NHS Foundation Trust on RIO IT system in March 2010
11. Supporting Carers and Family Members affected by the Substance Misuse of Others - A Somerset Study on Behalf of Somerset Drug and Alcohol Action Team; Dr Sharon Collins and Helen Begum; January 2009.
12. Numbers recorded on Somerset County Council Swift IT system- March 2010
13. Number recorded on RIO system as at 5.3.10
15. This figure is gradually increasing with more being developed
16. If only I'd known that – booklet and directory of useful contacts – Susan Hartnell-Beavis
17. Source- Somerset County Council Management Information Team
18. This includes 'OT reviews', 'comprehensive reviews', 'carers reviews' 'package reviews' amongst others. Source: Somerset County Council Information Management Team
19. The CAF is a standardised approach to conducting assessments of children's additional needs and deciding how these should be met. It can
be used by practitioners across children's services in England see Every Child Matters, Dept of Children, Schools and Families, July 2009.

20 http://www.somerset.nhs.uk/rightsteps/index.htm

21 The National Dementia Strategy – Living well with dementia, Department of Health 2009

22 Somerset Dementia Strategy, March 2009

23 Carers as partners in Hospital Discharge – ADASS February 2010


25 Evidence obtained from talking to 10 GPs at a Wyvern Health Board meeting.

26 Supporting Carers and Family Members affected by the Substance Misuse of Others- A Somerset Study on Behalf of Somerset Drug and Alcohol Action Team, Dr Sharon Collins and Helen Begum, January 2009.

27 Do Gypsies, Travellers and Show People get the support they need with stress, depression and nerves? - Bristol Mind.


29 The University of Sheffield School of Health and Related Research: Summary of a report to the Department of Health, 2004.

30 Four practice managers one from each area of Somerset representing approximately 25000 people

31 A consultation workshop was held on 14th Jan 2010 and was attended by Carers and a range of representatives from voluntary sector organisations in Somerset as listed in Appendix 5


33 POPPI information system Dept. Health

34 PANSI- Projecting adult needs and service information – Dept Health

35 Centre for International Research In Care, Labour and Equalities – Dept Health

36 Office for National Statistics Regional Trends data

37 Gloucestershire County Council are currently developing this model with their “circle of support “

38 Putting People First - A shared vision and commitment to the transformation of Adult Social Care -Department of Health. 2007
Carrying out Equalities Impact Assessments prior to implementation of service developments and changes is the agreed approach at Somerset County Council.

Delivery of the Young Carers Project will need to come through the CYPD governance structure, initially to CYPD Directors management board, to ensure developments are considered in the light of service developments generally.

Websites

5. www.swdc.org.uk/system-development/carers/service-map/
6. cert@sefton-carers.org.uk
7. www.statistics.gov.uk
8. www.carers.org.uk
19. Bibliography

2. Autism Act 2009
3. The National Dementia Strategy – Living well with dementia, Department of Health; 2009
4. Somerset Dementia Strategy, March 2009
5. Supporting Carers and Family Members affected by the Substance Misuse of Others- A Somerset Study on Behalf of Somerset Drug and Alcohol Action Team; Dr Sharon Collins and Helen Begum; January 2009.
6. Do Gypsies, Travellers and Show People get the support they need with stress, depression and nerves? - Bristol Mind, 2008
8. The University of Sheffield, School of Health and Related Research: Summary of a report to the Department of Health; 2004.
11. Parenting Early Intervention Pathfinder, Department of Children Schools and Families
12. Kings Fund Quality Standards for Local Carer Support Services; February 2000
13. Every Child Matters - Department for Education and Skills, 2004
14. World Class Commissioning Competences; Department of Health, 2007
15. The Health Status of Gypsies & Travellers in England; Summary of a report to the Department of Health, 2004
16. Meeting the needs of service users, their families and carers from black and minority ethnic communities- Somerset County Council, Adult Social Care Services, 2009

18. CSIP South West Regional Learning disabilities Family carer co-ordinators- Observations from Sept 2007 to April 2009

19. The Disabled Persons Act 1986
20. The 1990 NHS and Community Care Act;
22. The National Strategy for Carers, 1999;

23. The National Service Framework for Mental Health;
24. The Carers and Disabled Children’s Act 2000;
25. Carers (Equal Opportunities) Act 2005;


27. Our Health Our Care our Say; a new direction for community services, Department of Health, 2006

28. Drug interventions programme (DIP); Home Office 2003

29. We Count Too (2005) - Good practice guide and quality standards for work with family members affected by someone else’s drug use.

30. If only I’d known that – One Carer’s Experiences, Susan Hartnell – Beavis, April 2009
# Appendix 1: Somerset Carers- Summary of Service Mapping

<table>
<thead>
<tr>
<th>Service</th>
<th>Group/Provider</th>
<th>Commissioned by</th>
<th>For who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Living Centres</td>
<td>Somerset County Council</td>
<td>Active Living Board comprises of Age Concern Somerset, NHS South West, Compass Disability Services, Somerset County Council and the Local Authorities</td>
<td>Over 50's</td>
</tr>
<tr>
<td>Carers Direct</td>
<td>NHS</td>
<td>Department of Health nationally</td>
<td>All carers</td>
</tr>
<tr>
<td>Assistive Technology</td>
<td>Various providers</td>
<td>NHS Somerset, Somerset County Council, District Councils</td>
<td>All carers</td>
</tr>
<tr>
<td>Safe at Home Service/ Deane</td>
<td>Taunton Deane Borough Council</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Mendip Telecare</td>
<td>Flourish Homes</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Sedgemoor Lifeline</td>
<td>Sedgemoor District Council</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Careline</td>
<td>South Somerset District Council</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Magna Lifeline</td>
<td>Magna West Somerset Housing Association</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Health commissioning at local level</td>
<td>Wyvern Health</td>
<td>NHS Somerset</td>
<td>All carers</td>
</tr>
<tr>
<td>PALS - Patient Advice and Liaison Services</td>
<td>Somerset Community Health Services</td>
<td>NHS Somerset</td>
<td>NHS patients</td>
</tr>
<tr>
<td>Somerset Community Right Steps</td>
<td>Somerset Community Health</td>
<td>NHS Somerset</td>
<td>Anyone</td>
</tr>
<tr>
<td>Various - residential support, supported living, learning and community support, respite, training, support planning and a centre</td>
<td>Autism Solutions</td>
<td>Private Organisation</td>
<td>For those with autism and their carers</td>
</tr>
<tr>
<td>Carer Support Programme</td>
<td>St John Ambulance</td>
<td>Somerset County Council</td>
<td>Over 18's</td>
</tr>
<tr>
<td>Carers Network</td>
<td>Somerset County Council</td>
<td>Somerset County Council</td>
<td>Somerset Count Council employees</td>
</tr>
<tr>
<td>Carers' Support Workers</td>
<td>Somerset County Council</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Counselling for carers</td>
<td>Care First</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Courses, such as First Aid For Child Carers</td>
<td>Somerset Skills and Learning</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Service</td>
<td>Group/Provider</td>
<td>Commissioned by</td>
<td>For who?</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------</td>
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<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Disability Advocacy Service</td>
<td>A4e</td>
<td>Somerset County Council</td>
<td>People with a physical disability and/or sensory loss and their carers</td>
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<tr>
<td>Extended Family Pathfinders</td>
<td>Children and Young Person’s Directorate</td>
<td>Somerset County Council</td>
<td>Carers who are 18 years or under</td>
</tr>
<tr>
<td>Financial Assessment and Benefit Advice</td>
<td>FAB team - Financial Assessment and Benefit Team</td>
<td>Somerset County Council</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Partnership between SCC (Somerset County Council)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>and DWP (Department for Work and Pensions)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help in a Crisis</td>
<td>Care at Home - from independent sector</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td></td>
<td>domiciliary care contracts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Payroll Bureau Service</td>
<td>A4e</td>
<td>Somerset County Council</td>
<td>Employers</td>
</tr>
<tr>
<td>Short Break service</td>
<td>A4e</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Sitting Service</td>
<td>Care at Home - from independent sector</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td></td>
<td>domiciliary care contracts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somerset Direct</td>
<td>Somerset County Council</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Somerset Parent Partnership Service</td>
<td>Somerset Parent Partnership</td>
<td>Somerset County Council</td>
<td>Carers who are 18 years or under</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>For carers of children with special educational needs</td>
</tr>
<tr>
<td>Young Carers Project</td>
<td>Children and Young Person’s Directorate</td>
<td>Somerset County Council</td>
<td>Carers who are 18 years or under</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct Payment Advisory Scheme</td>
<td>A4e</td>
<td>Somerset County Council</td>
<td>All carers</td>
</tr>
<tr>
<td>Asperger Syndrome Consultancy Service</td>
<td>Asperger Specialist Team</td>
<td>Somerset Partnership NHS Foundation Trust</td>
<td>Adults (aged 18 and over) with Asperger Syndrome</td>
</tr>
<tr>
<td>Carer involvement</td>
<td>Carers Participation Group</td>
<td>Somerset Partnership NHS Foundation Trust</td>
<td>All carers</td>
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<tr>
<td>Employment Support Service</td>
<td>Somerset Partnership NHS Foundation Trust</td>
<td>Somerset Partnership NHS Foundation Trust</td>
<td>People with Mental Health problems and their carers</td>
</tr>
<tr>
<td>Learning Disability Service</td>
<td>Somerset Partnership NHS Foundation Trust</td>
<td>Somerset Partnership NHS Foundation Trust</td>
<td>Adults with learning disabilities and their carers</td>
</tr>
<tr>
<td>Carers Together Support Groups</td>
<td>Carers Together</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Consultation and representation</td>
<td>Compass Disability Services</td>
<td></td>
<td>Disabled people</td>
</tr>
<tr>
<td>with local government, the Health Service,</td>
<td></td>
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<td></td>
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<tr>
<td>Social Services, other voluntary sector and</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>charitable organisations</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Early Bird Plus Programme (through The</td>
<td>The National Autistic Society</td>
<td>Voluntary and Community Sector</td>
<td>Parents of children aged 5-9yrs with autism or Asperger’s Syndrome</td>
</tr>
<tr>
<td>National Autistic Society</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service</td>
<td>Group/Provider</td>
<td>Commissioned by</td>
<td>For who?</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>----------------------------------------------------</td>
<td>-------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
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<tr>
<td>Early Bird Programme (through The National Autistic Society)</td>
<td>The National Autistic Society</td>
<td>Voluntary and Community Sector</td>
<td>Parents of pre-school children with autism or Asperger's Syndrome</td>
</tr>
<tr>
<td>Home from Hospital</td>
<td>British Red Cross</td>
<td>Voluntary and Community Sector</td>
<td>NHS patients</td>
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<tr>
<td>Home respite care</td>
<td>Crossroads Care</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Hospice Care</td>
<td>St. Margarets Somerset Hospice Shop</td>
<td>Voluntary and Community Sector</td>
<td>For patients with a life threatening illness and their carers</td>
</tr>
<tr>
<td>Looking After Me</td>
<td>Expert Patients Programme Community Interest Company</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Supporting Parents Programme</td>
<td>Expert Patients Programme Community Interest Company</td>
<td>Voluntary and Community Sector</td>
<td>Parent Carers</td>
</tr>
<tr>
<td>Various - helpline and support</td>
<td>Al-Anon</td>
<td>Voluntary and Community Sector</td>
<td>Carers of people with problems with alcohol</td>
</tr>
<tr>
<td>Various - helpline and support</td>
<td>Families Anonymous</td>
<td>Voluntary and Community Sector</td>
<td>Carers of people with problems with mind altering substances</td>
</tr>
<tr>
<td>Various - Information and support</td>
<td>The National Autistic Group - The Somerset Branch</td>
<td>Voluntary and Community Sector</td>
<td>Parents of children with an Autistic Spectrum Disorder</td>
</tr>
<tr>
<td>Various - information, advice and support</td>
<td>Help the Aged</td>
<td>Voluntary and Community Sector</td>
<td>Older people and their carers</td>
</tr>
<tr>
<td>Various - information, advice and support through home visits, respite</td>
<td>Help the Aged</td>
<td>Voluntary and Community Sector</td>
<td>For those affected by severe mental illness and their carers</td>
</tr>
<tr>
<td>support, assistance with Carers Assessment, education and training</td>
<td>Rethink</td>
<td>Voluntary and Community Sector</td>
<td></td>
</tr>
<tr>
<td>Various - information, advice and support, leisure activities, training</td>
<td>Somerset Sight</td>
<td>Voluntary and Community Sector</td>
<td>For visually impaired people and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support and campaigning for change</td>
<td>Carers UK</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Various - information, advice, support and care</td>
<td>Marie Curie</td>
<td>Voluntary and Community Sector</td>
<td>For terminally ill patients and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support and local outreach centres</td>
<td>Headway Somerset</td>
<td>Voluntary and Community Sector</td>
<td>For people over 16 with head injuries and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, advocacy and activities</td>
<td>Age Concern Somerset</td>
<td>Voluntary and Community Sector</td>
<td>Over 50's</td>
</tr>
<tr>
<td>Service</td>
<td>Group/Provider</td>
<td>Commissioned by</td>
<td>For who?</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
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<td>--------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Various - information, advice, support, training and a helpline</td>
<td>The Stroke Association</td>
<td>Voluntary and Community Sector</td>
<td>For people who have suffered a stroke and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, training and a helpline</td>
<td>Disability Living Foundation</td>
<td>Voluntary and Community Sector</td>
<td>For disabled people and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, training and a helpline</td>
<td>The National Autistic Society</td>
<td>Voluntary and Community Sector</td>
<td>For those with autism or Asperger’s Syndrome or their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, training, a helpline and campaigning for change</td>
<td>Alzheimer’s Society</td>
<td>Voluntary and Community Sector</td>
<td>For people suffering with Alzheimer’s and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, training, helpline and campaigning for change</td>
<td>Contact a Family</td>
<td>Voluntary and Community Sector</td>
<td>Families of disabled children</td>
</tr>
<tr>
<td>Various - information, advice, support, training, helpline and campaigning for change</td>
<td>Counsel and Care</td>
<td>Voluntary and Community Sector</td>
<td>For over 60’s and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, training, leisure opportunities, campaigning for change and a helpline</td>
<td>Mencap</td>
<td>Voluntary and Community Sector</td>
<td>For people with a learning disability and their carers</td>
</tr>
<tr>
<td>Various - information, advice, support, training, leisure opportunities, campaigning for change and a helpline</td>
<td>Mind</td>
<td>Voluntary and Community Sector</td>
<td>For people with mental ill health and their carers</td>
</tr>
<tr>
<td>Various - legal information, advice and support</td>
<td>Disability Law Service</td>
<td>Voluntary and Community Sector</td>
<td>For disabled people and their carers</td>
</tr>
<tr>
<td>Various - support through website, newsletter, local groups and events</td>
<td>Carers Christian Fellowship</td>
<td>Voluntary and Community Sector</td>
<td>All carers</td>
</tr>
<tr>
<td>Young Carers Net</td>
<td>The Princess Royal Trust for Carers</td>
<td>Voluntary and Community Sector</td>
<td>Young carers</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Advocacy in Somerset</td>
<td>Voluntary and Community Sector (funding from Comic Relief - with additional money being found from the NHS Trust)</td>
<td>Young people and adults with mental health difficulties and their carers</td>
</tr>
</tbody>
</table>
Overview of Somerset Carers Consultation Questionnaire Results
### SOMERSET CARERS CONSULTATION QUESTIONNAIRE

#### Help for you

**1. Do you know how and where to ask for help for yourself?**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>73.4% (243)</td>
<td>17.5% (58)</td>
<td>5.4% (18)</td>
</tr>
</tbody>
</table>

If yes - please state where you would go
67.7% (224)

**2. What help or support do you currently get and how often?**

92.4% (306)

**3. Please describe what other services or support you would like**

64.4% (213)

**4. Do you know you are entitled to talk to someone about your needs as a carer?**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>73.7% (244)</td>
<td>18.7% (62)</td>
<td>5.4% (18)</td>
</tr>
</tbody>
</table>

If yes, have you done so in the last year, or at least been asked about your needs?
3.6% (12)

**5. Have you been given any information and advice about opportunities to take a break from caring?**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>55.3% (183)</td>
<td>36.0% (119)</td>
<td>4.2% (14)</td>
</tr>
</tbody>
</table>

**6. Have you been given details of local support groups?**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>64.7% (214)</td>
<td>27.5% (91)</td>
<td>4.8% (16)</td>
</tr>
</tbody>
</table>

If no, what information would you like?
3.3% (11)

**7. Have you been asked about advocacy services (if applicable)?** (Advocacy services are when someone is able to speak or act on behalf of the person you are caring for.)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>19.6% (65)</td>
<td>40.8% (135)</td>
<td>7.3% (24)</td>
</tr>
</tbody>
</table>

Not applicable
26.6% (88)

**8. As a carer have you been offered support for employment, education, training or other activities for yourself?**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>13.3% (44)</td>
<td>61.0% (202)</td>
<td>5.7% (19)</td>
</tr>
<tr>
<td>Education</td>
<td>8.2% (27)</td>
<td>49.8% (165)</td>
<td>5.7% (19)</td>
</tr>
<tr>
<td>Training</td>
<td>16.9% (56)</td>
<td>44.7% (148)</td>
<td>5.7% (19)</td>
</tr>
<tr>
<td>Other activities</td>
<td>20.5% (68)</td>
<td>42.6% (141)</td>
<td>8.5% (28)</td>
</tr>
</tbody>
</table>

If no what support would you like?
27.8% (92)
**Recognition**

9. **Do you think you are known or recognised as a “family or friend carer” by the NHS, social services or other agencies?**
   - Yes 48.6% (161)
   - No 18.7% (62)
   - Don’t know 10.3% (34)
   - Some but not all 19.3% (64)
   - Don’t know 2.4% (8)

10. **Do you think you are listened to and asked your opinion about?**
    | The person you are caring for? | Yes 44.4% (147) | No 17.2% (57) | Sometimes 32.9% (109) | Don’t know 3.0% (10) |
    | Yourself as a carer? | Yes 29.9% (99) | No 30.2% (100) | Sometimes 30.5% (101) | Don’t know 4.8% (16) |

**Help to understand and manage the person you are caring for**

11. **Were you given enough information about?**
    - The diagnosis / condition of the person you care for: Yes 62.5% (207), No 30.5% (101), Don’t know 3.0% (10)
    - The impact it may have on you or your family: Yes 42.3% (140), No 43.8% (145), Don’t know 6.9% (23)
    - If no, what else would you have wanted to know? 34.7% (115)

12. **Has anyone helped you in coping with and managing the person you care for?**
    - Yes 55.9% (185), No 35.6% (118), Don’t know 4.2% (14)
    - If no, what help would you like to have offered? 29.0% (96)

**Information**

13. **Do you think that you receive enough information about support and financial benefits offered to carers?**
    - Yes 42.6% (141), No 40.2% (133), Don’t know 10.3% (34), Don’t know 31.7% (105)

14. **How do you currently hear about the services and support that Somerset County Council or the NHS offers to carers?**
    - Direct contact from Somerset County Council or NHS staff? (e.g. Carers Support Workers, Carers Assessment workers, nurses, GP, social workers etc) 59.8% (198)
    - By calling “Somerset Direct” (Somerset County Council main number) 13.0% (43)
    - Somerset Partnership Foundation NHS Trust (for mental health issues) 7.6% (25)
    - ‘Word of mouth’ from other carers or carer’s groups 37.5% (124)
    - Events/meeting arranged specifically for carers 32.6% (108)
    - Somerset County Council’s website 1.2% (4)
    - “Your Somerset” County Council newspaper 6.3% (21)
Appraisal of Carer Services in Somerset

3.0% (10) NHS Direct
2.1% (7) Patient Advisory Liaison Service (PALS)
7.3% (24) Local newspapers
3.9% (13) Local radio

Information leaflets (if so, where did you pick up these leaflets?)
13.9% (46)

Information from other services/organisations or any other means - (please specify which)
19.0% (63)

15. Please give any ideas or suggestions about improving support for carers
54.4% (180)

Background Information (OPTIONAL)

16. Which of the following headings best describe the diagnosis / condition of the person you are caring for?
   - 28.1% (93) Old age (including dementia)
   - 47.4% (157) Physical disability (including sensory loss)
   - 23.6% (78) Mental health
   - 18.1% (60) Learning disability
   - 19.0% (63) Other

17. Do you as a carer have a disability?
   - 9.4% (31) Old age (including dementia)
   - 19.9% (66) Physical disability (including sensory loss)
   - 5.4% (18) Mental health
   - 0.9% (3) Learning disability
   - 12.1% (40) Other
   - 54.1% (179) No

18. How long have been in a caring role?
   - 3.9% (13) Up to 1 yr
   - 11.8% (39) 2-3 yrs
   - 11.5% (38) 4-5 yrs
   - 16.3% (54) 6-10 yrs
   - 10-15 yrs
   - 11.5% (38) 2-3 yrs
   - 4.2% (14) 3-4 yrs
   - 22.1% (73) 5-10 yrs
   - 22.4% (74) More than 15 yrs

19. Roughly how many hours a week do you think you are providing care?
   - 3.6% (12) Under 10 hrs
   - 8.8% (29) 10-20 hrs
   - 14.8% (49) 21-40 hrs
   - 65.6% (217) 40+ hrs

20. Are you?
   - 22.4% (74) Male
   - 74.3% (246) Female

21. What is your age?
   - 0.6% (2) Under 18 yrs
   - 10.9% (36) 19-24 yrs
   - 31-45 yrs
   - 32.9% (109) 46-65 yrs
   - 66-80 yrs
   - 2.4% (8) 18-30 yrs
   - 42.0% (139) 31-45 yrs
   - 46-65 yrs
   - 8.2% (27) 66-80 yrs
   - 80+ yrs

22. What is your ethnic background?
   - 90.9% (301) White British
   - 0.9% (3) Asian or Asian British
   - 0.9% (3) Prefer not to answer
   - 0.9% (3) White Other
   - 0.0% (0) Black or Black British
   - 0.9% (3) Mixed
   - 0.0% (0) Chinese
   - Other Ethnicity (please state)
     - 0.3% (1)

23. In which area do you live? (Please tick one)
   - 17.2% (57) Mendip
   - 28.4% (94) South Somerset
   - 19.0% (63) Sedgemoor
   - 8.2% (27) West Somerset
You do not have to give contact details but if you would like to receive more information about support for carers or direct feedback on the outcome of this consultation please provide your name and address below:

24. I would like more information about  
   50.8% (168) Support for carers  
   Please contact me by post  
   50.8% (168) Direct feedback on the results of this survey  
   Email  
   53.2% (176)  
   Phone  
   18.1% (60)  
   Other (please specify)  
   0.6% (2)  
   2.4% (8)

25. Name:  
   79.5% (263)

26. Address:  
   77.9% (258)

27. Email address:  
   33.8% (112)

28. Phone No:  
   65.0% (215)

29. To help us know the best way to reach carers please indicate where you received this questionnaire from:  
   84.6% (280)

Thank you for taking time to complete this questionnaire.
Somerset Carers Consultation Questionnaire

Q 2. What help or support do you currently get and how often?

10 (3.13%) people said they received help from a support worker

- A visit monthly from support worker. Day centre twice weekly. Support group x 2 per month
- care support worker, Stroke support worker
- Care Support Workers - 3 times a week., Williton Hospital Exercise Group
- Carer Support Worker - when needed. 3-4 times PA
- None. My Carer Support Worker is overloaded with work as she has taken on another surgery's carers
- Respite - 4 weeks per year. Carers Support worker - as req'd. Independent Carers Group - monthly
- Support from Care Support Worker by phone. Occupational Therapy, Somerset County Council
- Support from Carers Support Worker
- Support worker has seen me during year following extra stress from bereavement. I can now phone her
- Support worker who can be contacted if needed

12 (3.76%) people said they attend a support group

- A visit monthly from support worker. Day centre twice weekly. Support group x 2 per month
- Assessment visit. Up to 6 visit mutually arranged then 6 visits referred if required. Parent Support Group avail. monthly
- Attend carers support group, 6 week course of counselling from Care First
- Care Support Group once a month. Doctor
- Carer Support Group (Carers Together) also meetings arranged by Steph and Anne Hillman
- Counselling through doctor, Local carers Support Group
- I go to support group meetings when I can - once or twice each 2-3 months
- I go to support groups once a month
- Monthly carers support group
- Once a month Support group
- Support via a parent support group. A befriender from Barnardos charity
- There are support groups for parents of children with Aspergers and I am in contact with the Autism Outreach Team

No mentions of Community Support Worker or Community Assessment Worker

Q 3. Please describe what other services or support you would like

45 (14.11%) people said they would like a break or respite – even if just to go shopping or for a day

- 2 nights respite
- A Holiday
- A social worker. Benefits advice and help. Respite - information on housing, supported work placement etc
- A week away every 6 months fully funded for both carer and cared for. The week away being for the carer while the cared for was in respite
- A week's holiday per year with client staying in own home
• Access to respite Access to a phone number that can help me with particular situations, e.g. CAHMS - our case is now closed, but problems although better are still there.
• Day Centre place once a week or 2 or 3 hours sitting to give me a break. Present cost for this is £16.20 per hour. Via Brunel Care/SS. A bit expensive
• Help with shopping, removal of rubbish to go to tip etc and just to be able to go out for a coffee and chat to get a break
• Holidaying with person I care for
• I would like support with home visits for cleaning, providing meals and cover for a day's break or holiday.
• I would like to have a break more often
• I would like to have a break without the fear that attempts would be made to take my child away on the grounds I couldn't cope. I'd like someone to come in a help on an "as needed" basis but without the fear my child would be taken from me on the grounds I couldn't cope. While that fear exists and there is nothing to allay it, I won't ask for or accept any help or support.
• I would like to receive correspondence from the right people informing me of all my rights etc - holidays or sickness
• Information on breaks for both of us. Short term without me having to sort out
• Local day centres for my mother. Local respite care in the event my sister unable to have mum. Possible home help eventually if mum requires it. Home caring facilities or person to help. Day to day care or domestic work
• More opportunity for respite in Residential Home of choice
• More respite opportunities
• Night over to allow carer to sleep. Wife's past problems (now resolved) involved interrupted sleep
• Night sitter or night watch
• Occasional respite, but my husband will have no one in.
• Once carer becomes housebound then a regular morning (if not 2) or afternoon "patient sitter" so that I can get essential jobs done
• One more respite day would be welcome
• Opportunities for going on holiday
• Overnight respite care
• Possibly some respite weeks occasionally so I can take a break or holiday myself
• Regular, consistent and reliable support/respite. I'd love to be a whole person again - I am 100% carer and isolated
• Relief from care duty once or twice a week
• Respite - a local parent support group
• Respite (2 people said this)
• Respite care at short notice was always difficult to get, Counselling
• Respite care leading to full time care. This is ongoing through Social Services
• Respite care, time to give ME a break which is very much needed. Also help of someone qualified in Aspergers knowledge to take my son out to youth groups to socialise
• Respite care, time to give ME a break which is very much needed. Also help of someone qualified in Aspergers knowledge to take my son out to youth groups to socialise
• Respite information
• Short break would be nice if we could find someone or somewhere that appropriate care/support could be given
• Social events ie day's out
• Some form of live-in respite care.
• Some weekend breaks would be nice and 2 weeks holiday a year not just one week
• Sometimes I need a break - get out of the house
• Subsidised 24hr live in care so that I could go away for 3-4 days once or twice a year
• Very occasional evening sitting
- Weekend assistance and extension to 1.5 hours per day including weekends
- Weekly respite from time to time are to be arranged as soon as possible
- What monies are available now and in the future
- Would like someone to sit if I go out to a meeting, evenings or I have been to the doctors

25 (7.84%) people said they would like information or advice
- A monthly or quarterly magazine or news letter of what and when is happening in my area
- A phone service for advice or reassurance
- A social worker. Benefits advice and help. Respite - information on housing, supported work placement etc
- A website dedicated to this kind of work.
- An annual review (haven't had one this year). A benefits check. Advice on future housing for my son who is 41 and lives at home
- Any advice gratefully received
- Better local arrangements than currently provided by "Somerset Partnership NHS" in respect of carer information, support and facilities to meet each other
- Central point to access for information relevant to where I live eg website
- Expert advice on how to persuade my mentally ill son to seek help. Practical support for my 85 yr old mother - advice on housing etc
- Financial advice for the person I care for. Training in care, hoisting, choking, nutrition etc
- I would like to receive correspondence from the right people informing me of all my rights etc - holidays or sickness
- Information on breaks for both of us. Short term without me having to sort out
- Information on support when husband had stroke - it was 2 years+ before I had any support
- Interactive communication and update on services available
- More Financial support(not info, real cash). More time away from caring environment
- More information on financial and social services
- More involvement in how her treatment is progressing
- More knowledge of someone helping out from time to time if I need to go away
- More personal contact without judgement or misconceptions. Single points of information of help
- One person to contact about everything rather than having to think who has responsibility for which part of Dad's care (i.e.GP, Community Psychiatric Nurse, Social Worker, Dept of Pensions, etc etc )
- People who could enlighten one on the advancing problems that crop up
- Respite information
- The "cared for" person's surgery should have an advice list to give to the carer. A carer group to exchange info, support etc while the cared for are being looked after too
- To have someone to discuss my situation with and to know if any help could be available
- To know what as a carer I am entitled to

75 (23.51%) people said they would like support of one type or another
- 24/7 live in, Less tick boxes for government office paperwork
- A carer support worker at my surgery. The post has not been replaced after she left over 18months ago
- A social worker. Benefits advice and help. Respite - information on housing, supported work placement etc
- Am happy at present with support I had
- An occasional phonecall to ask if all is well
- As I don't know what support if available it's difficult to specify
• At the moment I am ok with the support and service I receive. I am in very close contact with my husband's consultant, CPN physiologist
• At this moment with the support I am coping
• Better local arrangements than currently provided by "Somerset Partnership NHS" in respect of carer information, support and facilities to meet each other
• Continuation of at least a yearly visit would be a support instead of hearing this has now to be withdrawn because of overloading
• Counselling to help through the difficult times
• Deane Helpline and more visits from Somerset Care have to be paid for and still waiting for attendance allowance decision
• Dementia groups - if there are any should be widely publicised. My parent has dementia and goes to one day centre once weekly. Somewhere to get help apart from "carers" coming in as they do not understand dementia and often make things worse
• Evening support groups. I work full time and cannot make daytime groups.
• Expert advice on how to persuade my mentally ill son to seek help. Practical support for my 85 yr old mother - advice on housing etc
• Financial Support so I can work fewer hours and support more at home
• Government to reinstate carers allowance which was stopped when I became a pensioner.
• Help finding diagnosis for my child
• Help for both parents as we have a son with special needs
• Help I do not have to pay for
• Help with bathing my husband occasionally
• Help with fuel cost?
• Help with partners MH needs - more with occupation planning
• Help with shopping, removal of rubbish to go to tip etc and just to be able to go out for a coffee and chat to get a break
• Help with sorting out benefits and filling in forms
• Home help, Gardener
• Home visits - occasional as I appreciate pressure on services
• Home Help to help with chores or gardening
• I get no help at all. I work two jobs to give her everything she needs as well as looking after her. Means testing is so unfair as it punishes those of us who work hard to support our families. Those on benefits seem to get the lot offered on a plate. I sometimes wonder why I bother at all.
• I have a very painful foot that limits my walking. I cannot get help with this so help with my health would help hugely
• I have had 2 operations including 11 days in intensive care - soon I may need help. I am 84 years Old
• I received help I needed when I asked
• I would have liked the support we eventually received to have been put in place when we first needed it. It was too little, too late.
• I would like a Carers Support Group just for those caring for someone with mental health problems
• I would like a CPN to visit my daughter who is mentally ill
• I would like more financial support and after care if daughter goes into hospital again, I would like to be trained and educated as I have been a carer since I was 19
• I would like someone to come and talk to me
• I would like support with home visits for cleaning, providing meals and cover for a day's break or holiday.
• Information on support when husband had stroke - it was 2 years+ before I had any support
• Meals on wheels
• Medical support for my sister (autistic)
• More carer support worker contact
• More connection with other carers, education, health
• More Financial support (not info, real cash). More time away from caring environment
• More help from GP
• More local carers groups as the nearest is Wells, raising public awareness for carers, esp young carers
• More local day time groups (various interests)
• More OT services for Tom
• More Social meetings with other carers or former carers
• More support direct to my daughter - so I am not so dependent for by her
• More support for dealing with dementia and things to prepare for
• More support from the Support Worker at our Carers Group
• Quite satisfied with care support at the present
• Regular contact
• Regular, consistent and reliable support/respite. I'd love to be a whole person again - I am 100% carer and isolated
• Rehab - someone to do exercises with my husband who has Parkinsons to increase mobility
• Reliability of NHS patient transport when hospital appointments are needed, lack of communication and consideration for patient at the office level
• Respite - a local parent support group
• Shopping, cleaning
• Short break would be nice if we could find someone or somewhere that appropriate care/support could be given
• Social Worker to relieve stress/anxiety
• Social Workers to work as a team with carers and not against them
• Somebody to talk to
• Someone to help to get though the mass of claim forms and to respond to them
• Someone to pop in now and again
• Someone who knows Louise and could give us support and advise when needed
• Sometimes as I myself disabled I am unable to take my wife to Neurys left Weds and Friday
• The "cared for" person's surgery should have an advice list to give to the carer. A carer group to exchange info, support etc while the cared for are being looked after too
• The carers carer being available. Everytime I called on him he did not return my phone call
• The support I have received has been very good
• There is not enough support in Somerset for establishment of MIND. We at New Direction are struggling to find money to expand to help more people with mental health impairments
• To meet more parents in my home town who have similar situations
• To talk to someone
• We would like more support at times for gardening, for sleep walking at night, getting lost
• Wife being taken out on outings

Q 8. As a carer have you been offered support for employment, education, training or other activities for yourself?

If no what support would you like?
• I am not going to get the support I need so have given up trying to fight the system and will sell my business and house to move to an area where there is support for my daughter
• Some ways of showing a male how to care for a female
• At 64 probably be retired anyway
• Concession for feed
• MS have sponsor for singing. Would like to continue
• Unsure at present
• No other
• I prefer to stay at home as I suffer from stress
• Relaxation activities to stimulate but not add to stress of situation
• Something like a life coach or mentor
• Knowing more about computers
• Not required
• respite
• Carers asked what they would like, carers given a forum to discuss common issues, Less "dumbed down" stuff than is now offered
• Respite
• I would like advice on how to get benefits for my daughter as I feel frustrated at the lack of information and have supported her financially for 8 months
• The opportunity too see and discuss what is available to me
• Courses that are flexible and easy to get to (transport) and affordable
• Help back into work. I am a carer since being made redundant
• Education
• More respite
• I am retired
• I am retired
• I do not know as there is very little time to think of anything else.
• I don’t need education or training, nor do I need employment. I already have a job - raising my child to the best of my abilities and give them the best opportunity I can with the resources I have available to me.
• Details of what is available in activities
• Domestic help for disabled person and me
• Not at the moment
• Voluntary group meetings and activities
• More money for our carers group
• but none are suitable as all during the working day
• Unnecessary - I am currently in education.
• I am not sure what support I would require.
• We did have support with form filling /claiming benefits.
• Might be helpful to meet up with other people caring for people with dementia
• Education
• Would not be helpful at this time
• My mother is OK with all the support she receives at the moment
• I think it will all happen, it's just that I've only just started using the service
• NVQ2
• Night school at low concessions would be good or even in daytime. Just an opportunity to learn something new
• Financial support for training/education. Already have 3 jobs
• Unsure
• Education, training and employment
• I am employed as well as a carer but would like to know where I stand re time off when I can't cope with both
• It would be good doing education and/or training that would help my family and maybe others. No information
• More training. To become more aware of different things and activities
• More info on qualifications and costs
- Respite - family/parent support groups locally
- No spare time
- How to get back into work after a break of 4 years
- My rights as an employee with a disabled son. FOC training to get knowledge of my son's condition and how to deal with the school system. A 1-2-1 contact
- Guidelines for benefits of work/education or retraining. Someone that could help/support on all aspects. There seems to be so many people you need to contact
- OAP
- A support worker and some actual facilities
- Not sure
- Information
- I work for NHS - would not need above at present
- Not needed
- I would like to learn more about Mental Health impairments to update my education skills but cannot afford college fees
- None at present
- Don't need any of these
- More groups locally
- There were meetings but I can't go because I work full time
- A key worker type person who could offer support with all of the above
- Care Support Group - Shortage of sitters, also cost
- More help at home for carers
- To have a chance to meet other carers with hobbies or talks etc
- More information on other groups; perhaps there could be
- Don't know
- Activities
- Coach outings
- None at present
- As a teacher I had to reduce my days and salary! to 3 days to care for my mother's needs on top of daily mealtime carers
- free education at higher level than basic skills.
- Haven't even time to think about something of this sort
- Training on breakaway techniques and self preservation
- First aid training, use of equipment, handling. I feel that we are doing much by trial and error
- More information to develop skills within an academic element
- To be able to get minimum wage!
- Training
- Meet up with other carers eg for a meal out
- Up to date information on leisure activities
- Relief from care duties weekly
- The counselling service was good and carers support. We come from a large family so wasn't so bad for us in support ways. Information was important and care consideration essential
- Nothing at present time

Q 11. Were you given enough information about?

If no, what else would you have wanted to know?
• She should have been diagnosed at 3 years or under not at aged 21! She had no counseling to help her to come to terms with the diagnosis and the family received no help either.
• All I was told, there was no cure - just to keep her comfortable
• Details of mum's physical problems. Understanding from her GP re diagnosis by consultant of Alzheimers
• Husband diagnosed with MS 35 yrs ago. Things were different then. Not much counseling around then, think it's better now
• Physical effort and mental attitude to a total change of lifestyle and future

• I was given help on the day of husbands being registered blind but I don't think this applies to everyone
• All I was told was they have the disease but you have to suffer it
• Dr Bansi of Taunton was useless but had to go to Bristol to get told MS
• Unsure as my knowledge of person caring for is superior to that of my GP
• Not usually invited to attend consultations with GP or consultant
• Not enough post hospital follow up care
• Just didn't realise how hard it would be

• Problems with injections for diabetes and the help available for living with benign Essential Tremors

• I would like someone to tell me about the condition and future impact on the person I am caring for
• Prognosis
• That every child has the right to an assessment but that you have to be determined to obtain one.
• Who to contact for what problem
• To have an explanation from the psychiatrist in charge
• The impact, the pretence, what it says above!
• I would like a proper diagnosis from the Mental Health Team
• Just how it will affect us as we progress in years plus how the illness will progress
• Available help now and in the future
• Continuation of treatment, information and help in the beginning
• the long term effect on myself and family
• More about dementia. More about incontinence at that time (ie 11 years ago)
• How to recognise symptoms of pain or distress and when to get medical help
• We have had to find most things about PD at the beginning. Now we are helped by the Consultant, the PD nurse, the PD monthly meeting and the PD Society.
• We have had to find most things about PD at the beginning. Now we are helped by the Consultant, the PD nurse, the PD monthly meeting and the PD Society.
• More specific diagnosis
• There are so many limitations to what we can do that we have to consider even the smallest outing to make sure we cover every eventuality.
• What was wrong with wife's medication and changes to her moods and coping
• Future housing options for my son, as we, his parents are ageing
• Vague and indistinct about medical matters
• Details of how the situation is likely to deteriorate
• Not enough information initially (2003). Found out gradually from Alzheimers Society - wanted to know more sooner
• NHS unhelpful. Good thing I'm a nurse so I can diagnose it myself
• More info about dementia
• Future prospects for condition
• Help with my dealing with "cared for" and explanation as to why she should no longer drive
• My wife was diagnosed with MS in 1984. There was little/no explanation at the time
• Information given as I requested the conversation

• Absolutely no thought or understanding what the caring role has upon me or my private circumstances.

• In the case of my long-term unemployed son, who has been suffering with depression for many years, doctors have refused to talk to me or refer me to a psychiatrist as they claim that only the patient can be treated. In the case of my 85 year old mother who recently fell, it would have been helpful to have been helpful to have been copied in to medical diagnoses/advice etc as she gets confused and forgets what she has been told.

• I would have wanted to know why my partner was behaving in the way he was, how I should have been dealing with it, and the possible outcomes based on the knowledge of the medical people dealing with him. Instead, we had to try to work out for ourselves that he was swinging from depression into a bipolar high - about which we knew nothing - which ultimately resulted in him leaving home and destroying his relationships with everyone he knew.

• At birth 45 years ago information was not up to modern standards

• Early intervention would have been invaluable. We were unable to liaise with the GP at the outset of problems

• More about his problems and the effect on the family especially younger siblings

• How things would develop. I had to look it up

• More of the impact on the family

• How debilitating it is

• Circumstances change - info to impact on the family needs to be updated from time to time

• Once a person is out of hospital no-one wants to know anymore (NHS). You're left to get on with it

• when wife was diagnosed 35 years ago the information received then was very uninformative. We take each day as it comes

• This happened in a different area of the county. I doubt anyone could have given this information

• I would want to know everything to do with caring

• My daughter has a dual diagnosis but because she has drug habit, mental health issues are ignored

• This goes back 40 years so is now academic

• More details of implications of illness. Counselling and support for family at time of diagnosis

• Long term effect

• Full information on the impact of all the disabilities

• Some help with improving the family situation

• Finding out about carers organisations, financial matters etc instead of having to find out myself

• At the beginning it would have been helpful to know about groups, see how others cope

• Just more time spent to explain a diagnosis, its implications and exact help available

• I would like to have had training over the years

• More early contact/involvement with Social Services

• How it would change Tom, his change in temper and aggression

• I would like more info on husband's mental health condition from Holly Court, Yeovil

• My son is adopted so medical history would have been useful at the start

• How to cope with all the extra work and extra problems on my own

• Condition of the person

• Condition of the person

• Where to go for all kinds of help on all different problems that could occur eg school, anger, home life

• We were given an info pack with contacts etc but when you're just coming to terms with a diagnosis it's hard to be self motivating

• What help was to be given

• The address of a marriage guidance counsellor
• Full details
• Just to have been there when it was all explained to my husband
• About specialist feeding and a dietician
• Everything!
• Are there others who feel responsible at a family carer
• We did our own research

• I can only be given the individuals impairment by that person and I know I need to understand more
• More information and communication
• More reference points that I can visit/read in my own time
• The amount of damage to the brain and management
• How to deal with things in general
• Probably would have wanted to be made more aware of the trauma and how to live with this
• I am 74, have angina and arthritis and worry about coping in the future
• No because it's ongoing different issues that have built up - so dealt with gradually
• The progression of Alzheimers. It's varied effects on people. I found out all I know on the internet
• We gleaned information about dementia care from the media
• More information about what we were facing
• How to deal with symptoms/condition - where to call for help or ignore
• All from Musgrove Park Hospital, none since
• I have been given nothing to tell me what happens with the condition my mother has
• But nobody else knew!!
• What a life of hell we'd just walked into

• Everything - We had no idea and no support for years. Had to contact MP even to get a social worker
• One has different situations every day and learns from this fact
• As a carer - what help is available, who to go to and where to contact. (Sometimes get it off other carers or if attending meeting which can be ad hoc)
• What to do in a crisis Dietary advice
• How hard it would make my life and the rest of my family
• More help to cope and unite as a family rather than split the family and cause more problems
• I did not understand what it would mean long term

Q 12. Has anyone helped you in coping with and managing the person you care for?
If no, what help would you like to have offered?

• Daughters - live away but came to stay during the time needed. SCC arranged for mobility aids
• Not until quite recently via workshops organised/funded by Somerset Partnership
• Home visits
• practical advice is fine if it is a practical problem but coping is hard
• The Social Worker
• Access to medical staff for advice etc without patient present
• Advice/guidance over making decisions on appropriate care
• Anything
• Psychiatric help, help with strategies for dealing and managing the cared for's behaviour
• Carer Support worker, SJA, Carer Support Programme Manager
• Not for the last 26 years, more recently yes
• I would like to know what help is available
• Professionals to come and really experience the life I lead - the solitude, the isolation 24/7
• Feel I can cope at present
• In the future I may need more help, at present I am coping
• Educational support
• From the Mineral Hospital and our GP
• Own family - although we don't call them unnecessarily

• Someone experienced to talk to - feel you can trust and call on for info, who to contact on 1 to 1
• I haven't reached that stage. At present I call on friends
• Relief from care duties
• I don't think once an annual review is enough. 24hr day care is ongoing constant
• Carers support worker - local GP, and nurses that came when dad died were very caring
• Daughter. Supportive staff at Barnfield House

Q 13. Do you think that you receive enough information about support and financial benefits offered to carers?
If no, what would you like?

• More immediate information regarding funding on both sides when someone goes into a home
• How do I know I have received all relevant info? Doubt if I am entitled to any financial benefits
• Someone visits for a while. It takes while to get the money sorted, then you don't see anyone
• I think we get what we are entitled to but would like someone to confirm
• Anything would be useful
• A printed leaflet itemising what a Carer is entitled to
• It is quite difficult to access what financial help is available or eligibility
• Financial mainly
• Reassurance all that can be received us being shared and offered to us
• A person to talk about finances, pensions and my own prospects
• information given to me not for me to seek it out via St. Johns Carer programme
• Support is brilliant, financial benefits was more difficult
• More support and info on benefits
• Support for Carers AFTER care has finished or taken away?
• That's a joke!!! Sorry but what financial benefits
• There should be someone who can explain what benefits to apply for
• To have a 1-1 with a person that knows what's on offer
• It's still a problem, very hard to access
• Probably more I could do but its an effort to probe for more info on financial help
• any benefits

• I’m a live-in carer for grandmother (age 101) I receive £50 per week for 96 hours at her home per week
• To know who qualifies for finance/benefits
• More money and resources given to Carer Support Workers in every GPs surgery
• But only joining Carers UK
• Have had no info re financial benefits
• I have no idea what is available. We do not do benefits!
• Non professional carers should be paid a proper living wage to compensate for the stress
• Info on benefits
A benefits check please. Advice on where and how we can find housing with the right kind of support
• Dept Works and Pensions are remote
• Some given by diagnosis staff but not for instance about reduction in council tax
• Information made available at the beginning, not find out as you go along
• It would be nice to hear about eg the benefit centres
• Am expecting to get this info from Social Workers etc
• Someone to discuss my current situation and give me advice.
• clarification as to why such differences seem to exist across the benefits system
• Clarification and correspondence
• All the info
• Little help
• Full amount of Carers Allowance
• Clearer and easier forms and for the carer allowance to be extra.
• One of my jobs is for CAD so was aware from there. No other info/help given
• Information
• Is there any information?
• Do we get the right money to EU laws?
• Initial involvement - family should know its rights, support and benefits available
• More detailed and easier to understand info
• Information was hard to find, a one stop shop for all info would be useful
• Financial help, No carers allowance, pay rent and council tax
• To be made aware of what is fully available
• Attendance allowance and its contribution towards a pension
• You receive information but no practical or financial help
• More information specific to me
• Only because I have attended St Johns Carer Group, Jude Glide

Currently I receive no financial benefit for caring for my husband. He receives £47 pw Attend Allow
• someone to talk to us about what we may be able to access
• how and what we can get benefits for, utilities or housing benefits

Any information I have had to find for myself. Carers are not informed of the help they can get

Once a problem is recognised - a list of help. Also for the professionals to get in touch first
• Should be more open to benefits or breaks for the individuals
• Should be more open to benefits or breaks for the individuals
• Not till I went on St Johns Ambulance course
• Not till I went on St Johns Ambulance course
• Big info packs on diagnosis
• I feel I’ve had to do a lot of looking - it’s hard when you don’t know what to look for
• A social worker/benefits advice and help/ Supported living advice and help
• Information to be given and to be freely available
• Not sure
• I would have liked to know about respite and sitting provided by Direct Payment
• Though there may have been workshops and information days
• Information
• Clarity about Carers grant
• A clearer account of financial assistance AFTER retirement age
• Money information
• Should be done at the start and not when situation is critical
• Information re physical support and occasional respite and financial benefits for caring
• St Johns Carer’s Cause was invaluable - so would now like to be kept up to date with available benefits
• More regular review of requirements of all financial and physical problems
• Nothing is explained clearly
• I’d like to know what’s available
• Support and information on benefits

better informed jobseekers when it comes to carers allowance 3 people did not know leading to wrong
• Standard rights - at present it seems to depend on finding right person to advise
• I was informed of Carers Benefit which I claim
• Any information
• Information
• Would like more information about both
• I had to ask and do research online to find out about benefits
• More money
• The people from the services help with all form filling to get the right amount
• I keep a watch out in the local press

• Have found out some benefits by myself. Useful to be kept up to date, what and where to find out.
• Not required as yet
• Need information, the social services like to keep things secret

• All information should be given as a package rather than having to find everything out yourself
• Since going on the carers course I feel I know most things
• Only hear information from other parents rather than specialist

• It was inconsistent - not clear and didn’t seem to know what talking about - made mistakes in advice.

Q 14. How do you currently hear about services and support for carers?
Other - (please specify which)
12 people specified local radio

Q 15. Please give any ideas or suggestions about improving support for carers
or any other comments
• Put some services in place in the isolated areas so that takes the pressure off carers
• We have a very supportive Doctors Surgery here at Creech St Michael which is of huge help and
reassurance. We can pop in at any time to ask for help and advice. We are very grateful
• Earlier support is needed while the person being cared for is well enough to help and guide the carer. As in my case help was received more after to started to affect my health
• Monetary help - not to be assessed
• GP Surgery made more aware of carers needs
• I think meetings for the carer and the person they are caring for would be good. I went to one Memory Group clinic with my mother and thought it was very nice to be included and involved in ways of helping mum
• Someone to explain to the person cared for how important it is for their carer to have help and respite. It's so difficult to tell them you need time off, you feel guilty and for older people its hard for them to admit it. I managed till I was 50 and waited for my husband to notice I needed a break, he never did and his first week in a home was very traumatic, he hated the idea and I so understood but my social worker at the time was on my side and helped greatly

• More publicity re the support which is available would probably be a good thing and even more emphasis on the fact that what one does automatically is caring! Removing the responsibility for the "cared for person" is the best bit of respite for carers. I feel probably more respite for the invalids would be a great benefit. Some may need persuasion to accept this. I get very tired just thinking for 3 people without a lot of very physical effort being involved, so for carers with much more personal/nursing work it must be exhausting. One has no life

• Ask staff and/or coordinators at rehab units such as Williton etc. My surgery involves Carer support workers (Wanumek House) from SCC and Stroke Association. Have meetings while patient is in hospital with carer and other support workers to introduce to each other

• Make carers groups at different times, not everyone can make the day sessions. More sessions in local villages. As much information as possible sent or emailed. Dates of social activities made available as soon as possible to be able to arrange shift swap at work if needed

• I think we have a very good service, thanks for all

• hard to say but we seem to get everything we need, but would like advice on anything new or updated

• Unsure - but an education (training) in how to fill in forms (such as attendance allowance) would have protected my personal savings from erosion, but alas I was shy of asking

• Care support worker available earlier in the process. Before patient leaves hospital. Where continuing Health Care is appropriate more information and help with application - understanding its implications, speeding up the process (ours took 8 months). Reconciling difference between what Social Workers suggest you are going to be provided with and what Brunel Care is able to achieve because of operational problems and logistics

• Perhaps more people just to talk through the individuals "caring life" and the day to day issues that arise

• Does not apply to me/my husband at the moment as he can do quite a lot, but looking to the future as I become older and possible less able I feel frequent visits by proper care people would be helpful and supportive

• I don’t like to go on the register or claim any benefits because I think they’ll say I should be working. Don’t think I qualify

• It can be very lonely when person cared for demands support and time spent with them as they deteriorate in active mobility and independence. To just hear another opinion is a help but being made to feel guilty when taking time out for my needs does knock any effort in trying to keep alert and alive. A drop in centre and knowledge that someone has time to listen to us and not be overloaded (as is now the case in Wellington) is very important

• I feel carers should be treated with more respect - as professionals dealing with difficult situations, by the DWP, doctors, hospitals. I feel carers ought to be involved with any care plans or treatment or consultations at the hospital, especially out patient services. As a carer who organised and arranged transport and aftercare for out-patient appointments I am usually left to wait in the car, totally unacknowledged and invisible and left to pick up the pieces if the appointment has been distressing. I need someone to ask ME how the appointment/tests went!

• I have received excellent support from both SCC staff and Adult Social Care staff

• An assurance that money for carers services is ring fenced and not part of the Councils general pot. More (and cheaper) “Sitting” arrangements to give carers a break. Attendance Allowance continued
I know you do a book which shows you the way to go. However, I had to fund dyslexia diagnosis myself, it was not identified as such at school. It would be better if the state system picked up on problems and took them further than they were initially taken in my sons case. I knew something was wrong but did not know how to go about getting an assessment. After asking for one for years and now getting a statement my son is making some slow progress. Aged 11 he is now starting to read and write. This has involved the help of many Somerset County Council staff.

The support we receive from Dr Cox and her team at Chantry House is brilliant, they all know at what stage my husband is at. They all see him regularly and all help to overcome difficulties. I have meetings without my husband and we work out how to overcome the next few months. We really are very very fortunate with care and support. If ever I have a problem one of the team is there to support us. My husband was 51 when diagnosed with Alzheimers and since then we have befriended Dr Cox and her team, so there is no room for improvement on my behalf.

Things have improved in my case since my husband was put on dialysis for kidney failure. Just someone keeping in touch would help. I believe there is a counselling service which I would like to use but don't know who to contact. Updated information sent as and when available.

There seems to be a black hole where day to day carer's help ends and hospital care starts. ie not so ill to need hospitalisation but too ill to be left alone for any length of time. Due to my own ill health I am not always able to cope with long periods of care.

Am I still a carer? Being classified as a carer and looking after my wife with Parkinsons and a heart problem for 3 years (24/7) my wife of 55 years had a major stroke resulting in her being looked after by NHS nursing in a Taunton Nursing Home, I try to see her daily when possible and I know that she is safe. BUT I have not had any contact with Social Services since her admission to the nursing home. Have I been discarded? I do believe that there should be a follow up as to the health and situation of people in similar situations. I have a disability, I live alone and sometimes wonder is it worth it! So the question is - am I still a carer or not?

Lately I have lost a daughter aged 43 yrs old so I have not been able to attend any meetings of any sort, no one has called to help. I was visiting the hospital for 3 months every day and I have now a grand-daughter 13 yrs old also to look after.

At Q14 I cite the GP and practice carer support worker and add Dr Rossiter only because the local support at Bracken House has deteriorated noticeably over the last year. I accept that there are staff shortages and a real recruiting problem that makes things difficult but Bracken House has had too many staff people transferred elsewhere and the imprisoned gained is that those staff left have simply put carers needs at the bottom of the "to do" list because the workload is too high. Please do something to get the staffing problem solved both quantitatively and qualitatively.

We need more time off by the right helpers ie "Rethink"

Counselling should be ongoing. More "carers" within the companies from Brunel Care etc) who understand dementia, the importance of consistency, understanding patients etc. having a bank of volunteers or paid staff who can do some sort of respite care.

When my daughter became ill with Psychosis I rang our GP, he was unhelpful and it took 2 months for him to refer her to Belmont House Mental Health Team. No one explained about benefits and as he was in the process of divorcing her husband, who went to live abroad she had no income apart from £20 per week child benefit for 6 weeks and was too ill to apply for anything. She was finally granted ESA of £64 per week and family child credit of £46 making £130. The ESA was stopped suddenly without a proper reason saying she was fit to work. She is NOT and the psychiatrist agreed. There should be someone attached to the Mental Health teams to advise people like us from the start of the illness as we have been so angry and frustrated.

When diagnosis done - give Mental Health guidance to carer to help them help their loved ones.

More direct services for patients /clients and less reliant on family carers.

An organised system of trained advisers calling to give information as to where to access equipment and other needs - particularly when the person cared for has moved in to the advanced stage of dementia. This staff should automatically "flag up" on the GPs screen and be referred to the trained adviser and the necessary support offered - especially equipment, incontinence advice etc.
Continuation of Care. Not to be forgotten in the system and to treat you as an individual, not pigeonhole you into there "sometimes" limited understanding of your illness, and how it may or may not affect you. I have found you sometimes more commonly found disabled couples helping each other out, in anyway they feel they can. Single points of reference, a combination of carer and information would help

A dedicated website would be of benefit. This could hold all the information required for carers.

Being able to get respite quickly when it is really needed instead of having to wait (if possible?). Getting the care company to be more efficient and realise that carers have a life of their own and are not sitting there all day waiting for them to turn up. Quality care has gone downhill over the last 10 years (not for me though). Carers do not spend their allotted time with the elderly - in and out and to get home as quickly as they can

More information about day centre care on a week by week basis so I can set up a dialogue with my sister about what she does. She has no language as such but there is some communication possible if I know about specific events. Any meetings must be within suitable hours

Every surgery needs a Carers Support Worker who can manage the workload given to them and be available to answer questions from Carers and help to support them with any problems they may have

I feel that I have wonderful support from my care assessment worker Jackie Murphy. She is the best but I had to seek help for myself from ringing MIND. I was not asked if I needed a little support from my daughter's doctor etc she was under. it would have been nice to have been asked as I have never experienced this situation before

early diagnosis, More information from GPs and practice managers. More money for daycare and respite care, One central point where carers receive information and help

I think the carers meetings should be on a weekly or fortnightly basis as once a month is not very good because we have just 2 hours a month

What about a Carers Pack to be sent to all on CA? or to families eg people on DLA/AA?

Greater awareness of the family GP. Increase in Carer's Allowance from Central Government

I think that ever disabled person should have to nominate a carer who should in turn agree to be contacted by a service provider to ensure they are made aware of what services and benefits are available or on offer. My wife takes so many drugs at times and is in so much discomfort that she cannot pay attention to a prolonged conversation.  I feel the strain so often and cannot unwind from the day to day pressures of looking after her.

Pay a living wage, give unconditional support, give support without implying the carer is incompetent and unable to cope simply because they are asking for help, have people able to give support who have personal (not professional) knowledge of what it's like to care for someone who's disabled, don't penalise carers financially because they are carers, don't assume DLA will cover everything because there's no way it can or will and it's not right to expect a carer to subsidise a disabled person even if that person is a family member. Have homes available that are disabled friendly and make them available when needed, eg ready fitted with stair lifts, wider doorways and hallways for wheelchair access or bungalows with wider doorways and hallways to make it easier for wheelchair users, baths with hoists or showers big enough to take a chair for safety (epileptics aren't supposed to have a bath only a shower in case they have a fit in the bath).

For carers to get a break without it costing. Because we have savings we do not qualify for financial assistance. My husband does not want to go into care and certainly when it costs about £500 for 1 week to give the carer a break occasionally some help could be given with paying

I am so relieved to have a carer support worker as it is nice to know there is someone to talk to if need

Rachel has left her post for another one and so far has not been replaced. She had a thankless task but fulfilled an important role. Carers do not want to read another "strategy" document that ticks all the boxes on paper but DOES NOT DELIVER. Communication with carers needs to be simple and to the point. I understand that this is difficult but it is important to try

Currently my elderly distressed mother has little contact with social worker or occupational health support staff. In fact the social worker has only visited here twice in over 2 years. In addition her GP does not make visits to households. Personally I need a social worker for guidance as I have discovered at times the management of my 90 year old mother stressful

I feel the "powers that be" do not appreciate the work that carers do, not only the work but the mental side and the loneliness
• I think that GPs should advise the carer of help available as I was a carer for my father for 4 years and
do not know any help was available and would have appreciated it more as I was also bringing up some
and it could be quite isolating at times. It wasn't until my husband became ill and was put in the
care of Holly House that I had some support
• More carer Support Workers - they are overworked!
• Need cash (not elaborate, time consuming DIY, employ other people and spend 20+ hours a week
calculating PAYE/POVD/CRB/Ni/Tax). Need greater flexibility of services. I work nights and am not the
only carer/nurse. My carer support worker is a treasure, other services not. Benefits agency
(DLA/Incapacity) more trained staff needed, not semi comatose 16 year olds
• I would like my own care support worker to listen to my concerns on a regular basis
• Would like to kept informed more - a newsletter?
• Clearer information as to help and services available, A name for each person responsible (and phone
number) regularly updated
• Carers can provide information for case studies highlighting issues to be solved. My experience
highlights in particular: ineffective communication, that time is more important to the person being
cared for than to the services providing the support. We all need to adopt a basic principle. Everyone in
the caring process makes a valuable contribution towards the needs of the person being cared for, but
the most important person in the chain is the person being cared for. Self importance in whatever role
is always subordinate to that of the person being cared for. This principle needs to be accepted as a
priority to all engaged in a care support role. Only then will all of the energy, resources and vast army
of carers be devoted to improve care and directed towards achieving it. It should be a national and
human desire and there will always be a need.
• Give carers the financial support they require or they may be forced to let the community care for the
cared for
• I have no further ideas at the moment. However, I would like to express my appreciation to those at
Yeovil Adult Social Care. They have helped and advised my wife and I in planning changes to our
house and in implementing them. They have also helped/offered help to support myself as the carer.
Both my wife and I are independent and at present are looking after ourselves. The Yeovil Adult Social
Care people have now backed off but the lines of communication are always open if I need to
recontact them
• This does not apply now but for many years we had to survive on a very low income which could be
very stressful. I am lucky that there are friends and family that stand in to give me time off but I have
Carer friends that are not so lucky.
• It's nice to have some help and support when the person you are caring for has gone into hospital and
hen you have to call for the ambulance and it's nice to have someone in the house when they come
home. Also it would be nice if could have someone near to help if the person you look after falls
• Maybe a monthly bulletin - perhaps emailed to relevant people with access to computer with useful
advice, contact numbers and timely tips
• I had a really informative time at the Carers Support Group with Jude Glide at St Johns, Taunton. The
classes were friendly and everyone was so caring of our needs. The information we were given was
excellent. From my own experience it is not easy for either the person needing the help or for the
carer, especially a very close relative to accept they need or have to give help. Perhaps it would be
helpful if a speaker from Carers Support Groups could go out into the community to give a talk on the
help that is out there, say to the TWG or Mother's Union or WI Groups, even if only one person to be
aware. The book "If Only I'd Known" is a really excellent book for anyone's bookshelf. I'll guess
everyone knows someone who needs the help of Jude Glides Carers Support Group at St Johns.
• I would like my opinion to be taken seriously!
• Very good support - well done
• As a fulltime working mother and carer, I do not have time during the day to attend the support groups
for carers. I need somewhere to go which is not during office ours. I take enough time from work for
hospital appointments and therefore can not take further time out to attend support meetings.
• More publicity and marketing material, readily available. Advertising in local newspapers. I am not
aware of leaflets in the surgeries. If they are available, then I think the nursing staff/doctors should
readily offer advice to obvious carers/family members who accompany elderly patients. It should be
standard practice. It should be discussed in front of the patient to encourage awareness of the
situation. Support from the surgery is important.

- More support could be given by family doctors
- Patients should not be discharged into the care of the community health team without there being full support for their families. It should never be assumed that families are coping, or that they are receiving support - in our case, that support was assumed to be in place but no-one ever checked.
- Ensure that carers know what help and support they are entitled to
- A yearly review exists for the person cared for. Some form of review of the carers condition and current worries/problems would be welcome especially concerning future needs as age takes its toll
- Indirectly by not putting the relative/friend cared for under further stress by eg promising a course to help but not coming up with the goods. Continual changes to staff - 1st gives an optimistic future, 2nd you'll never get well. CPN appointments mode - do not turn up and not even a call to explain and make a further appointment. No Care Plan even though patient had been sectioned. All above have occurred to people I know and not myself. I personally believe that the money spent on exercises like this and all the other talking shops should be directed at practical support for carers
- registering carers with the GP and GP Practice Manager to communicate with the appropriate service, CSW, CAW, Social Workers etc so carers are kept up to date with new legislations etc and informed of any changes of medication for the cared for person
- Sometimes someone will ring my mother to check if everything is OK. She does not always say the right things and I would like them to ring me. They have also called on my mother to check things and I would also like to be there when they call, but they do not let me know when they are coming and my mum does not think to tell me
- The support for my daughter is fantastic and the support I'm starting to get is great but when the person I care for gets admitted Rydon Ward don't listen to my concerns and then sometimes something serious happens and he tried to kill himself. I know the signs but they won't listen to me and when he's there no one even talks to him. Rydon do not offer enough support to him or us as a family and they can be really rude at times. I'm quite happy to discuss this with you
- I am not a registered carer. I am a wife with a husband who is registered blind and is immobile - housebound. Mr Guest has a state pension and attendance allowance. I am also 85 years of age
- I have just been in hospital and there was no help at all to look after my disabled wife. My son had to come from Dorset and leave his family and take time off work to look after her. I am out of hospital, my son's had to go home and I've received NO HELP at all. I have had 2 operations, had no help and try to look after my wife as best I could being a poorly man. Also I am 81 years old
- Stroke
- Social Workers appear not to listen or work as a team with doctors or nurses and carers
- The support that is offered does not help as it is the wrong kind of help. Carers do not do shopping or cleaning services I have really needed when I have been unable to get out
- More Carers Support Workers who can visit carers in their homes and talk directly to them or phone as older carers are not on the internet. Clear information in straight forward English. Simpler covers assessments - some carers don't know they entitled to an assessment of their own needs
- More consistent timing of visits from my wife's professional carers
- I enjoyed the day out at Dillington with various courses/discussions with other local cares - none of whom I knew beforehand. That was some years ago! It made me proud of what Somerset does for carers to know the range of help available
- Maybe for shy, low confidence people who don't enjoy mixing with a lot of people, a local to their area website where they can chat online or on a forum. By having a Carers Card- a credit card type card to carry in wallet/purse. If the carer carrying it has an accident there is a number on it which when called can give details of who and where the person the carers looks after is. There is a scheme in South Devon which works well, the card also allows discounts in shops. I think it was like a database of all carers that way no-one is left without the help they need and the carer knows that if any accident occurred the person they care for would be attended to, thus alleviating both parties worry. Also everyone's address in one place , there could be carers newsletters sent out highlighting government changes, things of interest, up and coming events for carers etc
• Carers to be treated as if what they do is important. To be valued and treated with respect.
Government to realise how cheap we cost the system! Even professional paid carers are looked down on with a poor salary scale and little chance for training, improvement qualification. More respite care or care in house to enable carer to have a break. Increase in amount paid in Carers Allowance, Increase in minimum amount you’re allowed to earn part time
• Mot sure - not really informed enough to give an opinion
• When I went on a course St Johns Ambulance in Minehead the stuff they were teaching was for people over 60 year old. My wife is 51 and there was not much for her to do and there’s nothing in Minehead for people with MS - nothing at all
• More help when we ask for it. More understanding by all people. taking notice of what we say and what we need
• I am sure there are many people coping with a family member or neighbour who have no idea there is a support network available to them. The focus seems to be on the "cared for" rather than the Carer. I feel each individual's circumstances and problems should be a matter for the whole "group" of members the support encompasses - Care workers, Family GP, Social Workers, Benefit Officers etc so the best plan of action is in place from the onset of care and everyone is aware the best has been put in place. It is important for the carer to know their contribution is acknowledged as part of the "cared for's wellbein
• More help needed when carer is ill
• I have been on very beneficial courses - St John and others. But nothing helps with the grief of losing your husband to mental impairment, I am now starting Counselling through GPs arranging and hope this will help. A course based in this loss and grief would be good
• My constant daily concern and worry is what would happen to my adult daughter when I have gone. I need somewhere to go to where I can organise a plan or advise. As my daughter is vulnerable I need to know who can be available to help her
• Very good support right from husband leaving hospital - almost too much information at once. St Johns events very helpful
• I personally feel that the whole carers/cared for system is fractured. Far too much information from too many sources and choice paralysis. Cares are, in my experience a stressed bunch of people. I would like to see one central office not 101 offices where you just get passed from one to the other and come out the other end no better off and feeling more stressed and frustrated. I could not claim financial help without it affecting my own already strained finances. We even went to a tribunal to get my "Cared for" DLA increased, it was turned down because I'm in his life and help even though I have my own life. I came away feeling angry and incredibly sad but also guilty for feeling that way
• More support from government who seem not to have any idea the problems carers and support workers have. there in my opinion should be a specialised minister for Carers and those cared for needs. here in Somerset we are well catered for but I believe this is not a widespread service throughout the country, so it should be the same no matter where you live
• I get good support from my Carers Support Workers and Social Workers
• There should be a central point where you can get all the facts and figures
• At the moment I am highly satisfied with information and the support I receive. However, I would appreciate help with housework without having to pay for it. I am hoping our fortnightly support group meeting at Robin Close, Bishops Hill will continue. These meetings are invaluable in that we share problems and receive information in a friendly atmosphere
• I was a carer for my father who has since died. I am also a carer for my husband who has suffered hip replacement, knee replacement, suffers with leg ulcers and is now type 2 diabetic
• Emotional and moral support ie talk therapy and listening at times of crisis, like admission to hospital or nursing home. Opportunities to explore the impact of patients condition on family and friends network
• Doctors should be giving carers advice, where to look for groups. I did not know groups or help existed. Social workers should listen to carers needs. Councils should not make you wait 6-9 months for decisions on major equipment
• To receive more support and information when a patient is first diagnosed and is recognised as needing a carer. That choices of help etc are clearly and fully explained. Respite care should be discussed more fully and not just mentioned vaguely. Lists of nursing homes, their approx charges and their suitability of nursing care for a patient's particular needs should be much more readily available from Adult Social Care Workers. I firmly believe that Somerset has an excellent standard of support and services available for carers but in some cases these services are not always made known in the early days of a patient's illness (or diagnosis) when carers and floundering and stressed. Maybe surgeries should be pointing carers in the right direction

• I am sure there are many carers like myself who have ongoing medical problems who would welcome occasional help when needed

• I could do with more money when daughter is in hospital not less and more support from GP

• I have an advantage in that I am involved with CAB as a volunteer and work as part time paid welfare benefits adviser. However, I know that many parents/carers are not fully aware of the benefits available or the implications of respite care and temporary loss of entitlement. I am also chair of Frome MENCAP

• I cared for my husband who has severe vascular dementia for approx 5 yrs but he is now being cared for in St Benedict's Nursing Home in Glastonbury. The help and support I received from Somerset Care and Somerset County Council was excellent I felt supported during the most difficult time in the last few years with me when he needed 24hr care. Social worker David Pope is still involved and supports me for the first 6 months of his care in the home

• I have not been able to have any carer support/counselling etc because I work and they aren't available in out of work hours. Perhaps this could be made available evenings or weekends. My only contact came when I didn't really know what would be needed. In the early days when I didn't know what life would be like perhaps contact could be made with carers at regular intervals

• Being able to understand and manage Tom's behaviour. Talk to other parents who have same problems as Tom

• In our professional life my husband and I own/run residential homes for young adults with learning difficulties. When our daughter was born 14 years ago with cerebral palsy we simply "got on with it". Any help/support we receive we go through osteopath, homeopath and kinesiology which of course we pay for privately

• Professionals need to listen to carers whether or not those cared for have agreed to include carers in information sharing. No professional can fully and effectively respond to needs of users without hearing the "inner story" assuming there care relatives/carers at all

• It would be useful to have a list of help - I know there is a big book but until the problem is diagnosed you do not know where to go. My son is dyslexic - it was not identified by the system. We had to work very hard to get a diagnosis as well as an assessment and the n a statement and then the necessary school. All this added to the whole family stress. It seems to be a battle. Once this was achieved outside support like Educational Psychologist and CAMS were "Closed"- that is the child's file was closed - I still need help!

• I do not live with my father and am only able to visit him approx once a fortnight due to working fulltime. so I am classed as a part time carer, making sure that all the necessary services run smoothly to enable dad to stay in his own home which is what he desperately wants to do. Although I am unable to visit very often I speak to dad once a day during the week and twice morning and evening at weekends

• Carers need to be listen to when being bullied in their community. Police should listen more as there have been problems with this in some areas and have led to suicides

• A main telephone number for Carers to call to get info on places to get help with everything instead of having to take multiple phone calls and be passed around from pillar to post and for the people you do speak to to have up to date knowledge or be willing to find out and not be given wrong info or feel like you get nowhere
• I think that on a diagnosis of illness/condition, the family/individual should be contacted by support worker a short time after. It was good having an information pack but when you are trying to come to terms with a diagnosis there is a lot to take in. If someone called and explained the services you would not feel so alone. My son had a diagnosis of Autistic Spectrum Disorder 3 years ago and I, only just finding out about services available, partly my fault because I battled alone. I still feel alone and I know support is out there, but when things are hard it is not always easy to ask for help. It is easier to accept help if offered.

• Carers Forum - not run by any council employee. Social worker dedicated to user not on a McDonalds menu basis. Openness and frankness about outside services available. They are hidden on grounds of costs. A little knowledge about the rights of individuals by SCC employees would be good

• You don't listen to us - so we end up not bothering to even ask!

• Information needs to be easily obtainable, One person who understands the situation and can give unbiased advice

• We have a Carers meeting every month. I as a carer am not happy because the person who I care for sees someone every week. This person sees people 4 to 5 times a month and the person I care for sees 4 people a week. I as a carer meet the carers group once a month which I think should have a meeting at least 2 times a month or more. It's a lonely job looking after someone but I need to see people as well

• Local Carers Group lacked a leader for months, this was shameful - now installed, however too late for me. The only close, but until recently, partnership mental team was helpful. The fact that Direct Payment Benefit was kept (in my opinion) a secret until another carer told me is disgraceful; again too late. It seems to be that if one doesn’t complain and do not badger help/advice comes late, especially if one attempts to be independent. The partnership contacts gave best advice and help and found a very good day centre. this year NHS Continence Service provided great help. My husband is now going into Care Home

• My wife and I are grateful for past help with past amendments to our home, such as stairlift and bathroom alterations. Also we are helped with financial expenses with disability allowances. Mendip Care and Repair Ltd have improved our life style and their support is very much appreciated by us both. Thank you.

• We have a very good support service

• Would like to be able to ring GP for appointment on day I ring. Not always able to attend appointments made for future dates due to daughter’s health and care needs. Local regular carers support groups. Local daytime activities for “cared for” people on flexible drop-in basis

• A central place/person for information and signposting. Extended reduced fee counselling - things are always changing for me and I would like to keep talking it through so I can keep growing. Some form of Carers ID for requesting concessions. Concessions at leisure activities eg Somerset Skills and Learning Courses

• Someone to talk to

• My elderly mother attends day centre at Greenhills Cheddar. I’ve tried to arrange a 2 week respite in there and I gave months of notice. When I phoned to check I was told no vacancy - go to Eileen Sydenham House, Bridgwater or Croft House, Williton, My mother would only consider the place she is familiar with. Consequently we had no break

• I would like to see more training for Doctors etc so that they are able to pick up on a mental disorder or autism quicker than they are just now. Some carers who are parents, their opinions are disregarded because their child is an adult by age but not necessarily by behaviour. We need to be listened to and believed when describing the true situation with the person concerned

• A meeting for carers with the people they care for - a small group locally. Chaired by a support worker or social worker so difficult issues can be raised (eg things that are not normally addressed by the carer and the person they care for) eg lack of privacy (for the carer), loss of earnings, the need for respite which in my case my mother has to be prepared to fund

• I am an unpaid carer for my wife
• It would help if there was somewhere a dependant with early onset could go without their carer needing to be with them. I would like a regular day off from my husband. A club or activity centre suitable for someone with moderate dementia but has poor attention span.

• Regular calls from Carers Support Worker even if only once a year to check how things are going.

• Even though not everyone would answer to this questionnaire I think a higher volume should be sent out to enable a better response. The title "Support for Carers" would stand out clearer.

• It would be useful for me to talk to somebody but if I try to ring I get an ansaphone and nobody gets back to you. The systems are there but they don’t work because after the initial interviews you are forgotten and left to fend for yourself. I am at present trying to get a loo seat and "armchair users" this is like banging my head against a brick wall. I have today spoken to my mother's GP and I've got an appointment for her to be assessed 7th Dec. She is driving me and herself mad now!

• Perhaps as soon as the need for caring has been recognised - GP referral - information booklet (simple). D/N referral - self referral to Social Services. Time with a support worker perhaps either daily or 3x weekly as a confidant and assist in care planning until conditions are stable. Also frequent follow ups. My husband is in care after my wrist operation but how do I cope with verbal abuse?

• Somerset does this bit well already

• I did not always find carers allowance department helpful

• As an ex carer I had 2 hours to myself on a Tuesday, another 2 hours on a Friday, this I paid for privately. Often when I needed to talk to someone they were not always available on these days. I could not leave my wife on her own. I saw Social Workers when my wife was sectioned, a day I will never forget. Two burly policemen handcuffed her and took her to an ambulance shouting and screaming. She was taken to a hospital where she stayed for 5 months. I constantly complained about her treatment there, she was later moved to a care home where she died. Had I had more help at home I could have kept my wife at home longer. Lord Lipsey (so called expert) said on the TV the other day "severe dementia patients should go into residential homes". I live in Minehead, Somerset - it would have been nice if my wife had gone into a home in Minehead. I had to travel 50 miles round trip every day to see my wife, Lipsey should get his facts right because severe patients won’t be taken into residential homes

• Satisfied with care given

• There are so many things I did not know until I attended St John's Course eg did not know I should be registered with my GP as a carer therefore eligible for flu jabs. I am sure many people are unaware of benefits available - perhaps as soon as GPs know a patient has a condition which requires a carer then some sort of action should be set in motion so that other people do not lose out as we have done

• Let MPs spend a reasonable amount of time acting as a carer of a person that required 24/7 care (under supervision of course!). maybe just enough they will understand the unpaid service given to the country by people (the majority) who have worked all their lives and paid very heavy taxes (direct and indirect). Where is the NHS promise from cradle to grave

• I feel it is very important for young carers to be supported

• Just to maybe have some people/person visit the carer as he/she may feel she can't get out or leave the person caring for

• An improved attitude by other agencies apart from CAW who is very supportive indeed for the stress of emotional caring for a relative who is in the main part within a care service

• Tell them what support is available

• I have been left for 8 years supporting and caring for my husband after a head injury at work which left him with depression. No one discussed with me the severity of his illness or ways that I can cope with it. He spent a month in Bracken House but they didn’t say why

• We receive excellent care
Most carers of the elderly are sons and primarily daughters. This generation is now having to work until into their 60s. One, becomes "the jam in the sandwich" with ageing parents and grandchildren who need caring for because both their parents are also working. My salary - as a teacher dropped by £6,000 a year so I could look after my mother's very basic needs - NOT caring for her as I would have liked. I never seemed to keep all the plates spinning in the air and this affected my health also. I have to work as my husband has a deteriorating disease. An awareness of these situations for carers would help greatly and a financially fairer situation - as in Scotland which my mother is paying for from her taxes.

They are not all old some are mothers some are children and support should be funded for these people appropriate to age. Seems alot of events are for older people caring for elderly relatives.

We are self-funding. Some professionals seem to think they cannot talk to us although I understand we are entitled to information. It took me a long time to find out about the CC sitting service. I had been given the impression that there was no one available to do the sits and then the Social Worker who came to tell me about it was learning about it with me. So - maybe your staff need to be made more aware of what is available. I would like to have 24hr live in care for my husband so that I could take a short break 1 or 2 times a year. Two agencies offered minimum 2 weeks at a cost equal to residential care home but I would be paying for heating, food, laundry etc - not viable.

It would be nice to know that there was a minimum entitlement - Financial support, time off/respite and access to helpful information (eg holidays, for self and/or self and partner), equipment/aids, training for handling etc. At present unless you are "in the loop" it can be very hit and miss whether you find everything you need. To date my best source of information and often support is other carers.

Regular contact as there has been none

I find it quite stressful but feel guilty off loading onto other people even though I know there are helplines out there for this purpose.

This is an impossible question as ALL caring situations are different. It is imperative for a social worker to be able to ask the right questions. Fortunately ours, Diane Murphy, is very good. NB Many people are so much on the defensive that it is difficult to break through to know where to begin to help.

They keep up the good work

Sorry - I'm too tired

Much clearer information on what is available and what we are entitled to. many things we didn't find out for years and consequently spent our own money eg free prescriptions - paid for these for about 4 years before we found out. Wheelchair - we bought 2 before we knew we could get them for free. Direct payments - wish we'd known about this a couple of years before we did. Only got them when we were at breaking point. Training – We rely on our employees to tell us things eg how to use hoist.

It may be useful to have scope to pursue opportunities within social field to seek employment and enhance abilities. "Payment to carers" = being carer is a job 24/7 there needs to be some scale grading linked to competencies and CBCW work and the length and level of commitment as a carer, this may attract more carers as this will also encourage carers to look upon this as a career rather than just for the money. It would also ensure a high level of expertise in areas where you may identify champions.

We are like many other elderly couples who care for one another and who try to manage and be independent and do not get any recognition. I am on mobility and have blue badge for parking as we use the car to get shopping etc. So I feel that there are many couples like ourselves and we do not get any support. We put in for Carers Allowance but were turned down because of my pension, like a lot of other couples we know

Make to top boss at the DWP do our job for a month at £55 per week for 35-168 hours a week and then we might get somewhere. In our dreams.

One did enjoy the carers day at Blagdon on the 2nd Nov 09. It was a treat and very very well organised. It ran from 10 until 3.30. Crossroads sitter was arranged and transport provided. Excellent.
• Availability of info for carers of who to contact re cared person for benefits, carers groups, doctors, how to contact your social worker, respite care, help in the home etc. Who carer can contact for support and help for themselves ie organisations, other carers - locally via meetings, telephone. Local workshops or regular meetings for carers to talk. Get a local register togerher of carers via local councils/parish councils. Local Carers courses available for carers to attend. Making courses known to carers - "government's pot" available with money to give to carers if they are told how and where to apply. Or given Food tokens/vouchers given to carers to use in shops or petrol.

• Help them get together in condition specific groups to offer mutual support
• All carers should be told what help is available
• At local doctors surgery it would be good to have one of the nurses designated to have special responsibilities for the carers in the practice, checking up on them, Then carers would not reach breaking point without somebody being aware
• Home visits from somebody to offer physical and emotional support for me as a carer
• More information should be available at Doctor's surgeries as they are the first point of contact for carers. I had to ask - the service was not freely offered. I guess that's a money issue.
• Offer more activities for special needs children, fun days for family. Trips for siblings who are carers so they can have fun without pressure. Courses to help mothers and fathers, grans and grandads to cope with special needs so that families aren't torn apart
• Workers given time to listen and advocate on behalf of us. not having repeat myself all time to different workers / teams ... I was busy caring - Direct work when needed in crisis, help when leaving hospital not just left to manage eg manual handling ( no offer of help lifting etc ) . Time out break if dads illness had been longer.
• More contact with Carer support worker - perhaps 3-6 monthly appointment. To make aware of extra support and plan for future. Helping to understand and accept progression of dementia and support to avoid crisis situations

Q 22. What is your ethnic background?

Other Ethnicity (please state)

None

Q 29. To help us know the best way to reach carers please indicate where you received this questionnaire from:

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<td>NHS</td>
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<td>Jackie Murphy - Carers Assessment Worker</td>
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<td>BBC Somerset Web Site</td>
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<td>Mencap AGM</td>
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<td>Somerset Direct Carers</td>
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<td>Brunel Care</td>
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<td>Frequency</td>
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<td>---------------------------------------------------------------------------</td>
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<td>Kate Wood</td>
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<td>CAW David Bobbett</td>
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<td>From the local press</td>
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<td>I saw a link in the Chard &amp; Ilminster paper.</td>
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<tr>
<td>Internet</td>
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<tr>
<td>Liz Pooley Carers Group</td>
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<td>Mencap District Meeting held in Pilton, Somerset</td>
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<tr>
<td>Mencap meeting for carers</td>
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<tr>
<td>My helper Jackie</td>
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<td>My team leader</td>
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<td>Peter Fletcher</td>
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<td>Taunton Deane</td>
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<tr>
<td>Through door</td>
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<tr>
<td>Through the paper and post</td>
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<tr>
<td>Windows Carers Group Co-ordinator</td>
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# Somerset Young Carers Questionnaire

## 1. Do you have a sick relative?

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## 2. If you need help, would you know how to find it?

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## 3. Have you heard of the young carers service and what they do?

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<tr>
<td>Count</td>
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## 4. Do you think you are listened to?

<table>
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<th></th>
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<td>25.0%</td>
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<tr>
<td>Count</td>
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## 5. Do you need someone to talk to?

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## 6. How can we improve getting information out?

- 87.5% (14) gave qualitative responses to this question

## 7. What ideas do you have to improve things for younger carers?

- 75.0% (12) gave qualitative responses to this question
Somerset Young Carers Questionnaire

Q6. How can we improve getting information out?

- Sending a monthly newsletter to all young carers about different activities and how other young carers cope with life
- Send out leaflets telling people the important information
- Advertisement - through schools and clubs etc. Make to apparent that help is available
- Use some time to ask every person some questions and see if they need to tell the boss or the higher authority
- The service Charlotte receives is fantastic, and they even give us advice on how to explain why her dad is ill as he has a mental illness
- Letters do not always come on time and sometimes one member gets invited to carer’s trips but not the others even though they are in the same group. Could do the odd talk in schools which would let children know of this service as sometimes you do not talk of being a carer or help a relative so you do not know of Young Carers Organisation
- Even though I haven’t been for a while I still manage to get information about events so I think it is quite good already
- Newsletter for YC - for info and to share ideas
- Going on more trips, Letters more interesting
- Posters, Tent info
- Fortnightly information not a term programme
- Newsletter with carers info
- Ask clearer questions on the questionnaire
- Ask clearer questions in the questionnaire

Q7. What ideas do you have to improve things for younger carers?

- Lots of get togethers eg cinema, a craft day, swimming, meeting at a cafe for a chat together. A day out on a farm
- None - it’s perfect
- Counselling, Help caring. Help for parents
- If they are having problems (like with homework) try to give them time during carers club or anytime to do the homework with somebody else maybe helping them
- None - it’s fantastic. Couldn’t ask for any more
- Keep informed of help and fun things regularly. Listen to what we want to do as well as your ideas. Do not treat us older ones as little kids. Meeting others in same situation does help however ad we are glad of what you do for us
- I don’t really have any, sorry
- All YC in Somerset got together
- More trips
- To have a break from caring
- Make it more accessible to all age groups
- Do more interesting stuff and go on good trips
Asperger’s Carers Survey Results

Q1. What currently works well?

- I gave up full time work to look after my son who is autistic as there is no care available near me. He is now 18 years old.
- One weekend a month is ideal. We can do activities our son does not enjoy but our other 2 children do.
- Agency Plus, Bridgwater - helpful Polish woman.
- My son David Kidd attends the Six Acres Resources Centre from Monday to Friday each week: he is picked up by minibus at our gate. He also usually stays at the Oak respite unit one week in four which he looks forward to. We have lived in Somerset now since 1977 during which time he first attended at the Obidge unit until Six Acres opened, so we have been well served for his needs all that time.
- The understanding and positive approach of the local Service Manager and our Carer Support Worker - unfortunately they cannot influence what does not work well.
- With a statement in place, we now have the provision of need in place for our son's education. We didn't really want to do this initially as we thought it wouldn't be necessary but unfortunately it proved not to be the case for us.
- Having direct contact with the Asperger Consultation and Assessment team in Bridgwater and especially with Julia Counsell. Also the voluntary job my daughter has working with dogs.
- We receive 7 hours per week respite care.
- Since my son Phil was diagnosed at 21 years, he now receives benefits as he is unable to work, which takes the pressure off a bit financially.
- Asperger's Peer Group Monthly Meetings.

Q2. What works not so well?

- You seem to be forgotten about if you don't need help all the time, it seems to be all or nothing.
- There is not much during the long summer holidays - more respite days or breaks would be nice.
- Training schemes with no future.
- The fact that our daughter's consultant and support worker are not trained in her condition and admit it! The consultant admits in writing that he is not trained in pervasive developmental disorders and not known for a specific interest in them!
- The non-listening approach which Somerset County Council had when we kept voicing our concerns. We would have preferred an open dialogue meeting with them to thrash out ideas/options etc, but we ended up at a tribunal.
- Having Social Workers or Support Workers not knowing how to treat as AS person or individual. I feel they need to be TRAINED before being assigned as AS person.
- The carer (respite) not always available. I would like to live in Draycolt independently but able to walk home every day for meals and washing etc, but can't afford to rent and needs to live alone.
- Wouldn't know - no services used.

Q3. What are the gaps?

- At the moment he is going to full time college but I am worried what will happen after
- School holidays
- The need for parents to be able to speak to professionals of adult problems. Financial problems ie. Overpayment of benefits and recovery of debt
- The problems of adult Aspergers who are married with children
- I feel we have been very lucky over the years and I am grateful to all the staff, the very caring social worker (Paul Best who has known David for many years). All their support has been great - long may in continue!
- The teams change often and there seems to be poor communication and records. The team in 05-07 was good but the following team seemed to have no continuity at all
- Not really sure yet, but have been warned by other parents that when your child reaches the age of 19 it gets REALLY tricky - as if it wasn't already!
- Not having trained staff. Not having a support worker staying for a long time. AS people do not like changes as it breaks down the security barrier around them and they feel vulnerable
- Not enough support
- Not enough places to go in a safe, secure environment
- More knowledgeable carers (specifically autism taught)
- Help to find local accommodation and internet work he could try from home.
- We are offered no support whatsoever

**Q4. What could be improved?**

- More after care when they are adults.
- Perhaps a "summer camp" style break for the children
- Adult employment issues. Only 6% of Aspergers have full time employment (ref: Martin Doyle/handout)
- An insistence on training for those of the "old school". It seems training is currently on an "if you want it" basis. Also records are pool. My daughter's records start at 2000 but she was visited by the Trust in 1997
- Communication with parents/open discussion dialogue rather than 2 parties ending up in costly tribunals. Time to sit round the table and discuss openly
- More training for staff. Listen to parents or carers of the AS person as they know what they are like having to live with the AS person.
- More hours of respite. More day centres or places where my autistic son could stay if need be. Overnight accommodation
- Only a change in Phil himself, he is quiet and intelligent, doesn't mix and wouldn't attend meetings or social outings.
- Everything!

_NB: As this appendix shows an overview analysis the figures do not include the people who did not answer the questions whereas the main report does include the ‘no replies’ consequently the numbers and percentages may differ slightly from those in the main report._
## Appendix 3: Somerset Carers Review - Carers Panels Themes/Questions for discussion

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<thead>
<tr>
<th>Applicable to:</th>
<th>Theme</th>
<th>Notes</th>
</tr>
</thead>
</table>
| Somerset Direct | **Information** | - What information do you routinely make available to carers and in what format?  
- How easily accessible is this and how do carers find this? How is it publicised?  
- Are there any opportunities to employ carers |
| All | **Accessibility** | - How accessible are your services outside normal working hours?  
- Are there proposals to extend your service  
- How flexible are the services you offer? |
| | **Assessment** | - Do you routinely ask about carers own needs and how do you respond to that? |
| | **General** | - What are the gaps / what improvements are needed |

*Updated by carers participating in panels on 3/11/09*
<table>
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<tr>
<th>Commissioners/Community Teams/Community health /Community Support Workers/Community Assessment workers</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How proactive are you in contacting carers about their needs?</td>
<td></td>
</tr>
<tr>
<td>• Have you considered the implications of being proactive in reaching hidden carers and how will you deal with the possible increases in demand in the light of resource restrictions?</td>
<td></td>
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</table>

<table>
<thead>
<tr>
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<th>Identifying carers needs/Carers assessments</th>
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<tbody>
<tr>
<td>• Who do you think should be involved in undertaking carer’s assessments?</td>
<td></td>
</tr>
<tr>
<td>• Is there the right balance between assessment and support available?</td>
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<table>
<thead>
<tr>
<th>Support</th>
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</thead>
<tbody>
<tr>
<td>• What should be included in a minimum offer to carers and how do you see this differing from existing arrangements?</td>
</tr>
<tr>
<td>• How do you think individual budgets will impact upon carers?</td>
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<table>
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<tr>
<th>Advocacy</th>
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<tr>
<td>• Do you think there is a need for advocacy service on behalf of some of the carers?</td>
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<tr>
<th>General</th>
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<tr>
<td>• What are the gaps / what improvements are needed</td>
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Updated by carers participating in panels on 3/11/09
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<tr>
<th>Commissioners</th>
<th>Strategy</th>
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<tr>
<td></td>
<td>• How can engagement with carers be improved developed?</td>
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<td>• What is a “user and carer hub” as described in the Somerset carers strategy?</td>
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<td>• Are the resources available more than stated in the Somerset Carers strategy?</td>
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<td>• How does transport figure within the Carers strategy?</td>
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<tr>
<th>All</th>
<th>Recognition</th>
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<tr>
<td></td>
<td>• How do you ensure that carer’s needs are recognised within your service?</td>
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<td>• What form does recognition take? E.g. payment /other?</td>
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<td>• How does a carer get equal recognition?</td>
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<th>Training /Managing the diagnosis/condition</th>
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<td>• What information/support/training do you provide for carers which is general and/or condition specific? (also medication and side effects?)</td>
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<td>• What are the gaps in training for Carers and for staff?</td>
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<td></td>
<td>• Are there any opportunities to employ carers in a voluntary or paid capacity as an expert, trainer or support role for other carers or for raising</td>
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Updated by carers participating in panels on 3/11/09
Somerset Carers Review

Interview proforma and requests for additional information post questionnaire distribution

Peter Fletcher Associates have been asked by Somerset County Council and NHS Somerset to undertake a comprehensive review of carers services. The review aims to find out what carers think of current services available, what support they would like to see available to enable recommendations to be made about future services. If you are a carer or your organisation provides support for carers then we would really appreciate if you could take a few moments to complete these six questions:

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<thead>
<tr>
<th>What in the current system works well?</th>
<th>What works not so well?</th>
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<th>What are the gaps?</th>
<th>What could be improved?</th>
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<th>Other Comments</th>
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Feedback on the results of questionnaires and consultation process will be provided at a series of stakeholder events in Feb/March 2010 – for further details see flyer attached

Thank you, Peter Fletcher Associates

Updated by carers participating in panels on 3/11/09
Somerset Carers Review
Evidence and Innovative Practice examples
## Somerset Carers Review
### Evidence and Innovative Practice examples

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1. Introduction

The Project Initiation Document for the Somerset Carer’s Review requested that the review compare services provided by other Local Authorities with a similar demography to that of Somerset, highlighting opportunities to ‘share best practice. A national search was to be carried out to identify models of good practice with a particular focus on:

- Innovative commissioning across health and social care
- Innovative services for carers

The search was to cover all age groups and where possible to identify value for money aspects and links to personalisation.

Although the amount of material published regarding new models of service provision is considerable, good research evidence and evaluation studies of these models are much less prevalent. Each section below will include a brief introductory overview of the evidence base available referencing a number of recent reviews of evidence followed by relevant good practice suggestions and/or promising service models. The recent report “Carers at the heart of 21st century families and communities” (2008) sets out the Government’s vision and lists a number of case studies for each of its themes and these will on occasion be duplicated here where they appear particularly noteworthy and relevant to Somerset’s demography. However, on the whole the intention has been to find different best practice examples in order to supplement this existing resource.
2. Commissioning

The Princess Royal Trust for Carers and Crossroads have just published two related commissioning guides in collaboration with ADASS, NHS Confederation, LGA, SCIE and the third sector for local health and social care commissioners. It complements the World Class Commissioning framework and includes information on the Carers’ Strategy as well as the wider policy context. They can be downloaded from the web addresses below.

1. Commissioning for Carers
   http://www.idea.gov.uk/idk/aio/13295634
   http://www.idea.gov.uk/idk/aio/13295835

Devon case study

In a national assessment (world class commissioning), they have chosen to have their performance as a commissioning organisation judged in part on their commissioning approach for carers.1 See Carers in Devon Commissioning Strategy Bulletins No 1 and 2 which can be found at http://www.devon.gov.uk/index/socialcarehealth/carers.htm
These bulletins are very descriptive of their overall approach including use of research evidence, interagency commissioning and consultation with carers.

Contact: Clare Cotter
Joint Planning & Strategic Commissioning Manager - Carers
01392 267860 clare.cotter@nhs.net

Hertfordshire case study

Gaining feedback on commissioning strategies is vital. In partnership with Carers UK the four Beacon councils for supporting carers (Hertfordshire, Rochdale, Sefton and Sunderland) have produced a questionnaire for carer feedback to support outcomes focused assessment. This tool is designed to make it easier for any authority that does not already have a routine process for getting carer feedback. The aim is that a questionnaire like this may one day form the basis of a national measure of how local authorities are delivering actual outcomes, rather than simply measuring processes. Some authorities are already beginning to use this questionnaire. http://beacons.idea.gov.uk/idk/core/page.do?pagId=6283626
They have also produced a balanced scorecard. This tool is designed to assist authorities in identifying how their carers’ strategies are delivering on the seven strategic outcomes of the White Paper. It will also give a structure for discussions with business relationship managers on these issues. The tool is available at http://www.beacons.idea.gov.uk/idk/core/page.do?pagId=6283626

Lancashire - Commissioning Short breaks case study
In Lancashire the council has established a list of domiciliary providers with evaluations based on the essential requirements and standard 2 (short breaks) in the King’s Fund document “How Good is Your Service to Carers?”. The chair and deputy chair of the Lancashire carers' forum were involved in the evaluation process which determined whether providers would be accepted onto the list. Only providers who are on the Carers Quality list are invited to tender for specialist domiciliary short break contracts, thus providing an incentive for continuous improvement and ensuring a carers focused service is delivered. All tender panels for carers’ support or breaks services now include carer representation.

2.1 Direct payments

The Carers UK survey of carers’ experiences of direct payments, Choice or Chore? (2008) identified the following 8 lessons for local authorities:

1. **Speed up the application process**
   Cut waiting times and simplify the assessment process. 1 in 4 carers waited more than a year from making an enquiry to getting their payment set up.

2. **Make it a real choice**
   Direct payments are not right for every care situation and no one should feel pressured into accepting them. This is enshrined in government guidance and councils should follow it.

3. **Provide employment support**
   Local authorities should commission, and signpost direct payment users on to third party support organisations who can manage functions like payroll. It is essential that good practice is shared between local authorities, see good practice example below.

**Ayrshire Independent Living Network case study**

*What does it provide for direct payment users?*

**Payroll Service:** works out tax, NI and staff wages, and the individual pay of the employees themselves. They charge £20.50 per month from the direct payment for this support, regardless of the number of employees.

**Training for direct payment users as employers in employment law:** can do training on a one to one basis and go to the person’s home to do it, or they or source training from Scottish PA Employers’ Network.

**Support PA recruitment:** advertising, posters, interviewing support, enhanced disclosures, references, send out forms before interviews, source free interview premises, termination/offer letters.

**Employment support:** provide contracts of employment, sorting out specific problems with members of staff as intermediaries in disputes, ensuring they have proper employers’ liability insurance. AILN go to the carer’s home, go through paperwork and talk them through it.

**How much do users pay?** £20.50 a month for payroll, rest of the support listed
above is free.

**How do direct payment users hear about it?** Mostly referrals from LA or the local hospital.

**How many people do they practically support?** Currently they provide payroll support to 140-170 users.

**Structure & Staff:** registered as a charity, user-led, run by a committee of disabled people, many of whom are direct payment users. Employ a full time direct payment Support Worker and two part time Payroll Officers, a management committee and volunteers.

**Contact:**
Ayrshire Independent Living Network, Independent Living Services, Pavilion 9, Ayrshire Central Hospital Irvine, Ayrshire KA12 8SS Tel: 01294 272260 Fax: 01294 311528 Email: mail@ailn.org

4. **Make sure all costs are covered**
   1 in 5 direct payment users were unable to buy all the hours that they had been assessed as needing. Local authorities must monitor direct payments to ensure that the cash awarded is sufficient to cover assessed hours. They should make sure that factors like high travel expenses in rural areas are taken into account.

5. **Allow families to employ family members**
   45% were employing a family member and comments from carers were clear how much this was valued. Whilst some local authorities have a relaxed approach to the rules around exceptional circumstances, others interpret them more strictly.

6. **Don’t back off, back up**
   Local authorities should have appropriate back up and contingency plans in place before a carer is required to manage the direct payment independently. Families should not be abandoned but should be reassured through regular contact.

7. **Value carers’ administrative support**
   Local authorities need to do more to financially recognise the administrative burden on carers. They should implement a fair rate of administrative compensation for time spent on administration such as payroll. They should also give carers training on managing direct payments at the earliest opportunity.

8. **Keep commissioning highly specialist services**
   Families miss out on vital support because they cannot find the right specialist services to buy with their direct payments. Even with a direct payment, local authorities still have responsibility for ensuring the needs are met so they must continue to commission and provide specialist services.
2.2 Individual Budgets

The Individual budgets evaluation network produced the following summary report regarding the evaluation of the impact on carers.

The Individual Budgets Pilot Projects: Impact and Outcomes for Carers

Individual Budgets (IBs), piloted in 13 English local authorities, aimed to give greater flexibility, choice and control. Although primarily intended to benefit chronically sick, disabled and older people, IBs could also be expected to affect carers. This study investigated the impact of IBs on carers in terms of assessment, support planning, costs and outcomes.

Key Findings:

- When carers of people with IBs were compared with carers of people using conventional services, IBs were significantly associated with positive impacts on carers' reported quality of life and, when other factors were taken into account, with social care outcomes. Positive outcomes for carers partly reflected being more able to engage in activities of their choice.
- Carers’ satisfaction with service users’ support planning was an important predictor of carer outcomes. IBs assessment and support planning offered more opportunities for carers’ involvement than conventional social care practice.
- Compared with carers of people with learning difficulties, carers of older people were particularly likely to appreciate holistic, family-based IBs approaches that took account of their roles.
- There was no statistically significant difference between the costs of IBs and conventional services, nor in the time spent. Better outcomes at no higher cost suggests IBs for service users may be cost-effective for carers.
- The 13 pilot sites varied in how help from carers was treated in service users' IB assessments. Especially early in implementation, carers’ own needs risked being overlooked. Where carers’ needs were included in IB assessments, this did not always comply with current legislation giving carers rights to assessments of their own needs.
- Sites also varied in how help from carers was treated in calculating the monetary value of service users' IBs. Typically IB amounts were lower if help from carers was taken into account. Only one site developed separate IB assessments and payments for carers.
- Only a minority of carers received any payment from service users' IBs. This was always far lower than the value of the help they actually gave. Local authority officers had very mixed views about paying carers from service users’ IBs.

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The study “also revealed some issues which need addressing at both policy and practice levels as personalisation in social care is rolled out more widely. First, there is evidence of inconsistent practice in relation to different groups of carers – this inconsistency may extend beyond the carers of older people and learning disabled people who were the main focus of this study. There is a need for clearer guidance for carers who take responsibility for managing an IB on how and what this can be used for. And there is a need for greater clarity and consistency on how far carers can be paid from the IB of a service user; the conditions (such as employment contracts) that should be attached to such payments; and the interactions between such payments and carers’ entitlements to social security and other benefits.2”

2 Ibid
3. Innovative Services for Carers

3.1 Duty to inform carers of the right to assessment

Key research and policy findings:

**SCIE Carers Act Implementation guide 9**
Information needs to be provided in a more systematic way. The impact of information strategies needs to be assessed.

**A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence** (Victor, 2009)
Carers tended to be satisfied with information services. There was weak evidence that information-based services improved carers’ knowledge of and uptake of services. There was also weak evidence from one study that the outcomes of information services may not go so far as to include making carers feel more empowered in their contact with service providers.

Potential mechanisms underlying the achievement of outcomes by information services suggested by the evidence included helping carers to feel less alone and that backup support was available if necessary, as well as providing access to the resources offered by services.

There was some evidence that the following contexts may influence the outcomes of information services: the extent, relevance and layout of information; staff manner; staff follow through and resolution of queries; ease of access to the service; and the helpfulness of the services to which carers are referred. These findings were tentative as each was only supported by one study and tended to involve relatively small numbers of carers.

Ideas for Practice

**Surrey case study**
Local partnerships in Surrey have set up a website to provide information for both carers and professionals. It hosts Care Radio, an internet radio station for carers, and is also linked to the national website run by Carers.

**Sunderland case study**
In Sunderland, a multi-agency approach to planning events for Carers' Week and Carers' Rights Day has ensured good local publicity.

Many local authorities have set up one-stop shops that are able to offer information on a range of services and benefits. Staff who have first contact with customers are able to ask them if they have caring responsibilities. However, one-stop shops may work less well in rural areas.
Devon case study
All referrals in Devon, including all first-contact details are taken through Care Direct. When appropriate, callers will be asked if they have a carer or if they have caring responsibilities.

3.2 Making contact with hidden carers

Key research and policy findings

- People who carry out caring responsibilities do not always recognise themselves as ‘carers’
- Health professionals are in a key position to identify hidden carers
- Health professionals do not routinely refer carers to social services
- Participation strategies that rely on consultation with those who already receive services are likely to further marginalise hidden carers
- Black and minority ethnic communities would welcome the involvement of their community representatives in providing them with information about available services

Wigan case study - Recognition and support of ‘hard to reach’ carers project

The project began in June 2004 and was based on research previously undertaken by the Princess Royal Trust for Carers. (Primary Carers – Identification & Providing support to carers in Primary Care. Following research and evaluation with other authorities, a carer registration scheme was developed by use of a registration card and implemented in the 62 GP practices (now 73) throughout the borough of Wigan.

A training manual entitled “Recognition of carers and young carers” for the use of GPs and practice staff has been developed and provided to all practices. The project worker offers and provides carer awareness training, supported by a handout, on the recognition of hard to reach carers to all practice staff. A notice board dedicated to carer information has been provided to each practice throughout the borough of Wigan and is kept updated by the project worker who also keeps the practices supplied with the carer identification cards

Contact:
Wigan Council Carers Support Team
Jill Pettitt
Carers Project Worker PCT Liaison
01942 705982 – j.pettit@wiganmbc.gov.uk

Harrow Case study - Health liaison project

3 SCIE Carers Act Implementation guide 9
The project helps identify hidden carers in Harrow by working in GP’s surgeries, local hospitals and Pharmacies.

A worker regularly visits all GP surgeries and holds surgeries for carers. GPs are given a carers information pack to give to their patients who are recorded as carers. Carers surgeries are held at the local Hospital. Local Pharmacists put a carer’s information leaflet into prescription bags, which provides information on local carers services and how to get support with caring. We are currently working with GP surgeries to set up an electronic appointment with the Carers Centre for new carers identified by GPs.

London Carers Directory 2008
Jasvinder Perihar. Well Being & Carers Strategy Manager
Jasvinder.perihar@harrow.gov.uk 020 8424 1023

West Sussex case study
Carers’ emergency schemes can be useful in encouraging carers to engage with services, especially where no other services are received. In 1997, West Sussex was successful in identifying large numbers of hidden carers through its Adult Carers Mobile Information Service. The project was originally funded by the Lottery, and due to its continued success and expansion – today it covers the whole county – it is now funded by West Sussex County Council through the Carers’ Grant. The project consists of a mini-bus and staff who offer a mobile information service for carers. The service is a first point of contact and carers are referred on, with their consent, to a network of carers’ support organisations in the area coordinated by the West Sussex Carers Network. The service aims to vary the times and places it visits to increase the numbers of people it reaches out to. Some staff work both on the bus and within the carers’ support network, providing a link between the information service and the members of the West Sussex Carers Network.

3.3 Carer assessment

Key research and policy findings

Research
The quality of the evidence available measuring assessment outcomes was weak because it was generally based upon small samples with no control group comparator. However, these studies suggested that assessment may lead to a wide range of outcomes. The most notable potential benefits were outcomes relating to emotional well-being and the uptake of support services. There was also some limited evidence of: increased knowledge; better physical health; and support to work. However, the achievement of positive outcomes via assessment was shown to vary considerably. In most studies, the proportion of carers who received additional services following assessment was relatively low, below half. In addition, where services were provided, carers were not necessarily satisfied with them. (Victor, 2009)
a) The conduct of carer assessments as part of the mainstream work of practitioners is variable.

b) The number of separate carer assessments is low. Less than half of carers in England (45%) & Wales (46%) have received a carer assessment.

c) Separate carer assessments are not an established feature of practice:

d) Practitioners are reluctant to complete separate carer assessments: They do not want to raise carer expectation. They identify support needs which services are unable to address.

e) The challenges faced by carers in their everyday lives can be complex, but the solutions sought by individuals are often very simple.

f) For example, carers often identify the need for a contact person or for information rather than labour intensive services.

g) The most likely service outcomes arising from a carer assessment are: help with personal care (32%); sitting service (31%). BUT - over half (56%) of carers who complete a carer assessment identify unmet needs, including: more flexible respite; counselling & other types of emotional support.

h) These needs are broadly similar to those identified by carers who have not completed a carer assessment. (Seddon, 2008)

There needs to be a good carer assessment protocol in place. The best starting point for information on carers’ assessment is SCIE’s Implementing the carers. (Equal Opportunities) Act 2004. (http://www.scie.org.uk/publications/guides/guide09/files/guide09.pdf)

This guide was published initially in 2005 and updated in 2007, and it has a 20-page section on CA that includes guidance and findings from research. SCIE’s guide makes a strong case for CA that is focused on outcomes and therefore suggests outcome-focused assessment tools.

**Assessment guide**

- Provide staff training on outcomes-focused work, with the inclusion of carers as trainers
- Give carers information about the assessment process, ensuring that they are aware when an assessment is taking place
- Give carers a list of things to think about (i.e. a self-assessment component) before a face-to-face meeting
- Use a partnership approach to carers' assessment, allowing carers to identify their own desired outcomes
- Use open questions and avoid a tick box approach
- Ensure that carers are made aware of any possible charges before services are arranged
- Ensure that carers have an opportunity to give feedback on the
assessment process

- Encourage flexibility and innovation in identifying services to meet carers' needs
- Use an appropriate, outcomes-focused assessment tool
- Ensure that carers are offered time to talk away from the cared-for person
- If necessary, arrange for the carer and the person they care for to be assessed by different people
- Ensure that the carers of those who refuse services are still offered assessment

Ideas for practice

Liverpool case study
They offer a choice of Carers' Assessments to ensure carers are in control of the assessment process. Carers can choose whether their needs are assessed jointly with the person they care for, or separately, and they can choose to complete a Carers Self Assessment form either in paper format or electronically via the Liverpool City Council website:

They have found that offering a number of options for assessment (particularly the Self Assessment Form) puts carers in control of the process and in identifying their own needs and how those needs can best be met. The Carers Self Assessment form is used by practitioners from across statutory and third sector organisations and is a particularly useful tool to engage carers that might initially be reticent about the assessment process thereby introducing them to the idea of assessment and support in a more person centred way.

As part of the Transformation of Social Care forward plan Liverpool aims to further develop the Carers Self Assessment to ensure it provides carers and practitioners with the necessary tool to access individual budgets.

Contact:
Jane Weller
Senior Improvement Officer (Carers)
Tel: 0151 233 6326 / 07921400355
Email: jane.weller@liverpool.gov.uk
(Research and Practice web site)

Kirklees case study
In Kirklees carers have been trained to co-facilitate carers' assessment training for assessors and to raise awareness about assessment amongst carers. The carers
have formed a ‘bank’ and can be called upon to attend training and awareness events. Participants are paid for their work and offered support where appropriate. Carers are also involved in development work around assessment and training. (SCIE guide 9)

**Beacon Council case study**

In partnership with Carers UK the four Beacon councils for supporting carers (Hertfordshire, Rochdale, Sefton and Sunderland) have produced a DVD and training pack for front-line staff to support them in carrying out effective carers’ assessments. Trainers, managers and front-line staff had all identified a need for a video-based tool to support training. While the best option is always to involve carers as trainers, the reality is that this may not always be possible, and this DVD ensures that carers' voiced are powerfully heard. (SCIE guide 9)

**Essex case study**

They are using a ‘self assessment’ form that they highly recommend. It is designed to help carers identify themselves in the caring role. It is disseminated via GPs and hospitals, libraries etc. However, they point out that one needs the organisational infrastructure set up to be able to look at them when they are returned.

**Contact**

Victoria James (victoria.james@essex.gov.uk)
01245 431177 (Research in Practice web site)

3.4 Young Carers

**Delivering Every Child Matters for young carers** is a document which sets out the barriers for young carers in achieving the ECM outcomes and how support for young carers can help local authorities evidence that they have met Joint Area Review inspection targets.

**Key research and policy findings**

Identification of young carers can be problematic. Many children live with family members with stigmatised conditions such as mental illness or drug and alcohol problems. In many cases, families fear what professional intervention may lead to if they are identified. Some families may also have concerns about the stigmatisation of being assessed under children's legislation.

Adult services, in addition to supporting disabled parents, have a key role in identifying young carers, as they will often be the first point of contact. At the point of assessing the cared-for person, adult services must ask whether the person they are assessing has children and, if they do, what impact they feel their disability has on them. Some children live with disabled siblings or grandparents and take on some caring responsibilities to support their parents who are the main carers. In the absence of their own parents, other children may live with grandparents who have care needs.
These issues highlight the importance of partnership working between adult and children’s services, voluntary sector, young carers services and education professionals. It is important that practitioners adopt a whole-family approach to the assessment of young carers, and joint working is vital for this to happen. Locally agreed protocols should support joint working and avoid disputes regarding assessment and/or financial responsibility. Although not a requirement, the appointment of a senior lead on young carers - with the authority to make decisions on any disputes - would facilitate seamless service provision.

The Princess Royal Trust for Carers offers an exemplar protocol for local authority joint assessment and support for young carers and their families. SCIE (Carers Act Implementation guide 9)

Young carers projects have been criticised from a disability rights perspective for deflecting scarce resources from disabled parents and towards children, and for labelling the children of disabled parents ‘young carers’, thus potentially undermining parents. In the light of this critique, young carers projects are becoming increasingly ‘family focused’ (as encouraged by the Department of Health and Social Services Inspectorate guidance etc.). It is important that projects now move towards this family model and rather than, for example, taking children out and giving them a ‘good time’, assist disabled parents to take their own children out instead. They also need to be much more proactive in assisting disabled parents to identify their own needs and to try to support them and help them to meet their own goals. In so doing, they will also be improving the circumstances of children within the family.

(Centre for child and family research: evidence issue 4 October 2002)

**Ideas for practice**

**Carers in Hertfordshire Young Carers Project.**

**A model of good practice for the Young Carers Secondary School Transfer Plan**

In June 2002 - June 2003 the young carers project worked intensively with 43 secondary schools in Hertfordshire. The school work involved consulting and assisting schools to set up an identification and support system for young carers. The young carers project is now in the second stage of the schoolwork, working with Primary and Secondary schools, building on the success of the first stage of school based work.

*For further information please contact;*

Marie Freeman  
Tel 01992 586969  
MOB 07917 186823  
Email: marie.freeman@carersinherts.org.uk

**Hampshire Young Carer’s Initiative case study**

An impressive website describing a number of carer’s services, one of which is a
Young Carer’s Development Worker who offers personalised training and advice as well as information, resources and sign posting.

Useful resources for Adult Services include:

- A leaflet ‘Supporting young carers and their families: Information for Adults’ Services’
- Key Principles of Practice
- The Whole Family Pathway

Hertfordshire case study

The Carers in Hertfordshire, Young Carers Project can offer Young Carers and their families: information, free breaks and activities for young carers, support groups for young carers and information and support within schools for young carers. Contact the Young Carers website www.koolcarers.org.uk. Tel. 01992 586969

Kent case study

Young carers in Kent have developed their own website which offers information to other young carers. They have also produced a DVD to raise awareness in schools about the issues facing them. (SCIE guide 9)

3.5 Emotional and social support

Key research and policy findings

i. Research - Carer support groups

The majority of carers were satisfied with carer support groups. A wide range of types of information and advice appear to be gained both from the input of professional group leaders and other carers to the group. This may be particularly useful for some Asian carers who find it difficult to access this type of information in a language they can understand elsewhere. The evidence also suggested that improvements to emotional well-being were achieved principally through the mutual support that carers provided to each other within the groups, through the development of confidence and a positive self-identity as a carer.

There was evidence of the achievement of social support in terms of meeting others, building friendships and participating in social activities. Some limited evidence suggested that support groups can also have outcomes in terms of facilitating access to and improving relationships with service providers. The weak quality of the evidence (which was based solely upon cross-sectional and qualitative data) in terms of outcome measurement means that it is not possible to conclude about the extent to which these outcomes are achieved for carers through carer support groups.
The studies suggested that the mechanisms underlying support groups included the quite tangible provision of resources, namely: information and advice; friendships and social opportunities; and the facilitation of access to and contact with service professionals. In addition, improved well-being may be explained by the occurrence of emotional processes including the expression, recognition, validation and normalisation of feelings and situations related to caring. Carers may also feel less isolated, value providing help to others and develop a better self-awareness of their role and needs. (Victor, 2009)

**ii. Research - Stress management, coping and counselling programmes**

There was a considerable body of outcome measurement evidence for these types of intervention. These studies generally used designs involving comparison of control groups or longitudinal outcome measurement which offer reasonable quality evidence of this type (even though flaws in the execution of designs meant that overall quality ratings were not necessarily high).

The evidence showed that the majority of participants were satisfied with the interventions. One study considered the number of carer needs which had been addressed. This showed significant benefit for the intervention group immediately after the intervention, but this was not maintained at later follow-up. Improvements in knowledge were identified in studies of interventions of this kind for carers. (Victor, 2009)

**iii. Research - Befriending schemes**

The one study identified which evaluated a befriending scheme for carers of people with dementia provided high quality outcome measurement evidence. This showed no evidence of benefit in terms of depression, anxiety, loneliness, positive affectivity or global health. This was based upon analysis which specified the intervention as access to befriending support. Analysis comparing depression amongst those who did actually use the befriending scheme with the control group did find a marginally significant difference in favour of the intervention group at fifteen months. This suggests that further exploration of the intervention could be warranted whilst bearing in mind the relatively low take-up achieved in this case. (Victor, 2009)

**Ideas for practice**

**Torbay case study**

Torbay Care Trust runs an emotional support scheme for carers. The scheme supports eligible carers who feel they are not coping well and would benefit from talking confidentially to a qualified counsellor, about emotional concerns affecting their caring role. Carers can be referred by care managers. Eligible carers can have up to 10 sessions, free of charge, with a participating, privately practising counsellor and they ‘pay’ with a voucher each time they go. Ongoing evaluation shows the scheme is beneficial.

*SCIE Carers Act Implementation guide 9*
Working with libraries in North Wiltshire case study

The Princess Royal Trust for Carers network member Carers Support North Wiltshire has built a relationship with its ten local libraries, delivering ‘Well Being Days’ which offer alternative therapies to carers alongside a chance to meet others, and ‘Drop in’ sessions with workers such as Financial Advisors. The County Librarian’s team is now planning story-telling sessions for children and siblings of disabled children. As well as delivering activities rated as ‘valuable’ by carers in accessible settings, this partnership helps the Council achieve its goal of diversifying library use. The Carers’ Centre is now reaching some previously hard to reach groups and has increased its referrals.

Contact: Lindsay Poulson, Joint CEO at lindsay@carersnw.co.uk or Tel. 01249 444110.

3.6 Education and training programmes for carers

Key research and policy findings

i. Research - Education programmes for carers

Studies of education programmes for carers provided relatively good measurement of outcomes as they were based primarily upon randomised controlled trial or uncontrolled longitudinal research designs. Satisfaction was reported with two interventions using a written booklet format. However, there were no or small differences in satisfaction amongst intervention and control groups for trials of stroke education programmes. Only one of these showed improvements to knowledge as well. This may be because the usual care and information provision for carers of this type is sufficient.

There was quite strong evidence of improvements to knowledge via other education programmes, specifically those for carers of people with dementia and of people with schizophrenia. There was mixed evidence about whether these interventions also led to some behavioural change in carers, for example, in coping strategies and services used. Further evidence would be needed to offer conclusions on this. Some studies showed some improvement to emotional well-being but generally changes were not reported. Thus the evidence on this as an outcome of carer education programmes was not convincing. There was some limited evidence that these interventions could also have benefits for the person receiving care. (Victor, 2009)

ii. Research - Training for carers

The outcome measurement evidence of these studies was rated as weak in quality, although some studies did use randomised controlled trial or longitudinal designs. There were generally high levels of satisfaction with the interventions amongst carers. The studies provided some evidence that carer training could validate existing expertise and provide new knowledge and understanding and lead to the development and application of new skills. However, some evidence suggested that the use of new skills may not be maintained over time. In addition, there was some evidence that carer training could improve perceptions of caring and ability to care, improve emotional well-being and provide social support. In most cases, there were
neutral outcomes for the person receiving care. The evidence suggested that the principal mechanisms explaining the achievement of outcomes were the provision of new (and validation of existing) knowledge about particular medical conditions and ways of managing symptoms and behaviours.

There was limited evidence that the provision of social support may also be important. The studies also provided some explanatory evidence about contextual features of the interventions that might influence the achievement of outcomes. Training style was highlighted in particular. Aspects that appeared to be beneficial included: interaction, personalisation, problem-solving with others and the use of examples and light-hearted analogies. (Victor, 2009)

Idea for practice

Sefton case study

In Sefton a lifelong learning and training officer is funded jointly from the carers grant and training to support carers to access training and education. Carers are also offered places on all mandatory training provided by the Health and Social Care training unit.

Training includes: understanding Parkinson's disease; manual handling; disability awareness; introductory dementia awareness; alcohol and older people, food hygiene, creative alternatives (therapeutic alternatives to help people with depression) and person-centred planning (SCIE Carers Act Implementation guide 9)

3.7 Income and employment

Key research and policy findings

Research

There was outcome measurement evidence (of weak quality) that this type of intervention may help carers to gain employment suggesting that it may be worth exploring this further.

There was limited evidence (of weak quality) that the following may influence the achievement of outcomes via carer employment projects: sensitivity to the emotional needs and situation of participating carers; the local availability of work on a part-time basis, for certain hours or on a flexible basis; and the appropriate provision of support services for the person receiving care. (Victor, 2009)

Ideas for Practice

Partnership working: Jobcentre Plus and the Carers Centres, Oxfordshire the three Carers Centres in Oxfordshire and Oxfordshire County Council are developing strategic links with Jobcentre Plus in order to help them raise awareness of carers and key issues: how to identify carers and how to support and signpost them to the local Carers Centres. A pilot awareness-raising programme for frontline
Jobcentre Plus staff was delivered by the Oxford Carers Centre, backed up by information packs for each member of staff.

Carers at the heart of 21st century and communities

**Hertfordshire County Council’s ACE Carers and Employment Project**

Hertfordshire County Council (HCC) is a delivery partner within the (ACE) Action for Carers and Employment National Development Partnership. It is part funded by the European Social Fund under the Equal Community Initiative programme.

**Hertfordshire’s project aims to:**

1. Raise the profile of the issues that working or potential working carers face
2. Achieve positive individual outcomes for carers
3. Document case studies in order to evaluate the barriers that carers have to overcome in order to maintain or return to employment, education and leisure
4. Develop and improve mainstream health and social care practice in relation to the Carers (Equal Opportunities) Act 2004
5. Influence commissioners and providers to develop more carer-friendly services and emphasise the business case for flexible working policies to support carers
6. Report to local and national partners

*Beacon council example:*

**Carers and Employment Project Team**

*Based at Adult Care Services,*

*Mount Pleasant, Hatfield, Herts. AL9 5PU.*

*Telephone: 01707 280721*

*Email: carers&employment.project@hertscc.gov.uk*

**Hertfordshire case study**

**CareWISE** is an important strand of Hertfordshire County Council’s work/life balance strategy. It aims to provide a range of initiatives to help employees successfully combine their caring responsibilities with work. CareWISE offers all carers working for Hertfordshire County Council the right to request to work flexibly. It also offers paid time off to attend carers’ support groups as well as access to an independently facilitated Hertfordshire County Council carers-only group. In addition, carers can take up to five days paid leave to deal with emergencies involving dependants. Further information is available from a Hertfordshire County Council case study and from the Action for Carers and Employment website. *(Beacon Council example)*

### 3.8 Leisure

**Key research and policy findings**

Engagement in leisure activities promotes physical and psychological well-being (ref: Stevens et al, 2004).
Leisure card - Waltham Forest case study

The annual leisure card scheme for carers is a development of an existing concessionary scheme where carers can access specified leisure opportunities at certain times at half price admission. This service has developed into an annual scheme where carers can access leisure services in six leisure centres free of charge. Carers are able to access:
- Fitness centre (Gym), Swimming Pool, Group Exercise Classes, Fitness induction, Sauna facilities, Single 2 hour crèche session per week, Members joining pack, 6 days advance telephone booking.
- Access is restricted to peak hours Monday-Friday 7am-5pm, Weekends 1pm-5pm.
- There are currently more than 41 carers accessing this service.

Sunderland case study

Sunderland City Council has an online guide *Opportunities for carers* that gives comprehensive information on local resources for leisure, learning, volunteering and work. *(SCIE Carers Act Implementation guide 9)*

3.9 Carer breaks

Key research and policy findings

Research

Overall, studies generally reported carer satisfaction with breaks. There was also strong evidence that breaks allowed carers to have a rest and experience physical and emotional relief. They also enabled carers to do everyday jobs, pursue social activities and interests and to a lesser extent, employment.

There was little robust quantitative evidence of improvements to emotional well-being achieved through carer breaks. However, several of the studies focused upon carers of people with dementia where the progressive nature of the condition might mean that carers’ emotional well-being might be expected to worsen over time. The studies did not adequately control for confounding factors such as these.

There was some qualitative evidence that carers felt breaks benefited their emotional well-being particularly in terms of facilitating a sense of normality, freedom, peace of mind and sadness at being separated or leaving the person receiving care and most notably, guilt about using such services. These feelings could be related to the acceptability of the alternative care provision to the relative or friend receiving care.

There was some limited evidence of improvements to physical health achieved through carer breaks and of improved social inclusion. However, there was also evidence that breaks could cause carers to experience negative emotions including anxiety about the person receiving care. Overall it was recommended that carer breaks should be a priority for service development. *(Victor, 2009)*
**Bournemouth–case study**

Setting up emergency back up for carers in Bournemouth

Message in a ‘bottle’
1. Each carer has a unique number
2. Plastic card, key fob, cardboard card, membership sticker
3. Booklet reminder
4. Carers Information Service
5. Identification for carers discounts

Debbie Hyde, Carer Co-ordinator (01202) 458204
deborah.hyde@bournemouth.gov.uk

**Sefton – case study**

Carers Emergency Respite Team (CERT) & Flexible Accessible Breaks (FAB)

The CERT Team provides short-term, home-based respite support to carers in crisis or emergency situations. Following a home visit to register with the service carers are provided with the contact details to enable them to access support which is available 24 hours a day and all year round, including weekends and bank holidays.

The team consists of four experienced and highly skilled staff who work on a six-day cycle, two days on call, two days back up and two days off duty. This is the minimum staff requirement to operate the service successfully. The team is supported by a coordinator, with regular team meetings and supervision. The team remit is to take over the carer’s role, which would include all caring tasks (excluding nursing procedures, which would be carried out by the Primary Health care team) and whatever domestic tasks are required to sustain the situation.

There are now over 7,000 carers registered with the carers centre and 1,236 carers registered with CERT. The service has expanded to include flexible accessible breaks. The FAB Team also consists of home-based respite support, but instead of emergency situations, it provides carers with the opportunity to take planned, one-off breaks from their caring role. These services are available to adult carers who care for other adults.

(Beacon Council)

Contact: cert@sefton-carers.org.uk
3.10 Carers support in health settings

Key research and policy findings

Some promising evaluations of carer support provided within health settings have indicated that this can be an effective means of identifying hidden carers and providing non-stigmatised assessable support and information for carers.

The case studies below for Torbay and Devon have been independently evaluated and these evaluations are well worth studying.

Ideas for practice

**Carers support in GP surgeries – Torbay**

Carers support workers (CSW) in GP surgeries were identified as a key target for Torbay Interagency Carers Strategy 2000/03. With initial funding from Social Services GPs were invited to bid for funding for CSW posts. In 2000/01, 8 practices were funded and in 2002/03 this increased to 15. An evaluation was carried out into the impact of the work on the health and wellbeing of carers which demonstrated that carers in contact with CSWs had reduced levels of stress and other health gains such as better sleep, improved concentration and less anxiety about their situation. The resulting report to the PCT executive in 2003 led to long term joint funding from Torbay PCT and Social Services to enable all 22 practices to employ a CSW one day per week. The role is seen as key to developing integrated support for carers in Torbay.

**Devon pilot evaluation of GP Carers project – 8 sites**

The importance to carers of one central, easily accessible, ‘hub’ through which they can receive guidance, advice and information about what is available to them in their own locality cannot be over-stated. Carers felt most confidence and trust in services derived from the GP surgery and preferred this, as opposed to social services offices, as the conduit for access to sources of help. A particular strength of the A&SW role based in the GP surgery is the ability to deliver a flow of information and advice at times which are appropriate to individual needs and sufficient for the particular stage in the journey through caring. Other benefits were identified and a series of recommendations for further development were outlined in the report produced by Research southwest and the University of Plymouth. Contact: Clare Cotter, 01392 267860 for copy of evaluation study.

**Hospital based resources for carers - East Sussex case study**

Care for the Carers and East Sussex hospitals NHS trust have produced a range of resources for supporting carers. These include a good practice guide for hospital staff covering topics such as information sharing, a carers’ information leaflet and a Care Passport, which allows carers to record the special needs, preferences and ways of communicating with the person they care for. (Carers at the heart of families and communities)
3.11 Providing support to Carers in Crisis

_Ideas for practice_

**Devon case study**

Rapid Response is the name given to a variety of services that can be deployed quickly and intensively to enable people to remain in their own homes, and so avoid unnecessary admissions to hospital or care homes. For example, community nurses, therapists and domiciliary care support workers.

The scheme is open to anyone who is a member of the Devon Carers Link – in effect to anyone who defines themselves as a carer regardless of the age/needs of the person cared for.

3.12 Support for carers of people with dementia

_Key research and policy findings_

Caring for a relative with dementia is psychologically demanding in terms of the intensity and duration. The ongoing changes in the care recipient over many years mean that carers are frequently required to adjust and adapt. To support the adjustment process, psychosocial care for carers must go beyond giving carers occasional breaks from caring, and needs to involve the long-term provision of high quality, tailored and timely multi-disciplinary and active education, psycho-education and skills training. Resources need to be available for emotional as well as practical support. There is a need to develop comprehensive local services that work in partnership both with the person with dementia, their primary carer and their wider support network. Carer support should be available across the entire ‘care-giving career’, and not limited to the time when carers are providing ‘in home’ care.

(Charlesworth 2008)

3.13 Carer support for mental health

_Ideas for practice_

**Bristol Carers Service**

*Working with carers of people with mental health needs*

**Carers Liaison Post**

Reaching carers at an early stage, working with staff on psychiatric acute wards

Carers Leads, referrals from wards, evening drop in for carers, training on carers issues, support groups, one to one meetings

*Contact: Margaret Price*

*Carers Service Co-ordinator*

*Karen Allen*

*Carers Liaison Officer*
3.14 Assistive technology and equipment

Ideas for practice

**Havering case study**

Since Telecare was launched in January 2007, it became very evident that carers would see the immediate benefits of this service. A survey of carers of Telecare users was recently conducted. The results of which clearly demonstrated that Telecare has decreased anxiety and increased their quality of life. For example being able to go shopping and in some cases on holiday, with the knowledge that their relative will be supported should anything happen.

Carers have had the opportunity to see the full range of Telecare sensors demonstrated to them at our show flat. This enabled them to see how Telecare works in a live environment and deal with any particular queries they had beforehand. Some carers have particularly benefited from the carer pagers that we provide for live-in carers who prefer to be alerted rather than involving the communication centre.

It is very evident that one of the main benefits to Telecare is the reduction in carer stress. *(Carers at the heart of 21st century families and communities)*

In Birmingham, Crossroads manages a moving and handling project. When equipment is delivered to a home, a referral is automatically sent to Crossroads, which sends someone to train the carer in how to use it properly. The project is funded through the Carers Grant. *SCIE Carers Act Implementation guide 9*
4. Cost effectiveness

The PSSRU study of long term care finance 2006 suggested that there is a particular need to provide more services, such as home care, directed at older people with carers. The home care service is the bedrock of community care in this country and yet it is still primarily directed at older people without carers. In the interests of effectiveness and cost-effectiveness, home care needs to be more available to older people with carers than it has been up to now.

Overall, however, the main conclusion is that it would be cost-effective to make much greater provision of day care, residential respite care, home care and social work/counselling for more carers of older people.

Bibliography

ADSS and Carers UK, London carers directory, (Description of a wide range of carer services) (2008)

Audit Commission, Support for carers of Older people, 2004

Commissioning for Carers, http://www.idea.gov.uk/idk/aio/13295634

Commissioning for Carers: an Action Guide for Decision-Makers
http://www.idea.gov.uk/idk/aio/13295835

Carers UK, Choice or Control: carers experience of direct payments, (2008)

Charlesworth, G., What forms of support are effective for family carers for people with dementia, Research in Practice, 2008

Crossroads Caring for cares, Putting People first without putting carers second, (2009) (some good practice examples)

Donnelan, H. GP Carers Project: Final Evaluation Report 2009, Research South-West and University of Plymouth


IDEA Knowledge, Self Assessment Tool – How is this council (and partners) supporting carers?(2006), www.idea.gov.uk

Kelly, B. et al, Supported to care? - Carers Views of Services, (2007) Glasgow University, Additional copies of this report are available at the following websites: Princess Royal Trust for Carers www.carers.org
Crossroads Caring Scotland: [http://www.crossroads-scotland.co.uk/](http://www.crossroads-scotland.co.uk/)
Pickard, L. *The effectiveness and cost effectiveness of support and services to informal carers of older people, A review of the literature prepared for the Audit Commission*, (2004) London School of Economics

Research in Practice, *Carer Assessment – the evidence, RIP web site* (2008)

Seddon, D. *Assessing Carers: The Evidence base* (2008), University of Bangor, ppt. presentation to Research and Practice conference


The Princess Royal Trust for Carers, Template reports (examples of good practice in Scotland) 2009

**Appendix 5: All stakeholders consulted with during the Somerset Carers Appraisal**

We would like to thank the many carers, staff and volunteers who have given their time to provide us with information and feedback about carer’s services in Somerset in carrying out this review. The names of carers and Carers Support Workers and Carers assessment workers have not been identified as part of the commitment to preserve confidentiality and non attributable comments.

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<thead>
<tr>
<th>Name</th>
<th>Title/Organisation</th>
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<td>Caroline Toll</td>
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<td>Jan Smith</td>
<td>Muscular Dystrophy Association</td>
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</tr>
<tr>
<td>Sue</td>
<td>In Touch</td>
<td>Invited to stakeholder event</td>
</tr>
<tr>
<td>Campbell Main Branch Officer</td>
<td>National Autistic Society</td>
<td>Email interview</td>
</tr>
<tr>
<td>Neil Smart</td>
<td>Parkinson’s Society</td>
<td>Invited to stakeholder event</td>
</tr>
<tr>
<td>Fergus Arkley Development Manager (South West)</td>
<td>Princess Royal Trust for Carers</td>
<td>Interview Email contact</td>
</tr>
<tr>
<td>Neil Singleton</td>
<td>Rethink;</td>
<td>Invited to stakeholder event</td>
</tr>
<tr>
<td>Chris Summerhayes –</td>
<td>Somerset Care At Home</td>
<td>Carers Panel</td>
</tr>
<tr>
<td>Jude Glide</td>
<td>St John Ambulance Somerset</td>
<td>Individual meetings, carers panel Stakeholder events.</td>
</tr>
<tr>
<td>Name</td>
<td>Organization</td>
<td>Contact</td>
</tr>
<tr>
<td>-------------------------</td>
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</tr>
<tr>
<td>Marianne Dinsdale</td>
<td></td>
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<tr>
<td>Ann Fowler</td>
<td>Somerset Sight;</td>
<td>Stakeholder events.</td>
</tr>
<tr>
<td>Phil Sealy</td>
<td>Somerset Older Citizens Alliance;</td>
<td>Invited to stakeholder event Email</td>
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<tr>
<td>Sue Hasler</td>
<td>St Margaret’s Hospice</td>
<td>Invited to stakeholder event Email</td>
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<tr>
<td>Rachel Lawrence</td>
<td>Stroke Association;</td>
<td>Stakeholder events.</td>
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<tr>
<td>Steph Steadman</td>
<td>Somerset Skills and Learning;</td>
<td>Stakeholder event Email</td>
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<tr>
<td>Ellie Porter,</td>
<td>Department of Work and Pensions</td>
<td>Interview Stakeholder event</td>
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<tr>
<td>Rachel Murray</td>
<td>NHS South West Carers lead, Learning Disability</td>
<td>Telephone discussion Email contact</td>
</tr>
<tr>
<td>Caroline Boseley</td>
<td>Way Ahead</td>
<td>Carers Panel</td>
</tr>
<tr>
<td>Social workers x 6</td>
<td>Local adult social care teams</td>
<td>Carers Panel</td>
</tr>
<tr>
<td>Operations Managers</td>
<td>Adult Social care</td>
<td>Team meeting</td>
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<tr>
<td>X8</td>
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<tr>
<td>Community Team Managers x 80</td>
<td>Adult Social care</td>
<td>Team meeting</td>
</tr>
<tr>
<td>Young Carers Project workers</td>
<td>Children and Young People Directorate Somerset County Council</td>
<td>Team meeting</td>
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<td>Carer leads</td>
<td>from:</td>
<td>Telephone email</td>
</tr>
<tr>
<td>---------------</td>
<td>----------------------------</td>
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</tr>
<tr>
<td></td>
<td>Devon; Cornwall; Wiltshire; Dorset; Gloucestershire; Sunderland; Oxfordshire; Lincolnshire; Essex.</td>
<td></td>
</tr>
<tr>
<td>Individual carers and Young Carers</td>
<td>Questionnaires Part of group meetings, larger events telephone and email contacts</td>
<td></td>
</tr>
</tbody>
</table>