

**ANNEX**

# **Oxfordshire Carers' Strategy 2013 – 2016**

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## Foreword

Caring for a relative, friend or partner is a role that many people will take on at some point in their lives. We know that there is a growing population of people who have care and support needs, which is likely to have a significant impact on the numbers of family carers there will be in the future. We therefore need to ensure that we provide and develop good quality tailored support to meet the needs of carers across the county.

Carers already play an essential role in the development of health and social care services in Oxfordshire and we are fortunate to have a well-established network of carer forums, which provide input and feedback on services here. The Oxfordshire Carers Forum, Young Carers groups and Oxfordshire Parent Carer groups meet regularly to consider carer related issues and comment on service developments and design. We are constantly encouraged and inspired by not only their commitment to the people they care for, but also the time and energy carers give to being part of these forums and our service developments.

Since the publication of the last Multi-Agency Carers Strategy, 2009 - 2012, carers and the issues they face have received more prominence nationally. It is widely acknowledged that most carers are selfless and dedicated to their caring role but are often also unrecognised and undervalued. Being a carer can all too often lead to isolation, poverty, ill health and loneliness. It is essential therefore to ensure that organisations in Oxfordshire work together to give carers the information and support for they need.

We need to work together so that there are real and purposeful developments for the benefit of carers in Oxfordshire.

**Cllr. Judith Heathcoat**  
Cabinet Member  
Adult Social Care  
Oxfordshire County Council

**Ian Busby**  
Chair  
Oxfordshire Clinical Commissioning Group

## Acknowledgments

Many carers in Oxfordshire were instrumental in the development of this strategy, giving their time and views to ensure the strategy reflects carers' needs and wishes in the county. In addition, a range of organisations have committed to the development of this strategy, supporting carers in Oxfordshire and contributing to delivering the commissioning intentions.

## **Making it happen for carers**

Often, carers see themselves as someone who is just looking after a relative or friend. However if the person you care for couldn't cope without you and you don't get paid, then you are a carer.

Approximately 61,500 people have identified themselves as carers in Oxfordshire in the 2011 Census. You may be one of them. Most people are likely to become a carer at some point in their life.

The Oxfordshire County Council (OCC) and Oxfordshire Clinical Commissioning Group (OCCG) Joint Carers' Strategy, which has been in place since 2009, has been reviewed and updated for the period 2013 – 2016. The Strategy will have detailed multi-agency partnership action plans to support its ambitions.

The strategy will deliver an undertaking to carers, so that:

- 1. You are recognised as a carer**
- 2. You are supported in your caring role**
- 3. You feel respected in your caring role and your importance is valued**

### **There are 7 agreed priorities for working with carers -**

#### **Priority 1: Improve carers' experiences of health and social care services.**

"I expect all services to recognise my needs as a carer."

#### **Priority 2: Give carers effective support and opportunities for a break.**

"When I need support or a break I know where to get help."

#### **Priority 3: Increase carer identification.**

"I am recognised as a carer."

#### **Priority 4: Improve the health and wellbeing of carers.**

"My own health and wellbeing is recognised as essential for the health and wellbeing of the person I care for."

#### **Priority 5: Help carers to fulfil their education, employment and training potential.**

"I know as a carer that my needs for education, work and training will be supported."

#### **Priority 6: Support carers through times of change.**

"I know I'll be supported when my caring role changes."

#### **Priority 7: Help those carers who have complex situations when they need more support**

"I have individual needs as a carer and when I need extra support I feel able to ask for help, know where to get it and receive it."

# The Oxfordshire Carers' Strategy

For people living in their own home who need care and support, a family member, friend or neighbour who can provide that support can be the most important resource at that time and is often the most important figure in that person's life. By providing this support, the carer can become the lynchpin for this person, providing care, continuity, a link between them and the world, including the services that they need to access, the existing relationships they need to maintain and the new ones they need to make.

It is vital that carers receive support themselves, as the role of carer can be challenging and demanding as well as rewarding and fulfilling. Negotiating the network of services and information involved as well as the necessities of actually providing the care and support required can add to the stresses the carer may experience. This is especially true if they are new to this role.

The Oxfordshire Carers' Strategy sets out the commitment which Oxfordshire County Council (OCC) and Oxfordshire Clinical Commissioning Group (OCCG) as the major commissioners of health and social care services in the county will make to carers for the period 2013 - 2016. This commitment recognises the crucial role which carers play in the life of the person who they care for and as the central figure in a framework of sometimes complex services and contacts which that person may experience.

## The Vision

**Carers will be recognised as key partners by health and social care services and will have access to the services that they need to support them in their caring role as well as to have a life of their own.**

**The seven priorities which the Oxfordshire Carers' Strategy has identified are -**

## **Priority One**

### **Improve carers' experience of health and social care services**

The network of services provided by health and social care organisations across the statutory, voluntary and commissioned services sectors are many, varied and often complex, both in what they do and how they fit together. Carers need to know that they will experience respectful, helpful and constructive responses from the people they meet in those organisations and the services that they will deliver.

Information provided about and by services needs to be clear, easily available and consistent in the messages it provides to the carer and to the person they care for. Advice and guidance provided by staff in these services also needs to be clear, accessible and reliable.

Services need to be both purposeful and reliable so that the carer and the person they care for can, together, feel confident about what will be provided. Carers need to be recognised as a key person in terms of direct care and sharing information, if that is the role they now have in someone's life, and services should work closely with them as well as the person they care for, to plan and develop the services which will support that person.

Carers will be offered a Carers Assessment and this should contribute to a Support Plan which acknowledges the needs of the carer as well as the needs of the person they care for. This could be developed as a separate Support Plan or as part of a joint Support Plan for the person they care for, which recognises the relationship between the carer and the person they care for.

"I expect all services to recognise my needs as a carer."

## **Priority Two**

### **Give carers effective support and opportunities for a break**

Support for carers can come from a variety of sources. Some supports will be informal and come from family, friends and the local community. Some supports will need to be more formal and be sourced through health, social care and other statutory services, and voluntary sector agencies.

Support for carers can also come in many forms; as information, advice and guidance; as practical care and attention for the person they care for; as emotional

support; as respite care to give the carer a break from providing care and to allow them some time of their own.

Information, advice and guidance needs to be clear, consistent, age appropriate and readily available to carers. Signposting to other services also needs to be clear and direct. Carers need good information about financial, legal and housing issues, as well as about health and social care services.

Some carers can benefit from training relating to specific conditions and services should be ready to offer this as required. Equally, carers should be involved developing training for paid staff, as they have experience and expertise which should be shared.

Opportunities for short breaks and respite from being a carer should be easily available and should be offered at times and in places to suit both the carer and the person they care for. Services providing short breaks should work in partnership with carers to ensure that the experience works well for both the carer and the person they care for.

There will be situations where care and support is needed in response to a crisis or an emergency. Carers need to know that services will be readily available should a crisis occur and who to contact when they are needed. A Crisis Support Plan should be set out for the person who is being cared for so that the carer knows that the correct safety net is in place should such a crisis occur. The Crisis Support plan should aim to prevent the person being cared being admitted to hospital or to a care home, unless this is where they expressly need to be.

Carers also need support to maintain their own good health and health providers need offer services which recognise carers' needs.

"When I need support or a break I know where to get help."

## **Priority Three**

### **Increase carer identification**

People providing unpaid care for another person do not always identify themselves as a carer. Services should encourage carers to recognise themselves as such and to register as a carer. Anyone who is a carer should then be offered a Carers' Assessment. This can then lead to the clearer recognition of the carers' needs, either as part of the Support Plan for the person they care for, or as a separate Support Plan for the carer, if requested by the carer. Young Carers should be offered a Young Carer Assessment.

As they come into contact with carers, services should recognise them as key players in the decision making and planning processes involved and work with them to develop the best outcomes for the person being cared for,

Increasing awareness of all carers and their needs within our communities helps to inform current and future service needs and the planning processes within the statutory services. It also helps to raise awareness within the wider community so that employers, schools, colleges, shops and businesses can recognise carers and their needs and improve the supports that they can offer.

"I am recognised as a carer."

## **Priority Four**

### **Improve the health and wellbeing of carers**

Being a carer can be demanding and stressful. Carers of all ages need to be supported to maintain good physical and psychological health. Health services should offer health checks, monitoring and advice to promote this. Appointment systems should be able to prioritise carers to acknowledge their time pressures.

Services which provide short breaks, respite care, emergency and crisis response should be available so that carers can feel assured that the person who they care for can be supported safely and well when they, as the key carer, are not able to be there. Carers need to feel that services are safe, reliable and respectful, so that they can take time out when they need to and not have to worry.

In some situations carers will be arranging for paid services to support the person they care for. If taking this role, carers need accurate advice about services and where to find them. Carers need to be recognised as a lead partner in the Support Plan for the person who they are caring for and recognised and respected as such by the professional staff they come into contact with

"My own health and wellbeing is recognised as essential for the health and wellbeing of the person I care for."



## Priority Five

### Help carers to fulfil their education, employment and training potential

Young carers need to be recognised where they have a role as a carer and to be fully supported to reach their educational potential, through the school, college and training opportunities open to them.

Working carers need to be supported to continue with their working life, if they choose or need to be in work. Statutory services will continue to promote good practice amongst local employers to improve the recognition and support they can give to their staff who are also carers.

"I know as a carer that my needs for education, work and training will be supported."

## Priority Six

### Support carers through times of change

Carers will experience changes during the time that they spend supporting another person. Some will be changes in their own situation and circumstances, others changes to and for the person who they care for. Services need to recognise the extra support carers may need through a period of transition, wherever they are in life. Some changes may be anticipated and planned for and others not.

"I know I'll be supported when my caring role changes."

## Priority Seven

### Help those carers who have complex situations when they need more support

Many carers have other responsibilities in their lives. Whether they are a carer for more than one person, have a job or need to attend school, becoming a carer does not absolve them of other commitments they may have in their lives. In addition they may have complex situations or relationships of their own, other demands on their time, or health complications of their own to manage.

Carers may belong to communities which it can be difficult for services to reach, or for them to access services from, for a variety of reasons. Some carers may find seeking support and advice a new experience and may find this difficult to

do. Or they may have felt let down or ignored in the past and be reluctant to engage with services again.

Services need to recognise all of these complexities and will need to achieve specific solutions to provide the support some people need in some parts of Oxfordshire's diverse and dispersed communities.

"I have individual needs as a carer and when I need extra support I feel able to ask for help, know where to get it and receive it".

## Summary

The following outcomes are expected as a result of delivering this Strategy:

- Partnership working with carers will contribute to the success of good care delivery across the county
- Carers will be supported to maintain their health and wellbeing alongside that of the person they care for
- Carers will be able to have time for themselves and breaks from being a carer
- Carers will be supported to remain in employment or education if this is their choice or need
- Carers will be supported through change and complex situations
- Carers will be supported to reduce the likelihood of crisis situations occurring and the consequent need for emergency admissions to health or care services
- Oxfordshire communities and Oxfordshire services will be able to develop increased resilience in the face of the population changes being faced within the county

The organisations which work across Oxfordshire to support carers have contributed to **The Carers' Strategy Action Plan**. This plan details the schemes they have committed to and the outcomes for carers that they aim to deliver.

# The background to the Strategy

## Introduction

In 2012, Children's and Adults' Services from Oxfordshire County Council (OCC), the Oxfordshire Clinical Commissioning Group (OCCG) and their partners began to work together to better understand the local carer population and to review local support for carers, with the aim to review and update the Oxfordshire Carers' Strategy 2009-2012.

Research and data from a variety of local and national sources was collated and analysed, and the views of carers, health and social care professionals, and other interested parties were sought. This evidence base informed the development of seven new priorities for carers' support in Oxfordshire. A consultation process with local carers and professionals confirmed that these were the right areas to focus on. The key findings from this consultation can be seen in Appendix A.

These seven priorities are now the main drivers for the Oxfordshire Joint Carers' Strategy 2013-2016. This strategy will inform the planning and commissioning of support for all groups of carers using social care and health services, including young carers, parent carers and those caring for people with mental health conditions.

The work to develop the strategy has considered and linked in with other key policies and strategies including

- Oxfordshire County Council Corporate Plan 2012/13-2016/17
- Oxfordshire 2030
- Oxfordshire's Joint Health & Wellbeing Strategy 2012-16
- Oxfordshire Older Peoples' Joint Commissioning Strategy 2013-16
- Social & Community Services Adult Social Care Business Strategy 2013–15
- Children, Education & Families Directorate Business Strategy 2013-15
- Oxfordshire County Council Equality Policy 2012-17
- Better Mental Health for Oxfordshire

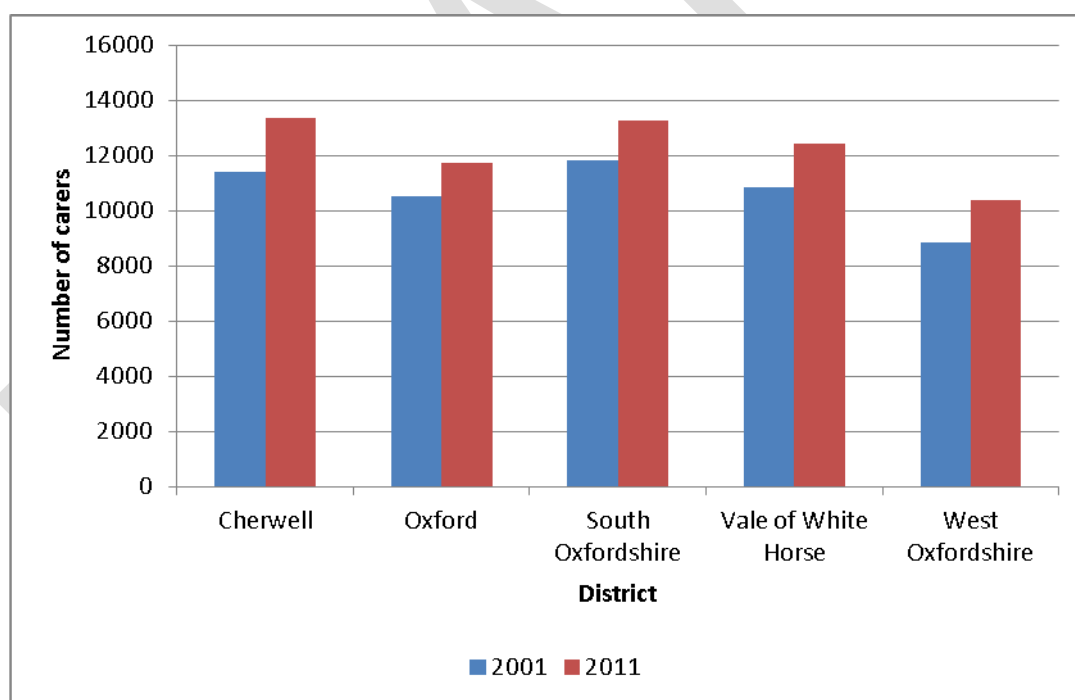
## Who are carers?

Carers are people who care, without being paid, for friends or family members who are ill, frail or disabled. Carers will use health services and are very likely to use social care services and support during the time they spend being a carer.

The help carers provide can range from picking up shopping once a week to round-the-clock care. They may live with their loved one or they may live some distance away. They may look after more than one person, or be one of the many 'sandwich carers' who look after young children and an older or disabled loved one.<sup>1</sup>

Carers come from all backgrounds and can be any age. They may be in full or part-time education or employment. Many need care themselves – not least because the detrimental effects of caring have taken a toll on their health and wellbeing.<sup>2</sup> Carers often face financial, social and health disadvantages because of their caring role.

Locally and nationally, carer numbers are rising. The 2011 Census showed that there were 600,000 more carers in England and Wales than in 2001 and over 7,500 of these are in Oxfordshire. The figure below shows how these figures have changed for each of the district council areas in Oxfordshire.



*Number of carers in Oxfordshire's district council areas; Source: Census*

For more information on who the carers are in Oxfordshire and their experience as a result of caring, see the *Carers and caring in Oxfordshire* evidence report.

<sup>1</sup> Sandwich Caring, Carers UK (2012)

<sup>2</sup> In Sickness and in Health, Carers Week (2012)

## A national vision for carers

The National Carers' Strategy *Carers at the heart of 21<sup>st</sup>-century families and communities*<sup>1</sup> sets out a plan for improving support for carers over the ten years from 2008 to 2018. Its vision is that carers will be universally recognised and valued as being fundamental to strong families and communities and it set five priority outcomes

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- Carers will be supported to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and will be treated with dignity
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods

The strategy was updated by the current Government in *Recognised, valued and supported: the next steps for the Carers Strategy*<sup>2</sup>, published in November 2010. Four new priority areas were identified

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well

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<sup>1</sup> *Carers at the heart of 21<sup>st</sup>-century families and communities*, DoH 2008

<sup>2</sup> *Recognised, valued and supported: the next steps for the Carers Strategy*, DoH 2010

# The "Carers and Caring in Oxfordshire" evidence report

The **Carers and Caring in Oxfordshire** report details the evidence collected while developing this strategy and setting the priorities for supporting carers going forward. This report is a result of research, data analysis and engagement with local carers and professionals to help us to understand who the carers in Oxfordshire are and what they need to continue in their caring role.<sup>3</sup>

The evidence clearly shows how essential carers and the care they provide are to the future of good social care in Oxfordshire. However, it highlights that there are some groups of carers who are more likely to experience the negative impacts of caring and some groups who face barriers to accessing information, advice and support services to help them care and maintain a life outside of caring.

Some of the key findings of the report are listed below.

## **Carer identification and support**

- There are large numbers of 'hidden carers', particularly young carers, people who are new to or early in their caring role and those who have lower intensity caring roles.
- Patterns in the 'triggers' for carer identification, including high proportions of hidden carers, combined with the way that carers report they use health services, and are treated by health services, shows that there is a greater role for GPs and other health 'gateways' to play in early identification and intervention for carers.
- Carers want a single, high quality and easy to access 'gateway' to advice, information and support.
- There are high levels of awareness and acceptance of Carers Oxfordshire, especially in the context of it as a relatively new service.
- Not all of carers' support needs can be met by carer support services in isolation, because some key needs relate to improving carers' experiences and involvement in wider social care and health provision.

## **Health and wellbeing of carers**

- Caring, particularly unsupported caring, impacts negatively on the health of carers, increasing demand for health services, yet current health services may be treating these health 'symptoms' of caring, without identifying and/or addressing the cause.
- Carers in poor health and/or with sustained or high intensity caring roles are more likely to report negative health and wellbeing impacts of caring.
- Older carers are a growing group who are more likely to be in poor health.

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<sup>3</sup> Carers and caring in Oxfordshire: Evidence report, Carers UK (2012)

- Carers of those with particular conditions could benefit from training to help them manage, e.g. dementia, mental health, stroke and end of life
- Carers of people with mental health conditions are more likely to report delays in carer identification and negative mental and some physical health impacts of caring. They are also more likely to report difficulties in making choices about their caring, and challenges in accessing appropriate respite support.

### **Carer experiences of social care and health**

- All groups of carers highlight good health and social care support for the person they care for and access to appropriate respite and breaks as key support needs.
- Carers report that they would like to have more support through health 'gateways' including GPs.
- Carer experiences of using health services, particularly in hospital settings, highlights that many do not feel sufficiently involved in key decisions around treatment and discharge and do not always feel prepared to manage health treatments. Evidence shows this can lead to negative outcomes for carers and patients, and increased demand for services, e.g. hospital readmissions and/or increased demand for GP services.
- Reported experiences of carers demonstrates that they would like to access more information, advice and support from hospitals, GPs and other health settings, including information on support for themselves, as well as on how to manage their own health conditions, and the medical needs of the person/s they care for.
- Carer experiences of health and social care pathways highlight that many feel that existing pathways are not sufficiently integrated or are not clear. The impacts of this can be delays, breakdown in communications and the need to repeat information. This makes it challenging for carers to manage the needs of the person they care for, and their own health and care needs, in an effective way.
- Many carers reported that they did not feel involved or treated as partners in assessments and support planning of the person they care for.
- Many carers reported that a key need was improvements in their experiences of wider social care, including timelines and delays around assessments, equipment provision and communication.

### **Young carers**

- Young carers experience a range of significant negative impacts of caring, on health, wellbeing and educational attainment.
- Stakeholders report that due to low young carer awareness among relevant professionals, negative 'symptoms' of caring can be acted on, rather than identifying the relevant young person as a carer.
- Young carers and parent carers highlight ensuring successful transition to adult services as a key need.

### **Parent carers**

- Parent carers are more likely to report delays in carer identification and are more likely to have sustained and high intensity caring roles.

- Three quarters of parent carers who responded to the survey had children who also provided care and were more likely to be caring for more than one person.
- Some groups of parent carers, e.g. those caring for children with mental health conditions, report barriers in accessing appropriate respite services. They also report barriers to accessing appropriate advice and information to support them in their caring role.
- Some parent carers and other stakeholders commented that services could be improved if parent carers were able to access a wider range of support from Carers Oxfordshire.

### **Working carers**

- Working and working age carers report that they need support to help them stay in paid work, including flexible working arrangements.
- Many employees find it challenging to balance paid work and caring responsibilities.
- Employees value flexible working opportunities as a way to help them balance paid work and caring responsibilities

### **Black, Asian and Minority Ethnicity (BAME) carers**

- There may be barriers to some BAME carers identifying as carers and accessing appropriate support. This is due to a range of issues and factors that include cultural differences in expectations and roles within families, which make it less likely that people identify as 'carers' or feel it is appropriate to seek outside support, language, and increased difficulty in finding appropriate support and respite services.



# The Joint Carers' Strategy Review and Update Consultation

The findings of the *Carers and caring in Oxfordshire* report informed the development of 7 new priorities for carers' support. Between December 2012 and February 2013, we consulted with carers and professionals in Oxfordshire to refine and improve these proposed priorities.

## The priorities

1. Improving carers' experiences of health and social care services
2. Giving carers effective support and opportunities for a break
3. Increased carer identification
4. Improving the health and wellbeing of carers
5. Helping carers to fulfil their education, employment and training potential
6. Supporting carers through transition to adult services
7. Helping those carers who need more support

## Summary of consultation findings

The key findings of this consultation demonstrated broad agreement with the 7 priorities, however there was some debate about the definition and scope of some of them.

"My parents are in their 80s living alone. I take them for numerous appointments and often stay overnight. I have suffered quite badly emotionally and am now on antidepressants for the first time in my life."

A female carer aged 55-64

**Improving the health and wellbeing of carers** was seen by all as one of the most important and it was felt that it closely linked with **Giving carers effective support and opportunities for a break** as regular breaks help to improve the health and wellbeing of carers – especially those who are older or in a more intensive caring role. Carers would also benefit from training in managing particular conditions to help them cope, e.g. dementia.

Carers need emotional support as the effects of caring can be draining and isolation is often a hidden problem. Carers and their families are already facing the effects of changes to the benefits system and people said that income was a major worry for them and that there was a great deal of anxiety around welfare reform. Some felt that financial wellbeing should receive more prominence in the priorities.

"There is a need to ensure services work together to provide a streamlined and easily accessed service. Carers are very busy people and have little time to spend hours trying to coordinate services."

A female cared aged over 65

**Improving carers' experiences of health and social care services** was seen as important and there were some recurring themes including

- Carers' experiences at hospital – carers need to be involved and respected as equal partners in care from admission through to discharge.
- GPs – many felt that GPs should be more proactive and are in the perfect position to identify and support carers. However, there were some who felt strongly that GPs were not the right people to do this as they are already overstretched.
- Lack of coordination between agencies – with so many differing needs and often being in contact with a number of agencies at once, carers would benefit from integrated services meaning less time wasted repeating themselves and chasing appointments.
- Effective communications – people felt that carers would benefit from clear information about health and social care structures and clear information about support services and what they are entitled to, including benefits advice.
- Different groups have different experiences – carers of adults with mental health conditions and young carers feel they have less positive experiences when accessing health and social care services.

“Identification of carers is extremely important – the starting point – since how else are services to be directed or focussed?”

A female carer aged over 65

**Helping those carers who need more support** was seen as a top priority and linked with **Increased carer identification**, could help support different groups including

- Carers from BAME groups who may not identify as carers, including non-English speaking carers
- Sandwich carers who juggle caring for older or disabled loved ones while looking after children and working
- Carers of people with mental health conditions
- Carers of people with substance misuse problems
- Young carers and parent carers

“Focus more on young carers and what they do as well as adult carers, because the difference is quite big. Look more at education for young carers and how they feel. Focus on supporting young carers through transitions like the big gap between GCSEs and AS/A-Levels.”

A male carer aged 16-24

There were some issues raised specifically relating to **young carers** including

- Young carers feel they have less positive experiences with health and social care services, such as not being kept informed and being excluded from key decisions
- Young carers need to be identified and supported in school and college – support when they are going through exams was highlighted as a particular need
- Young carers could be identified by other services e.g. drug and alcohol teams
- Some young carers could be identified from birth
- Problems with school attendance could be a trigger that a young carer is unable to cope and needs extra support at home
- Young carers should include very young carers who may not be in school

It was felt that **supporting carers through transition to adult services** was too limited and should be expanded to cover all the transitions that carers go through including

- Unplanned transitions
- Cared for moving into full time care
- Death of cared for
- Adult child of elderly carer moving into a home of their own
- Cared for child leaving school and moving back home full time

Although some participants felt that **helping carers to fulfil their education, employment and training potential** was less important to them, it was still recognised to be essential for young carers and those of working age. The particular difficulties with juggling a caring role and providing for a family were highlighted, as were the costs of specialist childcare for parent carers. Working carers would benefit from support groups and training that they could access outside of working hours.

Some people felt the strategy could have more of a focus on particular groups of carers including

- Carers of people with long term conditions
- Carers of adults with learning disabilities
- BME carers
- Young carers

Participants called for the final Carers' Strategy and any other communications to be simple, clear and jargon free. They feel it is essential that it is clear what will happen next.

Some felt that progress should be measured by the extent that subsequent actions have a positive effect on carers' lives – not just numbers. However, targets and accountability were still seen as important. People felt there was value in regularly gathering feedback and personal experiences from as many carers as possible.

“Caring for carers means less pressure on the authorities in the long term.”

A female carer aged 55-64