

The support available for carers in relation to Mental Health Services

Final Report and Recommendations

March 2009

Task Group Members

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Recommendations

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That the Health Overview & Scrutiny Committee be requested to approve the following recommendations:

1. That Swindon Primary Care trust explores the feasibility of carrying out training with local GPs to help them to recognise if a patient may be a carer and how to best meet their needs, including signposting to support organisations and inclusion on the Carers' Register.
2. That Swindon Primary Care Trust explores the feasibility of introducing Annual Healthchecks for all carers that are registered with their local GP.
3. That Swindon Primary Care Trust ensures that all carers that are registered with their GP are offered a flu jab on an annual basis, as outlined in the Swindon Carers Strategy and Action Plans 2006-2009.
4. That Swindon Primary Care Trust works with Avon & Wiltshire Mental Health Partnership NHS Trust to make the 'Information Pack for relatives and friends who care for people with mental health problems' widely available in a range of community settings, such as at all GP surgeries.
5. That Swindon Carers Centre, Swindon Primary Care Trust, Avon & Wiltshire Mental Health Partnership NHS Trust and the Great Western Hospitals NHS Foundation Trust widely promote the Annual Carers Rights Day to increase participation in the event by local carers and other stakeholders.
6. That Swindon Primary Care Trust engages service users and carers in the following reviews and reports the outcomes to the Health Overview & Scrutiny Committee:
 - Review of the Community Mental Health Team
 - Review of mental health care pathways at the great Western Hospital
 - Review of out of Borough specialist bed provision
7. That Swindon Primary Care Trust, Great Western Hospitals NHS Foundation Trust and the Avon & Wiltshire Mental Health Partnership NHS Trust be requested to take steps to promote the importance of health professionals working in partnership with people who care for someone with a mental health condition and to involve them in the care planning process as appropriate. Each Trust to present a summary of the action taken to promote the role of carers and the outcomes of this activity to the Health Overview & Scrutiny Committee in March 2010.

8. That the Health Overview & Scrutiny Committee develops a questionnaire to be sent to known young carers to determine what has changed as a result of the implementation of the “See the Adult, See the Child” protocol.
9. That the Health Overview & Scrutiny Committee reviews progress in better meeting the needs of mental health carers in March 2010. This review should include engagement with parents caring for children with mental health problems and carers of older people with mental health problems, as these two groups of carers have not been part of this report.

That the Cabinet be requested to approve the following recommendations:

10. That Swindon Borough Council, in conjunction with Swindon Carers Centre, Swindon Primary Care Trust and the Great Western Hospitals NHS Foundation Trust widely promote the Annual Carers Rights Day to increase participation in the event by local carers and other stakeholders.
11. That the Director of Human Resources and Change, Swindon Borough Council, explores the feasibility of promoting the health and wellbeing of employees who are carers through the SMILE initiative and Employee Assistance Programme.
12. That the Final Report and Recommendations of the Mental Health Carers Task Group be noted.

2. Foreword from the Chair of the Task Group

“If carers are to have the same opportunities as everyone else in society, and be able to have a life outside of caring, we need to improve support and recognition of what they do.”¹

For every person affected by a mental health illness, at least 10 others are affected by its consequences, including family, friends and work colleagues. In fact, 1 in every 40 people in the UK is caring for someone with a mental health illness. National research suggests that 1 in 4 people will have a mental illness at some point in their life and one third of GP appointments are related to mental illness.

For carers already known to healthcare services, there is opportunity to access help and support. However, there are a significant number of people caring for loved ones with a mental illness that are not receiving any form of support.

These carers also face the added stigma of caring for someone with a mental health illness and often find it hard to ask for support. Caring for someone with a mental health problem can be unpredictable, extremely stressful and for a large number of carers, very lonely.

This review was commissioned in response to concerns raised by local carers about the level of support that is available to them. This report aims to highlight the experiences of mental health carers in Swindon, celebrate their achievements in extremely difficult circumstances and to challenge health and social care commissioners and providers to consider whether more could be done to enable our carers to lead a fulfilling life outside of their caring role.

The Task Group has not aspired to identify solutions to many of the issues raised by local carers. Instead, we wanted to make more people aware of the struggle facing many mental health carers so that we could spark debate about how we could better meet their needs.

We were encouraged by the work that is already underway in Swindon to support mental health carers but it is clear that there is still some way to go in order to realise the vision for meaningful provision for the ever-growing number of carers in our community.

Finally we would like to thank all of the carers who gave up their valuable time to share their experiences with us.

Councillor Ray Ballman
Chair

¹ *Carers at the heart of 21st century families and communities*, Department of Health, 2008

3. Introduction

3.1 Rationale for the Review

In its Legacy Report, the Avon & Wiltshire Mental Health Partnership NHS Trust Public and Patient Involvement Forum summarised work that it had carried out with the Trust to improve the support available to carers.

When developing its work programme for 2008/09, the Health Overview & Scrutiny Committee decided to follow up on this work.

At its meeting on 17th September 2008, the Committee heard verbal evidence from carers and service users organisations and adult and young carers regarding the support available to them. Swindon Carers Centre and Swindon Mind also submitted written evidence.

In response to the wide range of issues raised at the meeting, the Committee decided to establish a Task Group to explore the support that is available to mental health carers in more detail.

The review was carried out under Section 7 of the Health and Social Care Act 2001, which sets out the power of local authority scrutiny committees to, "...review and scrutinise...matters relating to the health service in the authority's area and to make reports or recommendations on such matters..."

3.2 Report Overview

The report is divided into the following sections:

Recommendations	Details the recommendations from the review
Introduction	Outlines the aims and objective of the review and structure of the report
Background	Provides a background to the role of carers in supporting people with mental health problems.
Evidence Gathering	Outlines the approach taken to gather evidence and the evidence collected
Summary	Provides an overview of the review
Appendices	Contains appendices referred to in the main report

3.3 Review Structure

The review was carried out in three phases as outlined below:

Phase	Timescales	Activities
Phase 1 – Consolidation and Work Plan	September 2008	<ul style="list-style-type: none">• Task Group established• Setting of Terms of Reference• Identification of internal advisors and witnesses• Identification of existing information
Phase 2 – Evidence Gathering	September 2008- February 2009	<ul style="list-style-type: none">• Desk based research of national best practice• Meetings with internal advisors and witnesses
Phase 3 - Recommendations	February- March 2009	<ul style="list-style-type: none">• Development of final report and recommendations prior to presentation to the Health Overview & Scrutiny Committee

3.4 Aims and Objectives

To consider the effectiveness of support available for individuals who care for mental health patients and service users, including young carers, in order to ensure that their needs are being met and their health and well being promoted.

See Appendix 1 for the Terms of Reference of the Task Group.

3.5 Methodology

Evidence was gathered during the course of the review through:

- Reviewing the verbal and written evidence submitted to the Health Overview & Scrutiny Committee on 17th September 2008
- Desk based research of national policy, guidance and best practice
- Interviewing identified advisors/witnesses

4. Background

4.1 Who is a Carer?

A Carer is defined as:

“Someone, who without payment other than the relevant benefits and allowances, provides help and support to a partner, child, relative, friend or neighbour who could not managed without their help. This could be due to age, physical or mental illness, addiction or disability”².

Within Swindon, local carers have defined the role as³:

- Someone giving attention beyond that generally expected to a friend or relative who is ill, or old or frail, or disabled in some way
- Caring is unpaid
- Many take on the role without realising the impact on their own lives
- Many see themselves not as carers but as family members, friends or neighbours
- Carers need not live in the same house as the person they care for
- Some people care for more than one person
- Some carers have specific needs associated with their caring
- Young carers have distinct needs
- Support carers give can vary, change over time and be difficult to predict
- Anyone can become a carer

The 2001 Census shows that:

- 5.2 million people are carers in the UK, including 1.5 million people caring for a loved one with a mental health illness
- Approximately 550,000 young people are carers in the UK including 50,000 caring for someone with a mental health problem
- 21% of carers look after someone for more than 50 hours a week
- 25% of carers have been carers for more than 10 years
- Women have a 50% chance of being a carer by the age of 59
- Half of all carers look after someone aged 75 or above
- By 2037 the number of carers in the UK will increase by 60%

National research found that⁴:

- 11% of carers care for someone with dementia
- 7% care for someone with psychosis, schizophrenia or depression
- 8% care for people with both mental and physical illnesses
- 14% of carers care for people with learning disabilities or autistic-spectrum disorder

² Princess Royal Trust for Carers, 2005

³ Swindon Carers Strategy and Action Plans 2006-2009, Swindon Borough Council, Swindon Primary Care Trust and Swindon Carers Centre, 2006

⁴ Keeley & Clarke, 2002, quoted in Tihanyi and Cormac, p.162, “Meeting the mental and physical healthcare needs of carers”, in *Advances in Psychiatric Treatment* (2006), vol. 12

Several pieces of legislation protect carers and the people they care for. Examples of the rights of carers include:

- A right to assessment of their social care, life-long learning, employment and recreational needs, even if the person they are caring for does not want an assessment of their own needs. The assessment should take into account the carer's ability and willingness to meet the needs of the person they care for
- Carers must be told that they are entitled to a Carers Assessment
- Carers are entitled to their own care plan

4.2 National Policy

In 2008 the Government published the Carers' Strategy that sets out the short-term agenda and long-term vision for the future care and support of carers⁵.

The Strategy recognises the crucial role that an increasing number of people are playing within their communities as carers and the challenges this brings to living a normal life. The role of carers is even more important as a result of the shift towards independent living within health and adult social care.

The Strategy acknowledges that over the last ten years, the recognition and support available to carers has improved but that more must be done to tailor the support available to carers to their individual needs, to enable carers to balance their caring responsibilities with their life outside of caring and to enable the person they are caring for to be a full and equal citizen.

By 2018 carers will:

- Be recognised as expert care partners and have access to integrated and personalised support
- Able to have a life of their own
- Supported to stay mentally and physically well and treated with dignity
- Not forced in financial hardship

In addition, young carers will be protected from taking on an inappropriate caring responsibility.

In order to achieve this vision, the Strategy identifies several short-term changes that will be implemented between 2008 and 2011. These will be followed by longer-term changes between 2011 and 2018. An additional £255 million is being made available to implement the Strategy.

4.3 Young Carers

The 2001 Census indicated that there were 175,000 children and young people under 18 who carry out some form of unpaid care for a family member. 30% of these care for someone with a mental health illness. The majority carry out care tasks for up to 19 hours a week

⁵ *Carers at the heart of 21st century families and communities*, Department of Health, 2008

A young carer is defined as:

“Children and young persons aged 18 and under, who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would normally be associated with an adult. The person receiving the care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision”⁶

Young carers may experience a range of negative outcomes as a result of their caring role. These may include⁷:

- Difficult emotions such as anxiety, stress, guilt, self-blame, fear, depression, anger and resentment
- They may feel embarrassed of their situation
- Limited opportunities for social and leisure activities
- Feeling isolated and that they are different from their peers
- Fearing interference from statutory organisations
- Feel that they have lost their childhood
- Problems at school due to late or irregular attendance, having difficulty concentrating in class or completing homework, finding it difficult to mix with their peers, bullying and poor education attainment
- Fear of what the future holds and limited aspirations
- Physical and/ or mental health problems
- Difficulties in forming relationships in later life

Caring for someone with a mental health illness can be particularly frightening for a young carer as they may not want to leave them alone and may have to deal with unpredictable changes in behaviour. Both the parent and child may be affected by the parent’s reduced capacity to cope as a parent, leaving both feeling isolated and distressed. Living with a parent with a significant mental illness also increases the young person’s likelihood of developing a mental illness themselves⁸. Research also suggests that young carers are less likely to disclose their situation if their parent has a mental illness⁹.

Caring can also offer many positive outcomes for young people, including bringing families closer together, fostering maturity and independence and developing an empathy with others. However, families must be supported so that children are not expected to take on inappropriate levels of responsibility to enable them to live a full life outside of their caring role.

⁶ *The Blackwell Encyclopedia of Social Work*, M David, Blackwell Publishers Ltd, 2000

⁷ *Swindon Young Carers Strategy 2005-09*, Swindon Young Carers, 2005

⁸ *Children, Young People and Mental Health Factsheet*, Mind, 2008

⁹ *SCIE Research Briefing 11: The Health and Well being of Young Carers*, Social care Institute for Excellence, 2005

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The National Carers Strategy¹⁰ identified some of the concerns identified by young carers including:

- Gaps in support for the person they care for and the impact this has on them
- Many GPs, hospitals and schools do not recognise the role and pressures that are faced by young carers
- Gaps in emergency care for the person they care for
- A lack of short breaks and project-based support for young carers
- The need for closer working between children and adults services so that young carers are protected from taking on inappropriate levels of care

The Carers Strategy aims to:

- Provide additional support and guidance for schools through the healthy Schools Programme, SEAL and PSHE
- Broad training in schools and in other settings on the role of young carers and the issues this can cause
- Tailored training for GPs and hospital discharge teams for dealing with young carers
- Feeding learning from young carer projects into future provision
- Providing effective, joined up support for families to shift the emphasis from support to prevention
- Whole-family training for social services staff

The long-term vision is that:

“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 and to achieve against all the Every Child Matters Outcomes.”

4.4 The Challenges Facing Mental Health Carers

Casestudy: Carer A

Carer A cares for his wife. When his wife became ill, she was treated by her GP. At no point did his GP ask how he was coping or if he needed any support. He was not provided with any other information or signposted to any support organisations. He found the Carers Centre through a friend. He finds that it gets very lonely being a carer and it would mean a lot to him to receive get a phone call from his GP or practice nurse to check that he was OK. He also finds it difficult to access support outside of office hours, as he works full time.

People who care for someone with a mental health illness face many specific challenges as a result of their caring role. For example¹¹:

- Recognising you are a carer - It can be difficult for some people to admit to themselves that they are carrying out a caring role and the consequences of that role

¹⁰ *Carers at the heart of 21st century families and communities*, Department of Health, 2008

¹¹ *5 Key Facts about Mental Health Carers*, The Princess Royal Trust for Carers, October 2007

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- Risk of suicide of the person cared for – many carers caring for someone with severe depression or psychosis, there is a fear that the person being cared for will make suicide attempts. Carers also have to try to prevent these attempts or deal with the repercussions of unsuccessful attempts.
- Unpredictability of caring for someone with a mental health problem – carers may have to deal with challenging and difficult behaviour and personality changes in the person they care for. It can also be difficult to plan for the future given the unpredictability of ‘highs’ and ‘lows’. Carers may also have to deal with crises that occur out of hours, which can be stressful as immediate professional help may not always be available. In addition, mental illness can often be ‘hidden’ making it difficult for friends and family to realise that the extent of the problem.
- The stigma of mental illness – misconceptions regarding mental health illness may prevent some carers accessing the help and support they need, from friends and family and even professional support. This can make them feel extremely isolated and lonely.
- Confidentiality and information-sharing conflicts – mental health carers may experience difficulties in accessing sufficient information about their loved one’s condition so that they can carry out their role effectively. If carers are excluded from important discussions and decisions involving the patient, this can have serious practical, financial and personal consequences for both the carer and patient. Not being involved may also increase the carer’s feelings of isolation and loss. Some professionals may not be trained in how to deal with the complex needs of the patient and carer and may also be of the belief that involving carers more fully in treatment may reduce the time that they can spend with the patient.
- Jargon - There is a lot of jargon associated with the mental health system that can be confusing and intimidating and carers may not know where to go to find information and advice about mental health illnesses and treatments.
- Increased financial burdens – this may result from the person being cared for being unable to work for a long period of time and the unpredictability of their illness making it difficult for their carer at work. People with some forms of mental illness, such as bi-polar, may also spend uncontrollably
- Lack of specialist respite – it can be difficult for a carer to leave their loved one for any period of time without specialist respite. As a result, they have little ‘time off’
- Neglecting their own health – some mental health carers spend up to 60 hours a week in their caring role and may become ill themselves. Research has found that carers caring for people with mental health

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conditions are more likely to report high levels of neurotics symptoms compared to those caring for people with physical conditions or old age¹²

- The carer is often the only constant in their loved one's life – many patients experience sudden changes in the professional team that is caring for them and friends may lose touch. This means that their carer is often the person that knows them best and has on-going responsibility for their lives. This can put carers under a huge amount of pressure.

¹² *Mental Health of Carers Survey*, National Office of Statistics, 2001

5. The Experience of Carers in Swindon

5.1 Evidence Gathering

This review was established as a direct result of a wide range of written and verbal evidence that was provided by Swindon Carers Centre, Swindon Young Carers, Swindon MIND and adult and young carers who support loved ones with mental health problems.

The starting point for the Task Group was to review this evidence to identify the key issues for carers in Swindon. The Task Group then structured its review around these key issues, meeting with adult and young carers, service users and professionals from adult social care, children's services and the NHS to discuss the issues raised by carers in more detail.

Members felt that it was particularly important to find out what local strategies and policies were in place for the support of carers in order to determine the extent to which they have been successfully delivered.

The Task Group also considered best practice from elsewhere in the UK to determine whether there were any lessons that could be learnt to develop the support that is available for carers in Swindon.

5.2 Who Cares in Swindon?

In Swindon¹³:

- There were 15,750 adult and 450 young carers in Swindon in 2001 but only 3,000 carers are registered, meaning that many are not accessing the help and support that is available to them
- Given the growth of Swindon and the lack of awareness by carers themselves, this figure is likely to underestimate the number of carers in Swindon
- National research suggests that 25% of carers are caring for someone with a mental health illness
- 20% of people with caring responsibilities cared for more than 50 hours a week
- Estimated that carers in Swindon save tax payers £107 million per year

¹³ *Swindon Carers Strategy and Action Plans: 2006-2009*, Swindon Borough Council, Swindon Primary Care Trust and Swindon Carers Centre, 2006

5.3 Swindon Carers Strategy

“Carers are often the ‘unsung heroes’ in our communities; they deserve our full support to ensure that their own lives are as full and fulfilling as possible.”¹⁴

The Swindon Carers Strategy 2006-09¹⁵ sets out how all partner agencies involved in community care and development will help to raise the profile of carers’ issues and to promote the health and well being of carers. The Strategy acknowledges that there are many issues that are common to many carers but that each has a unique situations and specific needs.

The Strategy builds on the first Carers’ Strategy for Swindon that was published in 1999 in response to the Prime Minister’s Strategy for Carers.

The objectives of the Strategy are:

- To address how agencies should respond to what carers locally have said they need and want
- To implement Carers legislation and developments under relevant National Service Frameworks and other national policies and strategies
- To maximise the impact of the finite resources that are available in health and social care to support carers

The Strategy is supported by several action plans that have been developed by the Swindon carers Network and partner agencies. They are based around the following themes:

- Information - regarding the rights of carers and the support that is available to carers
- Recognition - both individually and as a group and identification of the needs of carers through a Carers Assessment and adherence with Carers Charters that should be in place in each service area
- Short breaks and respite - crucial to support carers to sustain their caring role. The Equal Opportunities Act 2004 emphasises the need for Carers to have access to social and leisure opportunities and this should be taken into account as part of a carers assessment
- Involvement in the commissioning and planning of services - both for their own needs and those of the person they care for
- Safeguarding the health of carers - including providing the right skills and knowledge to assist them with their caring role and to promote their emotional health and well being

¹⁴ *Swindon Carers Strategy and Action Plans: 2006-2009*, Swindon Borough Council, Swindon Primary Care Trust and Swindon Carers Centre, 2006

¹⁵ *Swindon Carers Strategy and Action Plans: 2006-2009*, Swindon Borough Council, Swindon Primary Care Trust and Swindon Carers Centre, 2006

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- Urgent/ alternative care - may be required if a carer has a crisis or emergency situation and are unable to carry out their caring responsibilities. In addition, each carer has the right not to assume a caring role and may wish to explore options for alternative care
- Financial Security/ employment for carers – many carers remain in employment or wish to seek employment in addition to their caring role. Many feel this provides them with financial and social independence and provides them with a life outside of caring.

The Carers Partnership Board that includes representatives from adult social care, children’s services, primary, acute and specialist mental health NHS Trusts and carers representatives monitors implementation of the Strategy and Action Plans.

Since 1999 the Government has provided each local authority with a centrally funded Carers Grant. The Carers Partnership Board uses the Grant to commission services. The breakdown of funding is summarised below:

	2008/09	2009/10	2010/11
Children’s Services	141,230	139,400	148,800
Adult Services	482,550	515,043	530,574
Currently unallocated	27,220	42,557	64,626
Total Grant	651,000	697,000	744,000

In Swindon the Grant has be used to develop carer support in the voluntary and statutory sector. In relation to support for mental health carers, this includes:

- Short break and respite opportunities
- Development if an information directory for carers
- Development of support for young carers including 3 age related Young carers Groups, A Young carers Support Worker and a Development Worker to support the delivery of the Young Carer Strategy
- Specialist Carers Care Manager to support staff within Community Mental Health Teams to improve support for carers
- Generic Carer Support Worker based at the Swindon Carers Centre
- A range of social activities, courses and relaxation therapies run by Swindon Carers Centre
- Support workers based at the Memory Clinic and courses for carers caring for someone with dementia
- Emergency support provided by the Crisis House and Crisis Teams

There are also clear links between the Strategy and related strategies such as for dementia and the stroke care pathway.

The current priorities for the Partnership Board are:

- To update the Strategy and Action Plans to reflect the new national strategy. Carers are leading this work via the Carers Partnership Board.
- A Carers Development Officer has also been appointed to lead on the development of the Action Plans.
- The development of joint care plans for carers, which was identified by the Joint Strategic Needs Assessment
- Ensuring that the needs of carers are incorporated as part of the personalisation of services. Carers are a potential pilot group for individual budgets
- Addressing the need for increased advocacy and support that was identified by carers through consultation

5.4 Support for Young Carers

Swindon Young Carers Strategy

There is a separate Strategy for Young Carers that is managed by the Young Carers Steering Group. The Strategy provides a comprehensive framework for developing the support that is available to young carers in partnership between the statutory and voluntary sectors, families and young carers.

The objectives of the Strategy are:

- To provide young carers with opportunities to express their views
- To meet the needs of young carers through services that are planned and provided in partnership by a range of agencies
- To continue to raise the awareness and understanding of professionals about the needs of young carers
- To define the responsibilities of individual agencies in respect of young carers
- To highlight the rights of young carers to assessment, services and support
- To raise the profiles of young carer in the business plans of agencies
- To ensure that young carers are recognised and supported in order to reduce the negative impact in the future physical and psychological well being

The Swindon Young Carers Steering Group supports the delivery of the Strategy and Action Plans, which is overseen by the Carers Partnership Board.

Supporting Young Carers

Below is a summary of the main support mechanisms that are available to young carers locally:

- All referrals for young carers are made to a central referral point managed by the Young Carers Support Worker who completes a specially developed young carers assessment to determine the most appropriate support to meet the needs of a young carer. Young carers and their

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parents can self refer and any professional working with the family can also make a referral.

- Swindon Carers Centre employs a Support Worker as a referral point for statutory and voluntary agencies, as well as for self-referrals. The Support Worker can also provide advice and support to young carers, carry out young carers assessments, liaise with the relevant services to ensure that appropriate support services are available to relieve the young carer if their responsibilities and to provide a link between the young carer, their family and support services.
- Swindon Carers Centre also employs a Young Carers Development Worker to raise awareness of young carers issues and to work with agencies to help them to improve their response and service to young carers.
- The Young Carers Group Co-ordinator is based in the Plus One Team within the local authority and manages the provision of young carer services within Community Education, which includes young carer groups, activities and short breaks.
- The Friends of Young Carers is a charitable group that aims to promote awareness of young carer issues, particularly in the Swindon business community. The group fundraises to provide individual and group activities for young carers that compliments existing provision.
- A Young Carers Forum has been established to enable young carers to have a voice and to inform the planning and development of services. Swindon Carers Centre supports it. In addition an annual young carers seminar is held for professionals to improve awareness and the response by agencies to the needs of young carers.
- A protocol has been agreed between Children's Services and Adult Social Care regarding their respective roles in relation to supporting young carers
- Each agency that has signed up to the Strategy should also have developed a young carers charter.

Identifying Young Carers

"See the Adult, See the Child' is a local strategy that identifies the impact of an adult's unmet mental health needs on their children. A "See the Adult, See the Child Protocol' was developed in 2002/03 that focussed on meeting the needs of children in acute crisis and was limited to parents with an unmet mental health or substance misuse need.

The outcome of a serious case review led to a refresh of the Protocol in 2008/09. Responsibility for the Protocol sits with the Local Safeguarding Children Board (LSCB). The refreshed Protocol will now apply to children in all

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'levels' identified by the Children & Young People's Plan¹⁶. This means that where a parent has an unmet mental health or other need, the needs of their children must also be identified and met across all services. The Protocol will apply to parents with a wide range of unmet including mental health, substance misuse, learning disabilities, physical disabilities or if they have been imprisoned or are monitored by the Probation Service.

It will also provide a useful framework to monitor how the needs of children are identified and met where their parents or carer has a need for support from adult services and to ensure that the needs of the parent are not seen in isolation. Professionals from both adult and children services will also receive additional training to support the delivery of the Protocol. There is also a need for Children's Services to improve its understanding of how Adult Social Care operates so that the two services can work together effectively.

Within Children's Services, a Common Assessment is used to identify a child's needs. This is usually used from 'Level 2' (vulnerable children) upwards and over 1500 workers have been trained to carry out a common assessment, including a large number of professionals from outside of Children's Services e.g. education staff, housing officers, adult social care staff. Parents must provide consent for a common assessment to be carried out.

Once completed, the common assessment is logged centrally by Children's Services. The parent and child are then invited to attend a meeting with either the professional that carried out the common assessment, such as a teacher at school, or to a meeting that is arranged centrally by Children's Services. Parents are always offered an advocate to attend the meeting with them.

Parents are generally pleased to participate in the process, as they are glad that someone has noticed that something is wrong and are offering to help. The Common Assessment process can help to identify long-term and interim support that is required by a parent and their child.

5.5 The Experiences of Adult Carers in Swindon

This review was commissioned largely as a result of the powerful accounts given by local carers who care for someone with a mental health illness to the Health Overview & Scrutiny Committee regarding their experiences as a carer. Members felt that it was extremely important to recognise the significant role that carers play in our communities and to explore some of the many challenges that they face on a day to day basis in order to determine whether more could be done to support them in carrying out their caring responsibilities.

¹⁶ *Children & Young People's Plan 2008-2011*, Children & Young People's Strategic Partnership Swindon, 2008

Carer Case Study: Carer B

Carer B has been sole carer for his wife for the last 6 years. She requires 24-hour care. He gave up his job, as his employer did not understand the demands of his caring responsibilities. His wife has not had a Community Psychiatric Nurse (CPN) for the last 4 years and does not have a social worker. She sees a psychiatrist every 4 months but it has been a different person every time. His wife has become violent towards him on several occasions. He called the Crisis Team for advice and they suggested that he called the police, which he felt he was unable to do. His wife has refused to go into hospital but there are limited opportunities for specialist respite. As a result, Carer A has not had a break from his caring role. He has never received a carer's assessment. His wife was recently diagnosed with Parkinson's disease and the Carers Centre arranged for an assessment to be carried out by Adult Social care to provide support for her physical condition. He and his wife have limited contact with friends and family and the Swindon Carers Centre is his only real source of support.

Members of the Task Group met with a group of 8 adult carers from the Mental Health Carers Support Group that is run by Swindon Carers Centre to discuss some of the issues raised previously by carers in more detail.

Below are the key issues that were raised by adult carers who care for a loved one with a mental health illness:

- **The needs of all carers need to be taken into account**, including those who support working age mental health services users, carers of children and older people with mental health problems. Every carer will have an individual situation and specific needs, which may change over time.
- **Carers are often unsure of their rights** and entitlements
- **Not all carers have received a carer's assessment**, some do not know that they are entitled to one and some wrongly assume that this is an assessment of their capability as a carer.
- **Most positive feedback is from carers who have had an assessment** of their caring role as they feel that their needs are recognised and they know where to access support if they need. However, some carers raised concerns about the extent to which there was meaningful follow up in response to the needs identified by the assessment. Many also thought that there was a need to ensure that assessments were carried out at an early stage.
- **Carers want readily available and easy to understand information at an early stage** about mental health, mental health services and where they can access help, advice and support. Most importantly, they want to be signposted to the right information and not left to try to find it themselves and just being told 'the facts' is not always helpful. Carers need to understand what's happening.

“Information is normally perceived as throwing facts at people, this only partially helps. When an episode of depression or psychosis is currently happening, the reception of the ‘facts’ alone is unhelpful as they cannot be retained and all the energy is focussed on the ill person and the illness.” (Carer)

- Although some **carers** feel health professionals listen them to, they **do not always feel that their views make any difference.**
- **Care Plans are seen as important** provided they are valued by mental health professionals and **carers want to be included in their development and review** if they are supported to do so. As the patient must give their consent for their carer to be told about their condition and treatment, some carers are excluded from this process if their loved one decides to keep this information confidential. Carers in this situation respect the decision of their loved one but find it extremely difficult to care for them if they do not know what they are ‘up against’.

“It makes me distraught not knowing. I don’t know what I’m trying to handle.” (Carer)

- Some carers feel that **health professionals do not consider their health and well-being** and the impact that their health has on the service user. Although there were examples of GPs being extremely supportive and proactive in considering the health and well being needs of carers, many carers said that their GP did not even ask them how they were when they attended appointments with their loved ones. The Carers Centre is trying to work with local practices to increase the awareness and knowledge of GP staff regarding the support needs of mental health carers, for example several drop in sessions were held at local surgeries during National Carers Week. However, many carers feel that more could be done to share good practice between practices. In addition, more follow up by mental health professionals to see how the service user and carer are getting on would be welcomed.
- **Some carers have difficulties in accessing respite or breaks** or are scared about what will happen if they do leave the person they care for
- **There is limited support for carers ‘out of hours’**, which is particularly vital at times of crisis. Some carers said that they would call their loved one’s support worker if they had to. Others said that they would contact the Crisis Team. Some carers thought that the Crisis Team has had a positive impact on carers and service users regarding access to services but some carers said that they had received varying degrees of practical help in the past.
- There are **issues regarding how carers are supported** if the person they care for is admitted to a hospital **outside of Swindon**. Carers may have to travel long distances to see their loved one, which can be time consuming and expensive. They may not be able to see their loved one as frequently

as they would like, particularly if they work or have young children. They may also have difficulties in accessing support from local professionals. In addition, many patients choose to stay at home rather than being admitted outside of Swindon, which places an additional burden on their carer.

“It is very important that carers of those who are seriously ill, being treated out-of-area or where the carer is caring for more than one person (or has other family responsibilities) are provided with support – not only be Swindon carers and not only during ‘office hours’”. (Carer)

- **Health and social care professionals often do not recognise when a person is carrying out a ‘caring role’** and this may prevent them from accessing support. One carer said that her GP did not recognise her as a ‘carer’ because she does not live with the person she cares for and she is not included on the practice’s Carers’ Register. Another carer said that her GP has never asked her about her caring responsibilities for her daughter who lives with her and that she is not registered as a carer. One carer said that she did not recognise herself that she was carrying out a caring role and needed some support until the Community Mental Health Team suggested that she made contact with the Carers Centre.

Casestudy: Carer C

Carer C cares for her husband. Her GP has been extremely supportive throughout her husband’s illness and made time to see her even if she has not booked an appointment if it is clear to practice staff that she is upset. She felt that there is a need to ensure that good practice is shared with all GP practices across the Borough.

- **The support provided by NHS organisations is seen as limited** and a large number of carers rely on community and voluntary organisations. Several of the carers that Task Group spoke to only received support from the Mental Health Carers Support Group that is run by Swindon Carers Centre. The group only meets once a month due to limited funding and places are limited to 12. Information sessions are held before each meeting, which are valued by members of the Group. Many of the carers felt that they would be completely lost without the Group and that it provided a valuable opportunity to talk about their concerns, worries and experiences in an environment where they will not be judged. However, concerns were raised including:
 - There is only sufficient funding to enable the Mental Health Carers Support Group to meet once a month, which means that many carers receive no other form of support between meetings. In addition, space on the Group is limited
 - It is difficult for carers who work full time to attend support meetings and most forms of support tend to be during office hours
 - Although some carers are referred to the Carers Centre by their GP or their loved one’s support worker, many came across the Carers Centre by chance

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- Some carers said that they felt that they had to 'push' their GP to refer them for support
- Many carers did not receive any support from other sources such as their GP or their loved one's CPN, support worker or social worker
- None of the carers that the Task Group spoke to from the Mental Health Carers Support Group had been invited by their GP to have a flu jab, even though carers are entitled to one. One carer had asked for a flu jab and been told that she could not have one because there were limited supplies

"I do get fed up. I get to the point when I think 'What's the point?' but you've got to pick yourself up and get on with it." (Carer)

- **Access to mental health services is poor where service users have other health needs** such as substance misuse problems or where an inpatient at a mental health unit is accessing services at a general hospital. In addition, one carer felt that there was a need for closer working between mental health; social care and housing services to support people with mental health problems. Her son was left homeless after being asked to leave a hostel after he self-harmed, placing both him and his family under a huge amount of stress.
- **Carers' own lives are affected** physically, emotionally, socially and financially, as well as having to take the lead in domestic life. For example:
 - Several of the carers that the Task Group spoke to had suffered breakdowns themselves
 - Where a carer's partner has become ill, they often have to take on sole responsibility for decision making, which can put them under additional pressure and make them feel more isolated
 - One carer explained that since her husband has become ill, she has not had the time, skills or money to be able to keep her home and garden well maintained
 - Many carers have to juggle their caring responsibilities with work. Several said that although their employers and colleagues were supportive when their loved one first became ill, they do not understand that their loved one requires long term care. This can create difficulties when they need more flexible working hours. Some carers have had to give up their job as a result despite them valuing the independence and break from caring that their job provided
 - All of the carers that the Task Group spoke to said that they rarely saw friends or family because they often do not understand their loved one's condition
 - The person that is ill does not always realise the impact that their illness has on their loved ones
 - Many carers said that they would not tell their loved one if there are struggling to cope or if they are ill themselves, as it places an additional burden on them

"It is hard to fully put into words the impact being a mental health carer has had on my life....It has had a dramatic impact on our emotional and

physical health, although with help from other carers we have – just about – been able to cope. In lots of ways we are having to pay a very high price for my son’s illness, but at least while we are here, it is a price we are willing to pay and it is not a price the state has to pay.” (Carer)

- **Support for carers needs to be more proactively promoted** e.g. in GP surgeries, inpatient units

“When it happens, it feels like you’re in a black hole. You just want someone to say that it’s OK.” (Swindon Carer)

- **Health professionals within general hospitals need to be more aware of the knowledge and expertise of carers** and involve them in the planning and delivery of treatment to their loved ones. Several of the carers that the Task Group spoke to had experience difficulties when their loved one was admitted to hospital for treatment of a physical condition. Concerns included:
 - Staff not providing any assistance with eating meals and in some cases not checking whether the meal had been eaten
 - Not providing carers with sufficient information about the person’s treatment or behaviour whilst an inpatient
 - Treating the carer as an ‘intrusion’ and ignoring their advice regarding how to handle their loved one’s behaviour
 - Not considering the impact that a person’s mental health may have on their ability to carry out physical tasks, such as calling for help
 - Not discussing discharge arrangements with the carer prior to, or at the point of admission. This was a particular concern for one carer who’s loved one was due to go into hospital for a hip replacement.
- The **needs of carers** should be given **more emphasis as part of discharge planning** from an inpatient unit
- The **take up of direct payments** by mental health carers locally is extremely low. According to Swindon Borough Council records, no mental health carers are in receipt of direct payments. None of the carers that the Task Group spoke to were aware of their entitlement to direct payments or how they could help them.
- Many **carers do not know how to raise concerns or make complaints regarding the NHS**. All of the carers that the Task Group spoke to said that although they knew that they could raise concerns with the Patient Advice and Liaison Service (PALS), they did not know that there were different teams for different NHS Trusts and they did not know who they should contact to raise concerns. Several carers had raised concerns but not felt that they had been taken seriously.
- The **links between the quality of local mental health services and the support required by carers**. Several carers said that their loved one’s

lead support worker changed frequently. This puts additional pressure on carers, as they remain the only constant in their loved one's life, that it often takes time for their loved one to build up trust with their support worker and that they often do not understand their needs and how to manage their behaviour

- There are lots of opportunities to support carers which are already taking place in Swindon but **any targets need to be valued, understood and have a positive outcome for carers**

5.6 The Experiences of Young Carers in Swindon

Case Study D

Carer D is 13 years old and is the sole carer for her Mum and her 18-month-old brother. Sometimes she does not go to school because she has to stay at home to take care of them. She also does not go out much because she is worried about who will look after her family. She also feels that she cannot take friends home because of her Mum. Kids at school also tease her because of her home life, which she finds really upsetting. She attends the Young Carers Group, which she finds really helpful to get away from her responsibilities for a while.

The main issue impacting on young carers **is the lack of recognition of their role by those working with the service user**. A survey carried out by Swindon Young Carers in April 2008 with 8 young carers found that young carers did not feel that their views were listened to and respected by health professionals. They also felt that health professionals did not understand their situation or take into account their rights, health and general well being as a carer.

They also had varying experiences in relation to the information they were given about mental health services. One young carer said:

"They told my dad and older members of the family but didn't tell me much except 'she will be OK'".

The majority of the young carers that participated in the survey received some level of respite care or breaks to help them cope with the pressures of caring for someone with mental health problems, mainly through Swindon Young Carers. In addition, the majority had received a carer's assessment, which was generally viewed as being helpful.

A key issue raised by the Health Overview & Scrutiny Committee was whether schools could do more to help identify young carers and to support them at school. 'See the Adult, See the Child' will require all schools to ensure that staff have the skills and knowledge to identify young carers and can access appropriate support to ensure that the needs of these pupils are met. This is

an issue that the Health Overview & Scrutiny Committee may wish to continue to monitor.

5.7 Support available from local NHS Trusts for mental health carers

In response to the concerns raised by carers, the Task Group met with representatives from local NHS Trusts to discuss the support that should be available to carers and what work is taking place locally to develop provision.

Great Western Hospital NHS Foundation Trust

The senior management team at the Trust are extremely committed to improving the support provided to all carers. Much work is underway in conjunction with carers support organisations and carers to identify how the Trust can take actively support carers when their loved one has to go to hospital.

An Action Plan has also been developed in conjunction with the Princess Royal Trust for Carers to increase the support available to all. This work is initially focussed on adult carers but representatives from the Trust have also met with a group of young carers to consider their needs. The Trust also hosted the Second Annual Carers Rights Day that was arranged by the Swindon Carers Centre in December 2009.

In relation to emergency admissions, the 'Front Door Team' includes a mental health liaison nurse who carries out an assessment and makes a referral to mental health services if necessary. The Team is based at the Accident & Emergency Department Monday to Friday and operates on an 'on-call' basis during the weekends. Each Ward should also have its own social worker.

Work is ongoing to strengthen links with the Avon & Wiltshire Mental Health Partnership NHS Trust. An operational group has been established to map patient pathways depending on whether a patient is admitted as an emergency or as a planned admission and if they are already known to mental health services. Three acute mental health pathways are being mapped, along with a separate pathway for older people. This links with the introduction of new national standards for mental health that will be implemented in 2009 and will also take into account the support needs of carers.

The Trust also plans to introduce 'flags' on its electronic patient record system. When implemented, this will include whether a patient is a carer or has a carer. The initial assessment carried out by hospital staff should also identify whether a patient has a carer, and their age in order to identify young carers, as well as whether they are a carer themselves.

Carers can stay overnight and reclining chairs are provided in each ward. Staff should have a discussion with the carer to agree whether they wish to carry out some caring tasks for their loved or whether they would prefer that these tasks are carried out by hospital staff.

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Training for staff includes the implications of the Mental Capacity Act and the needs of patients with mental health problems. There is an emphasis on how nurses can become more skilled in managing challenging behaviour within an acute setting. This work is being carried out in conjunction with the Mental Health Liaison Nurse from the Victoria Centre who specialises in working with older people with mental health problems. The training also deals issues in relation to confidentiality and the importance of involving carers in the care and treatment of their loved ones as fully as possible.

The Mental Health Liaison Nurse has an important role in carrying out 'inreach' within hospital to support hospital staff to better meet the specific needs of older people with mental health conditions and to ensure that the patient also receives care and treatment from acute mental health services if appropriate.

Avon & Wiltshire Mental Health Partnership NHS Trust (AWP)

The Trust recently appointed a Carer Engagement Lead, who is a carer herself and is extremely active in promoting the rights of carers nationally. She has worked with the Trust over the last 6 years and led in the development of the Carers Information Pack.

Work that has been taking place by AWP to increase the support available for carers:

- A mental health awareness campaign was held in Summer 2008 in conjunction with AWP's partners in order to promote the health and wellbeing of service users and their families. The Trust intends to repeat the campaign in the early summer of 2009
- A pilot was held at Sandalwood Court in Swindon regarding the process to involve carers in the care, treatment and discharge of their loved ones. This included when the time is right to provide carers with the Carers Information Pack. The process has been reviewed as a result of the recent Inpatient Review. The current process that should be operating in all inpatient units is:
 - The carer is invited to meet with the service user's named nurse to discuss the needs of the service user e.g. how to manage behaviour, any routines or special needs. The carer should also be provided with a copy of the Carer Information Pack and asked to think about whether they have any support needs
 - If the carer does not come into the inpatient unit at the point of admission but staff identify that they are the main carer of the service user, they are sent a letter identifying their loved one's nurse and inviting them to an appointment to meet them. If the carer does not make contact, this is followed up by a phone call
 - The named nurse should act as a first point of contact for the carer and be able to signpost them to access help, advice and information if they require it
 - Discharge plans should include details of the Out of Hours service for carers to use in an emergency
 - The modern matron is responsible for ensuring that this process is followed

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- All inpatient units are encouraged to have a notice board with relevant information for carers including local support groups, how to contact the PALS Team and details of the Carer Lead at the Unit
- There should be an identified Carer Lead on each inpatient ward. A toolkit has been developed for Carer Leads to enable them to provide advice and support to colleagues. In addition, they are a channel for disseminating good practice, policy and procedure. A network is being established to enable Carer Leads to meet on a regular basis
- Induction training for all staff includes a session on the stages of caring and the varying support needs of carers. It is important that AWP staff can recognise when a carer may need support and can confidently signpost them to access support services, as well as recognising their own role in supporting carers. The session also focuses on the importance of working in partnership with families and carers
- A whole day training session is also available to staff on a voluntary basis that goes into more detail about supporting carers and partnership working e.g. carers assessments, managing confidentiality
- AWP has developed its own Carers Strategic Framework, which aims to outline the Trust's vision for supporting carers. It also aims to compliment each of the PCT/ local authority Carers Strategies in the areas it serves. A Carers Implementation Plan has been developed and is due to be presented to the AWP Board for approval in the next few months. It outlines activity that is currently taken place and planned activity that must take place in response to the Homicide Action Plan to support carers and families. It has been developed in conjunction with champions from each Business Support Unit (BSU) across the Trust. The contents of the Implementation Plan will be disseminated to staff via the BSU champions and Carer Leads. The final version of the Implementation Plan will be shared with partners.
- A Trust-wide Carers Forum is in existence that involves carers, workers and voluntary and community organisations. It aims to share best practice from across the Trust

Issues or areas for development

- There is a need to ensure that inpatient staff are aware of local support organisations and that close links are developed to enable them to signpost or refer carers
- There is a need to ensure that carers clearly understand the role and remit of the Crisis Team so that they have realistic expectations of the support that it can provide
- There is not a dedicated Family Intervention Support Worker for Psychosis in Swindon, which would be welcomed by many carers
- There is a need to encourage workers to be more creative in addressing the needs of carers for respite
- Continuing to share the good practice that is developing in Inpatient Units with Community Teams
- In North Somerset, the Primary Care Trust and AWP jointly commissioned several carer support workers. They had an important role in advising other professionals in how best to support carers and providing direct support to carers with complex needs

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- There is a need to raise awareness of Direct Payments for mental health service users and carers. Direct Payments will enable greater choice
- As commissioners, Swindon PCT monitors AWP against several performance indicators, one of which is the number of carers 'receiving a service'. The current target is for 13% of carers to receive a service. Key to the delivery of this target is ensuring that effective data collection processes are in place to identify where carers are not being offered support so that interventions can be put in place to address this issue. Both the PCT and AWP see this target as a key priority and there are plans to explore whether this target can be reviewed to include:
 - The number of carers offered a service
 - The number of carers receiving a service (there is a need to clearly define what 'receiving' actually means in practice)

Swindon Primary Care Trust (PCT)

Swindon Primary Care Trust (PCT) is responsible for commissioning, or purchasing, community, inpatient and specialist acute inpatient mental health services for the people of Swindon.

A key issue raised by carers was the impact of their loved ones being admitted to an inpatient unit outside of the Borough. This means that carers have some distance to travel to visit their loved one on a regular basis, which impacts on carers not only financially and on their time but can also create issues around transport, child care and time off work.

The Task Group was keen to determine why some patients are placed outside of Swindon for treatment and how carers can be better supported when this situation arises.

Members were reassured that a patient should only be admitted to an inpatient unit outside of Swindon on the rare occasion where a bed is not available at Sandalwood Court. Applewood Ward at Sandalwood Court has 12 inpatient beds and is currently operating at 80% capacity, which is recognised as the optimum capacity nationally. As a result, Sandalwood Court should have the flexibility to admit a new patient in the case of a crisis. In addition, the increased emphasis on therapy and recovery planning over the last 12 months has resulted in a reduction in the duration of stay, relieving pressure on beds.

If a bed is not available at Sandalwood Court, an assessment process is in place to determine the most appropriate placement for the patient on a short-term basis. The needs of a patient's carer should be taken into account as part of this assessment. There should also be a clear focus on returning the patient to Swindon as soon as possible.

The situation is different for specialist acute care. All specialist acute placements are outside of Swindon. This is due to the small number of patients involved, the specialist nature of the staff required, the high costs in

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providing such a service and the need to ensure clinical quality and the safety of patients. As part of the assessment of a patient, the care manager should be identifying the needs of their carer and ensuring that they are kept informed regarding the care plan. The care plan should also focus on treatment to aid recovery and to enable the patient to return to Swindon as soon as possible.

There are currently no plans to review the provision of specialist services. However, the PCT is leading work to review how primary care and specialist mental health services can work better together to ensure that service users are effectively treated at an early stage to prevent the escalation of their condition and the onset of a crisis that may result in a specialist placement outside of the Borough. The reviews involve primary care, acute and specialist staff, the third sector, service users and carers. Three reviews are taking place:

- Review of the Community Mental Health Team – including caseloads and the role and effectiveness of GPs in supporting mental health services users and their families. The aim of this review is to ensure that the Community Mental Health Team is focussing on service users with the greatest need and has the capacity to provide more targeted support.
- Review of the Crisis Team – including the role of the third sector in supporting service users and their families alongside AWP at times of crisis to ensure that the Crisis Team is focussing on service users with the greatest need. There is also a need to ensure that service users, their families and health and social care professionals understand the role of the Crisis Team and what it does and does not do.
- Emergency Department Liaison at the Great Western Hospital – as outlined earlier in this report, three care pathways are being developed to better meet the needs of mental health service users who attend Accident & Emergency (patients known to mental health services, patients not known to mental health services and older people). The intention is to build on the older people's 'inreach' service to provide more appropriate care for patients with a mental health condition.

In addition, a workshop is being held involving the local authority, PCT, AWP and the third sector to review approximately 40 historical cases where a service user has been placed outside of the Borough to identify:

- How could each patient's care have been managed differently to prevent the escalation of his or her condition?
- Was the placement appropriate?
- What processes are required to prevent the escalation of a patient's condition and therefore avoiding the need for a specialist placement?
- Any learning that can inform the three reviews referred to above?

A pilot is also underway to create a specialist Eating Disorder Support Worker post within the Community Mental Health Team. The aim of this post is to provide support, guidance and advice to other workers who support service users with an eating disorder. The increased emphasis on effective treatment in the community should avoid the escalation of a patient's condition which

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may result in them requiring costly specialist inpatient treatment for their physical and mental health. The success of the pilot will be determined by patient feedback and the quality of care provided to service users.

The PCT has commissioned a further 12-month pilot for a specialist Older People's Mental Health Worker linked to the adult locality teams in Wroughton and Old Town. These locations have been picked due to the older profile of the population. The worker's role will be to ensure that every service user and their carer receives the right treatment and advice through:

- Managing the top 10% of complex and extreme cases
- Providing advice and guidance to other workers
- Providing 'inreach' to people in their own homes to facilitate early diagnosis of dementia

The Joint Commissioning Board, which is responsible for commissioning mental health services, has made it clear that there is a need to reduce the number of put of Borough placements and that local services should be better equipped to manage the needs of the majority of patients and avoid the need for specialist placements which are not only expensive but may impact on the long term well being of the patient and their family.

The Task Group acknowledges that work is taking place to attempt to reduce the number of patients requiring treatment outside of the Borough. However, there is a need to ensure that service users and carers are better informed as to why a placement outside of the Borough may be required and the care plan that is put in place to support the service user to return to Swindon as soon as possible.

6. Summary of Findings

The Health Overview & Scrutiny Committee was extremely concerned by some of the issues raised by carers, which led to the commissioning of this review.

Mental health carers do an extremely tough job and we cannot thank them enough for their continued efforts. The Task Group members have been humbled by all of the stories of the carers that we have met with and we are in awe of their sheer grit and determination to 'get on with it' regardless of what their situation throws at them.

However, we must not leave these carers unsupported. Many of the carers that we have heard evidence from have said that their own health and well being has suffered as a result of their caring role and many feel trapped in situation to which few of their friends, family or health and social care professionals can relate.

The Task Group has heard about a great deal of work that is taking place at a strategic level in order to ensure that health services are better at identifying mental health carers, assessing and meeting their needs. The feedback from carers is that in many cases, the support that they desperately need is not forthcoming from frontline services.

The needs of carers does appear to be a priority for all of the NHS Trusts that we spoke to and there is a commitment at a senior level to drive change. The challenge now is to cascade this commitment throughout the NHS to ensure that frontline staff always stop to think whether there is a carer associated with every patient that they treat and whether that carer has their own needs that ought to be met.

Several issues have come up frequently during this review:

- **Recognition.** Healthcare professionals do not always recognise that an individual is carrying out a caring role. This applies to adults and young carers. Frontline professionals need to have a better understanding of what being a carer entails, who may be acting as a carer and be proactive in finding out how carers could benefit from more support
- **Communication.** Lots of encouraging work is taking place to improve services for service users and carers. The issue is that carers are not always aware of this work; feel that no one is fighting their corner and that they have nowhere to turn. The NHS has to make it clear what support is available to carers and how this can be accessed and carers must speak up to tell the NHS what information, advice and support they need. In addition, communication must continue throughout the period when a person is acting as a carer. A mental health carer may assume this role for decades. Their needs do not go away and frontline professionals must have an ongoing dialogue about their needs.

- **Partnership working.** Fundamentally carers are crucial partners in caring for a service user. They are often experts in their loved one's behaviour. Healthcare professionals must recognise that carers are partners in care and actively involve them in the planning and delivery of care. The barriers caused by patient confidentiality are a big issue for many carers. Healthcare professionals need to be supported to understand what patient confidentiality means in practice.
- **Challenging the stigma attached to mental health.** People who care for someone with a mental health illness face as much stigma as service users. As a result, many carers do not feel able to ask for support, even from their own GP. We must continue to tackle this issue head-on to ensure that carers do not become isolated.

Clearly this report alone cannot bring about the wide reaching change that is required to address these issues. However, we hope that this report has helped to highlight the experiences of mental health carers in Swindon and that the local authority, NHS, the third sector, service users and carers can continue to work together to provide mental health carers with the support they rightly deserve.

APPENDIX 1

Health Overview & Scrutiny Committee

Support available for carers in relation to Mental Health Services

Terms of Reference

<u>Aim</u>	To consider the effectiveness of support available for individuals who care for mental health patients and service users, including young carers, in order to ensure that their needs are being met and their health and well being promoted.
<u>Rationale</u>	<p>In its Legacy Report, the Avon & Wiltshire Mental Health Partnership NHS Trust Public and Patient Involvement Forum summarised work that it had carried out with the Trust to improve the support available to carers as part of the 'Carers Project'.</p> <p>The PPI stated in its Legacy report that:</p> <ul style="list-style-type: none"> • The results and comparisons of the 'Carers Project' will need to be followed up as it is anticipated there will be significant outcomes to be addressed • Work with Young Carers to ensure that 'packs' are used in Trust as they are in Acute Trusts • Work with the User/carer groups and Young Carers in implementing the Young Carers questionnaire – as designed by them – work is ongoing in Wiltshire and BANES <p>When developing its work programme for 2008/09, the Health Overview & Scrutiny Committee decided to follow up on this work.</p> <p>At it's meeting on 17th September 2008, the Committee heard verbal evidence from carers and service users organisations, adult and young carers regarding the support available to them. Swindon Carers Centre And Swindon Mind also submitted written evidence.</p> <p>The Committee agreed to establish a Task Group to explore the issues raised at the meeting and the written evidence in more detail.</p>
<u>Scope</u>	<p>Includes:</p> <ul style="list-style-type: none"> • National and local policy and guidance including the impact of the 'Carers at the heart of 21st Century families and communities strategy' in Swindon • How are individuals who care for patients with mental health problems identified and can more be done to ensure that more carers are identified and offered support? • What are the main barriers for carers in accessing support? • How are the needs of carers assessed? • What support is available for carers in Swindon? • Are there any gaps or need for improvements in order to meet needs

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	<p>and demand?</p> <ul style="list-style-type: none"> • How does being a carer impact on an individual's own mental and physical health, social and economic well-being? • How are young carers identified and supported, particularly at school? Does more need to be done to support them, not only to carry out their caring responsibilities but also to help them in their own lives? • Explore the impact of the closure of the psychiatric intensive care ward at Sandalwood Court on carers • To consider best practice nationally • To discuss the areas for development with Swindon PCT, Avon & Wiltshire Mental Health Partnership NHS Trust, Swindon Borough Council and Swindon Carers Centre to determine: <ul style="list-style-type: none"> - If the support that is available for mental health carers in Swindon is fit for purpose - If the perceived gaps in support for mental health carers are actually being addressed by existing services - If potential solutions to address gaps in provision can be explored in more detail • To develop recommendations based on the outcome of the review <p>Excludes:</p> <ul style="list-style-type: none"> • This review is limited to the support available for individuals caring for patients with mental health problems and does not include a detailed review of the wider support available for all carers • It is acknowledged that many of the support mechanisms are available to all carers 				
Resources	<p>Task Group:</p> <ul style="list-style-type: none"> • Councillor Ray Ballman (Chair) • Councillor Peter Mallinson • Councillor Mick Bray <p>Officer Support:</p> <ul style="list-style-type: none"> • Emma Powell, Scrutiny Officer 				
Timescales	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 15%;">Start</td> <td>First meeting 6th October 2008</td> </tr> <tr> <td>Finish</td> <td>Final report presented to the Health Overview & Scrutiny Committee on 4th February 2009</td> </tr> </table>	Start	First meeting 6 th October 2008	Finish	Final report presented to the Health Overview & Scrutiny Committee on 4 th February 2009
Start	First meeting 6 th October 2008				
Finish	Final report presented to the Health Overview & Scrutiny Committee on 4 th February 2009				
Outputs	<ol style="list-style-type: none"> 1. Chair of the Task Group to provide an update to the Health Overview & Scrutiny Committee at its meetings in November and December 2008. 2. Chair of the Task Group to outline the review findings and recommendations to the Health Overview & Scrutiny Committee at its meeting on 4th February 2009. 				

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Methodology	<ul style="list-style-type: none"> • Desk based research of current policy and practice • Desk based research of best practice nationally • Analysis of written and verbal evidence submitted to date • Interviewing identified advisers/ witnesses
Expert Witnesses/ Advisors	<p>Internal: Angela King, Planning and Partnership Manager, Adult Social Care Jean Pollard, Director Children & Families Paddy Bradley, Director, Schools & Learning Caroline Fowles, Group Director Housing & Adult Social Care Cabinet Member for Health, Housing & Social Care Cabinet Member for Children’s Services</p> <p>External: Swindon Carers Centre Swindon Young Carers Project Swindon MIND Service Users Network Swindon (SUNS) Age Concern Swindon Swindon Local Involvement Network (LINK) Swindon PCT Avon & Wiltshire Mental Health Partnership NHS Trust Joint Commissioning Board</p>
Evidence Documents	<ul style="list-style-type: none"> • <i>Minutes of the Health Overview & Scrutiny Committee, 17th September 2008</i> • <i>Written evidence submitted to the Health Overview & Scrutiny Committee, 17th September 2008 by Swindon Carers Centre and Swindon MIND</i> • <i>Carers at the heart of 21st Century families and communities: a caring system on your side, a life on your own, Department of Health, June 2008</i> • <i>Swindon Carers Strategy and Action Plans 2006-2009, Swindon Borough Council and Swindon PCT, 2006</i> • <i>Swindon Young Carers Strategy 2006-2009, Swindon Borough Council and Swindon PCT, 2006</i>
Site Visits	None identified

APPENDIX 2

Sources of Evidence

Reports/ Briefings Produced for the Task Group

- Support for carers of people with mental health issues (mental health carers): Carers Views, Swindon Carers Centre, September 2008
- Working with Carers in Swindon: Members Briefing, October 2008
- Carers Grant 2008-11
- Copies of letters from witnesses in relation to mental health services
- Direct payments for carers briefing, Scrutiny Unit, November 2008

Minutes of Meetings

Evidence was heard from the following witnesses during Task Group meetings. Copies of available minutes are available from the Scrutiny Unit.

- Chief Executive, Great Western Hospitals NHS Foundation trust
- Development & Commissioning Manager, Strategy & Commissioning (Children), Swindon Borough Council
- Director of Nursing & Performance, Great Western Hospitals NHS Foundation Trust
- Head of Carer Engagement, Avon & Wiltshire Mental Health Partnership NHS Trust
- Manager, Swindon Mind
- Mental Health Carers Support Worker, Swindon Carers Centre
- Mental Health Commissioning Lead, Swindon Primary Care Trust
- Planning & Partnership Manager, Commissioning, Swindon Borough Council
- Service Manager, Swindon Children's Fund, Swindon Borough Council

National Reports, Policy and Guidance

- *Carers at the heart of 21st century families and communities*, Department of Health, 2008
- *Children, Young People and Mental Health Fact sheet*, Mind, 2008
- *Key Facts about Mental Health Carers*, The Princess Royal Trust for Carers, October 2007
- *Meeting the mental and physical healthcare needs of carers*, Keeley & Clarke, 2002, quoted in Tihanyi and Cormac, p.162 in *Advances in Psychiatric Treatment* (2006), vol. 12
- *Mental Health of Carers Survey*, National Office of Statistics, 2001
- *SCIE Research Briefing 11: The Health and Well being of Young Carers*, Social care Institute for Excellence, 2005
- *The Blackwell Encyclopaedia of Social Work*, M David, Blackwell Publishers Ltd, 2000

Local Reports, Policy and Guidance

- *An information pack for relatives and friends who care for people with mental health problems*, Avon & Wiltshire Mental Health NHS Trust, 2005

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- *Avon & Wiltshire Mental Health Partnership NHS Trust Balanced Scorecard Quarter 1 (Swindon)*, Joint Commissioning Board, October 2008
- *Caring matters: Swindon carers Centre Newsletter Autumn 2008*, Swindon Carers Centre, October 2008
- *Caring matters: Swindon carers Centre Newsletter Spring 2009*, Swindon Carers Centre, March 2009
- *Health Overview & Scrutiny Committee Minutes of Meeting held on 26th April 2007*, Swindon Borough Council, April 2007
- *Inpatient carers project process summary and checklist*, Avon & Wiltshire Mental Health NHS Trust, 2008
- *Joint Commissioning Board Minutes of Meeting held on 19th February 2007*, Swindon Borough Council, 19th February 2007
- *Psychiatric Intensive Care in Swindon: report to Joint Commissioning Board*, Avon & Wiltshire mental Health Partnership NHS Trust, November 2007
- *Swindon Carers Strategy & Action Plans: 2006-2009*, Swindon Borough Council, Swindon Primary Care Trust, Swindon Carers Centre, 2006
- *Swindon PCT Impact Assessment (Low secure inpatient beds) Report to Swindon Borough Council Health Overview & Scrutiny Committee*, Swindon Primary Care Trust, 26th April 2007
- *Swindon Young Carers Leaflet*, Swindon Carers Centre, 2008
- *Swindon Young carers Strategy 2005-2009*, Swindon Young Carers, 2005

Other Sources

- *Caring youngsters play a vital role*, Swindon Evening Advertiser, 10th December 2008
- *Who carers for the carers?*, Swindon Evening Advertiser, 17th December 2008
- *Living life despite dementia*, Swindon Evening Advertiser, 12th December 2008
- *Taking on a caring life*, Swindon Evening Advertiser, 10th December 2008

Websites

www.awp.nhs.uk

www.carers.org/swindon

www.carersinformation.org.uk

www.dh.gov.uk

www.mentalhealthcare.org.uk

www.mentalhealthcarers.org

www.mind.org.uk