

WILTSHIRE YOUNG CARERS STRATEGY 2006-2009

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Abbreviations

There are a number of abbreviations used in the Strategy, in order to save space. These are:

- **Y/C**- Young Carer
- **LEA**- Local Education Authority
- **PHF**- Primary Heads Forum
- **WASSH**- Wiltshire Association of Secondary School Heads
- **EWO**- Education Welfare Officer
- **EWS**- Education Welfare Service
- **C&F**- Children and Families Branch of the Department for Children and Education (Wiltshire County Council)
- **DCE or C&E**- Department for Children and Education (Wiltshire County Council)
- **AWP**- Avon and Wiltshire Partnership NHS Mental Health Trust (responsible for the Community Mental Health Teams or CMHT)
- **DACS**- Department of Adult and Community Services (Wiltshire County Council)
- **PCT**- Primary Care Trust (Health)
- **PCHT**- Primary Health Care Team
- **SMIG**- Strategy Monitoring & Implementation Group
- **YAW**- Youth Action Wiltshire
- **DPA**- Data Protection Act

Who are Young Carers?

A young carer is a child or young person (aged from 5 to 25) whose life is affected by caring for at least one family member, over and above just “helping out”. This could include caring for:

- ***Parent(s)***
- ***Grandparent(s)***
- ***Sibling(s)***
- ***Close relative(s).***

The positive impacts of caring can include **maturity, responsibility and life skills** and a **close and loving relationship** with **parents**.

“I think it’s really good. I can do loads of things my friends can’t. I’ve been able to cook a Sunday dinner since I was ten.” (A young carer)

The negative impacts can include **stress, depression, restricted social, educational and career opportunities**, and **less time** for oneself.

“There comes a point where you just want to leave and you think you can’t take any more...then you feel guilty because you think you should be at home with him all the time.” (A young carer of a mentally ill father)

“I am now 20 years of age and I suffer from depression myself. I’m on medication and some days I hate myself, I hate the person that I am, I don’t care what I look like, I just don’t care. Some days I just drink to get through the day because I can’t handle reality and seeing a member of my family the way they are, because I remember him before he was ill.” (A young carer)

Caring can, therefore, affect the physical, social and psychological wellbeing of a young person into adult life.

A family member may need the help of a young carer because of:

- A learning difficulty
- Physical or sensory impairment
- Long-term and/or chronic illness
- Mental illness
- Drug and alcohol related difficulties

Young carers can live in lone parent families and be the main carer. Some help the well parent to care, some help both parents to care for another child and some have more than one person in the family who needs care.

“Because I live by myself with mum, I have to look after her whenever she’s ill.” (A young carer)

What is our Vision for Young Carers?

Our vision is that there should be no young carers because appropriate services are provided to disabled parents/siblings.

The Strategic Aims

Our multi-agency Strategy has been developed with the involvement of young carers and their families. The ultimate aim of this Strategy (and thus of the Agencies signing up to it) is to reach a point where there are no more young carers because appropriate services are in place to support all of the cared for people. However, this position is some way off. In the meantime our strategic aims are intended to meet the 5 key outcomes of Every Child Matters:

| Key Outcomes | What the outcomes mean for young carers |
|---------------------------------|---|
| 1. Be Healthy | Encouraging good physical, mental and emotional health |
| 2. Stay Safe | Identifying children and young people with caring responsibilities and assessing their needs |
| 3. Enjoy and Achieve | Promoting educational achievement and attainment and developing support services for young carers |
| 4. Make a Positive Contribution | Allowing choice and control for children and young people with caring responsibilities |
| 5. Achieve Economic Well-being | Overcoming socio-economic disadvantages to achieve their full potential in life. |

In order to achieve our strategic aims, we have devised a number of objectives, based on the 5 outcomes:

- To recognise that children have the right to be properly parented and cared for.
- To recognise that many families where a parent or other family member has a serious illness or disability are able to care for their children without the need for intervention by the statutory services.
- To ensure that services are provided to the sick or disabled parent to assist and enable them to carry out their parenting task.
- To recognise that the impact of caring on a young person varies and it is important to assess needs on an individual basis.
- To continue identifying children and young people who are carrying out significant caring responsibilities for parents and/or other family members.
- To ensure that the support needs of young carers are more effectively met by a wider range of agencies, working collaboratively.
- To continue raising the awareness and understanding of professionals about the needs of young carers and the potential impact of their caring role.

- To provide services to support young carers in their caring role and/or help to minimise the adverse effects of their caring role on their health and development.

The Strategic Aims will be achieved through implementing the Action Plan (see page 16) and by ensuring that:

- The responsibilities of the individual agencies who have signed up to the Strategy are clearly defined
- The rights of young carers to a carer's assessment, to services and support are integral to the assessment processes of all the agencies
- Young carers know where to go to ask for help, when needed and to be confident of a positive response
- Appropriate services are provided to the parents to enable them to carry out their parenting role
- The profile of young carers in the planning process is raised, as part of core business of the agencies involved
- Young carers are recognised and supported in order to reduce the negative impact on their future physical and psychological well-being
- Consideration is given to the regular support needs of young carers over and above the respite breaks provided through the Carers Special Grant
- Staff in all the agencies receive regular training to maintain the focus of the needs of young carers in their work with families.

By signing up to this Strategy the partners recognise that young carers have the following rights:

- **Recognition** (including the right to a young carer's assessment)
- **Choice** (to choose whether they wish to continue to be a young carer)
- **Individuality** (the right to be treated as an individual)
- **Co-ordination** (being provided with appropriate and well co-ordinated services)
- **Participation** (being involved in the planning and delivery of services).

The Legal Framework

The statutory agencies involved with this Strategy acknowledge their responsibilities under, and have taken into account in the preparation of the Strategy, a range of legislation, regulations and national guidance with regard to Young Carers, including:

- The Children Act 1989
- Working Together to Safeguard Children (DOH 1999)
- Framework for the Assessment of Children in Need and their Families (DOH 2000)

- Mental Health Act 1983
- NSF Mental Health Standard 6
- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- Young Carers Service Framework (Quality Protects 2003)
- Every Child Matters
- Carers (Equal Opportunities) Act 2004.

What has already been done?

The Wiltshire Young Carers Project was set up in 1996 as a three year development project. This was the result of young carers helping to organise a county conference to raise awareness about their needs and see whether there was support for setting up a project. These young people were also involved in helping to secure funding for the initial development project.

The first Young Carers Strategy (2000-2003) was produced as a result of the project's work, in partnership with local young carers, parents, representatives from Wiltshire and Swindon Social Services Departments (Adults and Children's Services), Health, Education, the voluntary sector (including the carer support agencies) and Allied Dunbar (now Zurich Financial Services).

A number of the aims of the first Strategy have been achieved, including:

- Support groups for young carers in all parts of the county (using the Carers Special Grant)
- Regular opportunities for residential respite breaks for young carers (using the Carers Special Grant)
- Programmes of joint training between Adult and Children's social workers (focussing on joint assessments and joint working)
- Better identification of young carers (increasing number of young carers have become involved with Youth Action Wiltshire)
- A joint working protocol between Children & Families and Community Mental Health teams (which helps to ensure that the needs of young carers are not overlooked)
- The opportunity for children and young people to register with their GP as young carers (so that the GP is aware of their situation and can take action, as necessary)
- Regular consultations sessions with young carers, through the Young Carers Forum (to ensure their views and wishes are taken into account)
- A newsletter, website and chatroom for young carers, produced by YAW (to ensure that they are kept informed).

All the above aims will continue to be developed under this new Strategy.

"To help us cope we go to a young carers group at the youth centre, it helps you to mix with other people in the same situation." (A young carer)

It is important that the Strategy is not seen as just a document. Achieving the actions set out in the Action Plan to improve the quality of life for young carers is more important than the document itself. The Action Plan will focus on the needs of young carers living in Wiltshire and it will be the task of the Young Carers Strategy Monitoring and Implementation Group to ensure that improvements are being made.

Anyone signing up to the Strategy will be expected to take responsibility for ensuring that the actions they have agreed to are carried out.

The partner agencies that have signed up to the Strategy are:

- The Department for Adult and Community Services
- The Department for Children & Education
- The three Primary Care Trusts in Wiltshire
- Youth Action Wiltshire
- Connexions

What are the effects of caring?

- All children and young people whose parents have a disability or illness will not inevitably need to provide care for them or experience difficulties resulting from their situation.
- Disabled parents who need help with the task of parenting may be entitled to an assessment of that need. For many children and young people growing up coping with the disability or illness of a family member does cause difficulties which can significantly affect their lives.

“It’s hard always having to always pretend that everything is OK, so you don’t let your mum know how difficult your life is because she’s ill.” (A young carer of a mother with a long-term illness)

“It really stresses you out, they’re always ill and it just goes on and on and on……” (A young carer of a parent with long term illness)

Young carers may experience some or all of the following:

Social Effects

- Emotional anxiety, stress, guilt, self-blame and an obligation to care
- A sense of embarrassment and stigma
- A sense of being ostracised by their peers and/or local community
- An overwhelming sense of isolation and loneliness
- A belief that they are the only one in this situation
- A reluctance to take friends home
- A lack of recognition, praise or respect for their caring contribution.

“You just get on with it and put the rest of your life on hold.” (A young carer)

Effects on Physical and Emotional Health

- Being tired
- Feelings of loss, grief and sometimes bereavement
- Feelings of anger at other people’s reactions
- Reluctance to seek help/reveal their caring status
- The difficulties of providing intimate or personal care
- Physical and mental health problems e.g. back injury

“Sometimes I just have a bag of crisps for my tea because dad’s spent all the money on cat food so there’s no food for us in the house.” (A young carer of a mentally ill father)

“I’ve been lifting him for quite a while now. I soon learnt how to do it by figuring out what did or didn’t hurt.” (A young carer of a disabled father)

Concerns about the Future

- A fear of what the future may hold
- Feeling restricted in educational opportunities
- Feeling restricted in career choice and opportunities
- Difficulties with making and sustaining positive relationships
- Feeling restricted in life choices.

“I don’t know what’s going to happen when my parents die.” (A young carer of a sibling)

Special Considerations

1. Mental Health, Alcohol and Drug Dependency

Young carers supporting a parent with a mental illness may suffer considerable emotional strain, particularly as their role is even more likely to be unrecognised. For young carers supporting a drug or alcohol dependant parent the issues are the same.

“I have to take time off school when my mum gets ill. I spend a lot of my time comforting her when she gets upset. I find it hard to cope when she says to me that she wants to kill herself.” (A young carer of a mentally ill mother)

The effects of caring may impact on the emotional wellbeing and mental health of the young person. Managing the parent’s emotional and behavioural problems can cause the young person anxiety. Sometimes, when a young carer feels it is not safe to leave the parent on their own, s/he may miss out on educational and or social activities.

“I feel really guilty if I talk about her. I can’t tell anyone because you can’t trust people. So I keep it inside and it becomes a big secret. But then I snap and people don’t know why. It’s very difficult.” (A young carer of a mentally ill mother)

It is essential that professionals working with these groups are aware of all the family members, including children, who are carers. The needs of the carer(s) should be assessed and appropriate services provided, to ensure that their needs are not lost.

2. Disability/Long-Term Illness

A high proportion of young carers look after someone with a disability or long-term illness; this includes caring for someone with a sensory impairment. Young carers in this situation often assume greater responsibility for practical, physical tasks, as well as coping with the associated emotional stress and responsibility. They may experience physical ill health and/or injury because of their caring role.

“I help her in the bath, help her get out of bed and sometimes do the shopping and go to the bank to get her money for her.” (A young carer of a disabled mother)

“I got a job in a factory when I left school and the first thing they taught us was lifting and handling. Nobody came to our house to give me that advice on looking after mum. My back really ached at the end of the day.” (A young carer of a disabled mother)

Those professionals working with the family should ensure that young carers are offered a separate young carers assessment. This will enable the professional to see the full picture; to alert other professionals as appropriate and to provide the young carer/parents with information about young carer support services, about the particular condition, etc.

3. Caring for a Sibling

Many young carers are caring for a brother or sister with a disability or illness. Often, these young carers will be playing a supportive role to their parents, but the impact on siblings should not be overlooked or undervalued. Many disabled children need intensive care, seven days a week, and sometimes at night as well. This level of care impacts on the whole family and the siblings may take on caring tasks in order to share the work with other family members.

“When I take my brother out and he’s ill, people stare like he’s some sort of monster.” (A young carer of a disabled sibling)

In these situations, the professionals involved with the family need to ensure they assess the role and individual needs of each family member, and provide support and signposting services, as required.

“My brother is always going out. He’s been horse riding, went swimming in a special pool, been on holidays and goes out with a volunteer. I stay at home.” (A young carer of a disabled sibling)

How does being a young carer affect school?

This must be seen as a priority area of concern as the majority of young carers are of compulsory school age. Some miss school because of their caring responsibilities; many more are frequently late and/or have difficulty completing homework. Whilst at school a young carer may find difficulty in concentrating because of tiredness or concern about the person at home.

“Sometimes I get behind with my schoolwork and have to take extra homework to catch up.” (A young carer)

Some young carers have had long periods of non-attendance, may appear at school purely for registration or may attend parts of lessons. This may be the result of the cared-for person needing help during the day or because of concern or guilt about leaving the person at home alone.

“Having days off means that you can’t easily catch up.” (A young carer)

Some schools have shown a reluctance to recognise the difficulties faced by young carers; some are still unaware of the existence of young carers in their school; some schools have internal communications problems; some are very supportive and understanding once they are aware of the difficulties.

“If you’re bullied and you hit back you get into trouble yourself. People like other kids and teachers need to understand, but they shouldn’t feel sorry for us. There should be someone at school to talk to (not a stranger but someone we know).” (A young carer)

All schools are expected to be sensitive to the individual problems faced by young carers. The Government’s National Strategy for Carers encourages schools to designate an appropriate person to act as the link to the statutory services and young carers projects.

“The bullying means that it’s difficult to trust teachers or friends, so in the end you feel like it’s better not to tell anyone.” (A young carer)

Part of the purpose of this Strategy is to encourage schools to work more closely with the other agencies involved with young carers to ensure that they are recognised and their needs met. One way of achieving this could be for more awareness-raising in schools so that they become attuned to asking the right questions and looking for signs that indicate a child is a young carer. This would be particularly helpful in situations where, for example, a parent wants the school to know that their child is a young carer but the child does not want this.

“We need more leniency with homework and coursework and help so that we can catch up on missed work.” (A young carer)

A young carer at school may experience some or all of the following:

- A lack of understanding from their peers

- Being bullied and/or teased at school
- A perception of a lack of understanding by their teachers
- Tiredness or struggling to concentrate in class
- “Acting out” behaviour
- Rushing or failing to complete homework on time
- Difficulties in attending after-school or out-of-school activities
- Arriving late for school or leaving early
- Regularly missing school
- Parents being unable to attend parents evenings
- Academic under-achievement
- Limited opportunities for further or higher education
- Difficulty in explaining to their teachers what is happening
- Having to change schools, receive home tuition or opt out of education.

“Other people in my class don’t understand. Sometimes I get picked on- they say ‘at least my mum is normal.’ ” (A young carer of a mentally ill mother)

Identification, Recognition and Support

Identification, recognition and support are key themes in the Action Plan (see page 16).

Identification

Young carers and their families tend not to self-refer to the statutory agencies and they rarely ask for help. They prefer to hide their caring role for fear of the consequences. The culture and structure of services can work against identification, particularly where professionals are “client” or “patient” focussed, rather than considering the family as a whole. Young carers can also fall into the “gap” between services e.g. between children and adults services.

“I want the chance to talk to someone about what I do and things I’d rather not do. It needs to be someone who I trust and who will listen to me properly.” (A young carer)

The first contact a family may have is with their GP or other community health professionals. It is crucial that these workers are aware of and can help the family to ensure that the needs of the young carer for advice, help and support are not overlooked.

“If you or your family are already in contact with professionals like the doctor, a social worker, occupational therapist or community nurse, then they should always tell you about young carers (Youth Action Wiltshire) and give you information or help you make contact.” (A young carer)

Recognition

Professionals need to be aware of the family’s anxieties about the possibility of children being “taken away”, being accused of child abuse and fears of family breakdown. Workers involved with families need to be sensitive to these fears and worries when recognising and identifying young carers in a family.

“I want to be recognised, listened to, heard and believed.” (A young carer)

Support

Under current legislation (the Children Act 1989 and the Carers (Recognition and Services) Act 1995) young carers have the right and should be encouraged to ask for an assessment of their needs. An assessment should be carried out using the Framework for Assessment and should consider the needs of all the family members.

The agencies working with the families of young carers need to be aware, when deciding with the family on the services to be provided, that the focus should be on providing services that will:

- Enable and support the parents in their parenting role
- Relieve the young carer of her/his caring responsibilities

“I’d like some help to come in for my mum at times when we need it.” (A young carer)

Action Plan Introduction

The attached Action Plan sets out how the key themes of identification, recognition and support will be taken forward by the individual agencies, in order to improve the quality and consistency of services to young carers and their families.

Strategy Action Plan- Young Carers Strategy 2004-2007

| <u>Heading</u> | <u>Agency</u> | <u>Action</u> | <u>Timescale</u> |
|---|------------------------------------|---|---|
| Ensure strategy implementation | <i>All Partner Agencies</i> | <ul style="list-style-type: none"> ▪ All partner agencies to endorse the strategy ▪ Strategy Monitoring/Implementation Group (SMIG) to identify and engage partners ▪ SMIG to maintain links to other local planning groups ▪ SMIG to meet quarterly | By April 2006 Ongoing Ongoing Ongoing |
| Consulting with young carers to ensure the Strategy is implemented and continues to meet their needs | <i>YAW</i> | <ul style="list-style-type: none"> ▪ Regular consultation with Young Carers and feedback to SMIG | Ongoing |
| Identification/Recognition | <i>All Partner Agencies</i> | Each agency to produce a written protocol outlining and describing its role and responsibility for young carers that covers: <ul style="list-style-type: none"> ▪ Identifying worker/s with lead responsibility to be a point of contact ▪ Ensuring appropriate staff are aware of young carers needs (including referral and assessment) and their responsibility to meet them e.g. through induction and effective staff training ▪ Ensuring staff are aware of the services available to young carers | April 2006 April 2006 Ongoing April 2006 |

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|---|---|---|--|------------------------------------|
| Review the effectiveness of the Protocol for joint working with families with disabilities | <i>DCE/DACS/AWP</i> | <ul style="list-style-type: none"> ▪ Implementation of the DACS/AWP/C&F Joint Working Protocol | Review 2006 | June |
| Develop information for young carers | <i>DACS/C&E/YAW</i> <i>LEA/WASSH/PHF/Connexions/EWOs</i> | <ul style="list-style-type: none"> ▪ Each relevant agency to produce information about: <ul style="list-style-type: none"> □ young carers assessments (DCE/DACS) □ respite activities and support □ help for young carers at school □ helping young carers to enter into and remain in work/ life time learning | Ongoing Achieved Review | June Sept 2006 Sept 2006 |
| Carers registers | <i>PCTs</i> | <ul style="list-style-type: none"> ▪ Identify young carers on carers registers in GP surgeries and ensure relevant support and signposting ▪ Seek to establish trigger for children/young people on young carers and cared for persons medical notes, at hospital admission and at discharge | Ongoing | |
| Referral and assessment | <i>DACS/DCE/AWP</i> | <ul style="list-style-type: none"> ▪ Implement Y/Cs assessment checklist (as part of Y/Cs assessment) ▪ Develop statistical recording system using CareFirst ▪ Include assessment of the needs of Y/Cs as part of the DACS eligibility criteria for a community care assessment ▪ Implement the DACS/AWP/C&F Joint Working Protocol ▪ Ensure joint training between DACS/CMH/C&F teams continues | Achieved Achieved Achieved Review | June 2006 |

| | | | |
|---|--|---|---|
| Educational services and support | LEA, WASSH, PHF/Connexions/EWOs | <ul style="list-style-type: none"> ▪ Target phased transition periods to identify and support young carers- role of EWS ▪ Encourage each school to identify a lead person in each school wherever possible, to take specific responsibility for the needs of young carers ▪ Include a question on school admission form on illness and disability in the family, and the impact on the child | <p>Sept 2006</p> <p>Sept 2006</p> <p>Seot 2006</p> |
| Meeting health needs of young carers | PCT/surgeries | <ul style="list-style-type: none"> ▪ School nurses and health visitors to identify and sign post ▪ PHCT to refer for assessment, counselling and support, where needed ▪ Health promotion role in managing stress etc | <p>Ongoing</p> <p>Review April 2006</p> |
| Direct support to young carers | YAW/SMIG | <ul style="list-style-type: none"> ▪ Provide information; support groups; activities ▪ Produce a user-friendly Y/Cs card, with contact numbers for support/advice ▪ SMIG to consider how to reach those families with Y/Cs not accessing services ▪ SMIG to monitor the development of a common database (with appropriate safeguards) | <p>Ongoing</p> <p>Review January 06</p> <p>Ongoing</p> <p>Review Oct 2006</p> |