



Being a young carer in rural England: Summary report

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Foreword

Experiencing Major Life Events in rural communities

Most people have a defining event in their life which fundamentally shapes their reality and their future prospects.

Our work on Major Life Events provides compelling evidence from rural people about the challenges of using and delivering specific services in rural areas.

We have focused on investigating both the experiences of service users and also the work of service providers in order to reveal what it is like to live in rural England.

The aim of our work is to understand more about the challenges and thereby help to stimulate and inform better service provision for people living in rural areas.

We have chosen to focus on five events:

- cancer;
- stroke;
- having a baby;
- being a young carer; and
- losing your job.

The full reports were undertaken for the Commission for Rural Communities (CRC) by the Institute for Public Policy Research (ippr). We would like to thank the expert input from our steering group consisting of representatives from Department for Food and Rural Affairs (Defra), Department of Health, University of Gloucestershire, Macmillan Cancer Support, Local Government Association (Staffordshire), Rural Services Network, Humber and East Riding Rural Pathfinder, Citizen's Advice and several independent rural experts.

See www.ruralcommunities.gov.uk for the full report.

1. Introduction

In the UK there are 175,000 children under the age of 18 who are informal (unpaid) family carers. There are also 230,000 young adult carers aged 18-24, Rural young carers face particular barriers in accessing and receiving services and support, compounded by distance, lack of adequate public transport, isolation, stigma and lack of privacy¹.

The onset of a disability is a major life event that affects all members of the household, including children and young people. The impacts include the subsequent changes in household income as a result of higher expenditure and lower earnings, and the increased risk of entering poverty. The social exclusion experienced as a result of being or becoming disabled can be compounded by the remoteness of rural areas and the corresponding lack of access to services.

Linking disability to young people's roles as carers is very problematic and needs to be situated within a wider discussion about disability and social exclusion. Not every young person living in a household where a family member has a disability will undertake care work. Many of the young people in this study had low levels of responsibility – similar to those in households with no disability – but attended young carers' projects, through which most of the study participants were recruited.

Where young people had more responsibility it is important to be clear that this was not because of the presence of disability in itself. More precisely, the social model of disability distinguishes between impairment as a physical condition and 'disability' as the social and economic disadvantage which results in society's failure to respond to the needs of people with impairments. It is the latter, then, in terms the failure of both the state to provide services effectively and society to enable individuals with a disability to have independence and freedom from discriminatory economic and social barriers that forces young people into the role of carer.

As far as we are aware this is the first piece of research to consider the experiences of being a young carer in rural England. This research first considers the caring responsibilities young people have and the impacts on their lives of these responsibilities, then outlines the support services young people and their families receive.

The study

The research is based on 40 detailed interviews with young people aged 11 to 21 years who were living with a family member with a disability and had some caring responsibilities in their families. Interviewees were recruited through service providers from the public, private and voluntary sector. The sample was purposively selected to include a wide range of ages, experiences and support needs. Interviewees came from a range of rural settings – the districts of Eden and Berwick-upon-Tweed in the north of England, South Holland in the east and North Devon in the southwest. Interviews were also conducted with local and regional policy managers and frontline support providers working directly with young people or their families in rural England.

All of the interviews, which were undertaken in the period September 2008 to July 2009, were recorded and transcribed to capture the detailed insights that form the basis of our findings.

In this summary we identify areas for action and positive outcomes which may result from these. These suggestions are offered to encourage new thinking among practitioners and to provoke innovative solutions. It is important that these suggestions are not seen as a set of one-way demands on central government; rather, we aim to stimulate discussion and encourage a range of organisations to work together to agree practical solutions.

¹ Commission for Rural Communities (2008) "Services needs and delivery following the onset of caring amongst children and young adults: evidence based review" (CRC, Cheltenham).

2. Disability and social exclusion

Three-quarters of disabled people become disabled during adulthood – because they either have an accident or develop an illness². When an adult becomes disabled the adjustments required for their family can be considerable. Changes in the household's income and in work patterns (including one or both parents becoming unemployed) increase the risk of poverty and social exclusion.

However, becoming disabled is not a random occurrence but rather entrenches and deepens pre-existing disadvantage. This is illustrated, for example, in the fact that people without qualifications are nearly four times as likely to develop an illness or impairment as those with a degree (according to analysis of more than eight years of the British Household Panel Survey)³. In general higher levels of education ensure access to better paid employment and therefore higher income. Those who are unemployed are more than twice as likely to become disabled than other groups. People in low status occupations are also at greater risk. Health shocks not only affect those in the lowest distribution of income and affect them more severely but are likely to leave those with the severest disability worst off.

People with disabilities or long-term illnesses make up a significant proportion of the rural poor⁴. Living in a rural area presents additional barriers for those who have become disabled and their families, as well as affecting the way in which children experience the onset of disability. The level of social exclusion is compounded by remoteness and the corresponding lack of transport and distance from services, as well as oft-times discriminatory attitudes from local communities.

The risk of poverty

We live off the benefits of DLA and child benefit [...] So it makes it harder.

16 year old female and 15 year old male, care for their mother and father, South Holland

More than a third of children living with a disabled adult live in low income households⁵ and more than half of families with a disabled child are living in or on the margins of poverty⁶. When there is a sudden deterioration in a family member's condition or they have an accident the fall in disposable income from changes in employment or higher expenditure can be significant.

Changes in expenditure

The extra costs incurred when a family member becomes disabled can be considerable; they include medical expenses, specialist services or equipment and housing adaptations. On average, the additional expenditure required amounts to around 25% above normal expenditure [compared to people without a disability]⁷.

It is also the case that higher expenditure is incurred in rural areas⁸. Some families who were interviewed had to make compromises between what they could afford and what they needed, and at times made do with housing that was inappropriate or in disrepair. Individuals can claim Disability Living Allowance (DLA) to cover the additional costs of personal care and travel. The size of the allowance varies according to the claimant's needs. However, it has been found that benefits only cover around a quarter of the additional expenditure required⁹, and do not cover a rural premium, which allows for the extra costs of delivering services in rural areas.

² Burchardt, 2003

³ Burchardt, 2003

⁴ Milbourne, 2006

⁵ Parckar, 2008

⁶ Gordon et al, 2000

⁷ Parckar, 2008

⁸ Commission for Rural Communities, forthcoming

⁹ Burchardt, 2003

The lack of financial compensation for the costs incurred by disability can only add to the chance of entering poverty for many families. In fact, once the income of households with a disabled member is equalised to take account of these additional costs, those who enter poverty after the onset of disability rises from 14% to 40% of households¹⁰.

Changes in employment

One of the main reasons why households experience a fall in income is because the disabled person experiences a reduction in their pay, works fewer hours or loses their job¹¹. Around a fifth of people leave employment in the first year after becoming disabled¹². Labour market discrimination also means that those with a disability find it harder to get a job and are often lower paid. The proportion of people earning less than £7 an hour is higher for those with a work-limiting disability across all levels of qualification, and about 10 percentage points higher than those without a disability overall¹³.

On the whole, adults in families that include a disabled person are less likely to stay in work than those who are not affected by disability. One in five partners of disabled adults who are their family's sole earner leave work after their partner becomes disabled. Similarly, mothers of disabled children are half as likely to be in paid work than mothers who do not have disabled children¹⁴. This is likely to be because paid employment is not compatible with the new or increased caring responsibilities. The main trigger for entering poverty for those of working age in rural areas is loss of earned income¹⁵. Those most affected will have low earnings and will lack qualifications.

Access to services

A lot of these young carers' families do wait to move into crisis before the support comes on board and you know families who have you know they have been thrown into this role with a diagnosis, it is very difficult for them to start to look at outside support, and if they don't know about it is very difficult for them.

Front-line service provider, statutory sector, Berwick

The ways in which the disadvantages that accompany the onset of disability translate into social exclusion are complex. Access to services can be determined as much by the user's socio-economic background as by the way in which service delivery is organised. It is also the case that many families pay a service 'poverty penalty', with those who most need services being alienated from exercising their entitlement to it. This may be because they are more excluded from information about the help that is available or are less demanding of services.

Rurality and exclusion

People fail to access services for a wide range of reasons. The services themselves may be inaccessible, not least because of the physical barrier presented by living away from centres of population. Poverty is higher in more remote rural areas¹⁶, and access to services is more likely to be constrained by a lack of information, lack of appropriate and affordable transport, and poor service coordination. Barriers to access can also come from low expectations surrounding disability, poverty and stigmatisation.

Persistent diversion of funding away from pockets of deprivation in rural areas has entrenched and aggravated need. It can also make it harder to identify families that are at risk of relying on a child because it tempers people's expectations of the service provision to which they are

¹⁰ Burchardt, 2003

¹¹ Pillai et al, 2007

¹² Jenkins and Rigg, 2003

¹³ ONS Survey, 2008

¹⁴ Burchardt, 2003; Langerman and Worrall, 2005

¹⁵ Shucksmith, 2003

¹⁶ CRC, 2008

entitled.

Rural areas in general have fewer contact points for advice and information and the families interviewed for the study were often unaware of the support available to them. Some young people were left to find out about services for themselves.

Accessing information through alternative sources such as the internet is particularly difficult in rural areas, not only because of limited broadband coverage but also because the cost may be prohibitive. Internet access also varies significantly between regions¹⁷.

Rural communities are made up of diverse populations that include both affluent and low income households; this is often because these areas attract retired people, commuters and a high proportion of second home owners. Even if they are aware of the help that is available, some families may be reluctant to come forward because they are afraid of being stigmatised. They may also feel that doing so will compromise their privacy, which is more likely to be the case in smaller communities.

Social attitudes towards disability can leave families with a disabled member isolated from social support networks. Some young people found that people did not understand their family member's condition, or that the person they cared for was discriminated against because of their disability. Others said they had had to deal with negative attitudes from service providers.

Some of the young people's parents found it difficult to have to accept help for themselves or for their partner. This was usually because they did not want to feel 'dependent' on someone else for care or to have to accept the reality that they or their partner may need extra support. Most of the young people who talked about their parent refusing services, were also reluctant to accept assistance. This was often because they did not like people interfering in what they saw as a private family matter.

3. The impacts of gender

Gender assumptions about who should take on unpaid care work also interact with the impacts of poverty. The result is that 'young carers' are, in the main young people in single parent households. However, gender expectations also mean that children of a disabled mother and girls in general are likely to take on more care work.

In our study the gender of the parent who was not disabled was significant in determining whether or not they carried on working or gave up work to care for their partner. Although the mother tended to adopt the primary caring role when other members of their family needed care this was not the case for fathers.

Half of the young people in the study were caring for their mothers, who were the biggest group of people with care needs. This reflects the findings of the National Survey of Young Carers (which concerns more than 6,000 children)¹⁸ and of other UK surveys¹⁹.

Gendered assumptions about care mean that women rather than men are expected to take on unpaid care work. On the whole, men earn 22.6% an hour more than women. As a result, it may be less likely that men will become full-time carers or take time off work to care for a family member than women because of the differential impact of the loss of their earnings. Indeed, men may even increase their hours to compensate for the loss of their partner's earnings. This means that they often have little time to care, so responsibility for disabled family members falls to others, including children. This was the case for some of the young people interviewed, including one 16-year old who only got help when her father lost his job.

For well over half of the young people in our sample, children thought of as 'young carers' are in fact children living in a household with a single mother who has a disability. This corresponds

¹⁷ ONS, 2008

¹⁸ Dearden and Becker, 2004

¹⁹ See Becker and Becker, 2008; Dearden and Becker, 1998; 1995

with findings from other UK studies²⁰. One young person interviewed who lived in a single parent household was acutely aware of her mother's financial worries when she stopped working after an accident. Her mother also felt that she was more likely to be made redundant because she was receiving statutory sick pay.

Gender is a factor in determining the level and type of care work that individual children do compared with their siblings. Research has found that girls are more likely to be involved in all aspects of care and became more involved as they got older²¹. Many of the young women spoke about having more responsibilities than their brothers.

Gender differences also impact on the type of care work that young carers undertake. Dearden and Becker (2004) found that 85% of girls undertake domestic work compared with 69% of boys. Similarly, almost twice as many girls undertake intimate care than boys.

Evidence suggests that, in the absence of appropriate support, the choices that the person with care needs makes regarding their care, and the gender of the carer, may explain why a daughter rather than a male partner fills this role²².

4. The impacts of care work

They were going to put me on depression...tablets, but then they said it's easier to go for counselling, see if that will work better, 'cause they don't like putting you on depression tablets when you're under 18 [...] and I've got to go to anger management classes.

17 year old female, cares for her mother, market town, South Holland

The government's National Carers' Strategy states 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'²³. The Children Act (2004) underpins the Every Child Matters agenda, according to which every child should:

- be healthy;
- stay safe;
- enjoy and achieve;
- make a positive contribution; and
- achieve economic well-being.

Although it is difficult to disentangle the impact of care work from the effects of poverty, unemployment, poor housing and social class, not all of the young people in the study achieved these outcomes. The inability to do so was further aggravated by issues relating to living in rural areas.

Be healthy

A growing body of research over the past 20 years has shown that emotional and physical wellbeing can be affected by care work. For the young people in this study, physical ill-health was less frequently reported than the emotional impacts of care work, particularly worry and stress. Research has consistently shown that young people who carry out care work tend to have high levels of stress compared with other young people²⁴.

Poor emotional and mental health can often lead young people to neglect their own physical health. Young carers' projects have reported a tendency for young people to put their health at risk by engaging in risky behavior or misusing substances as a form of escapism from care work. Young people's health may also suffer if parents do not receive the support they require to help them look after their children's basic needs.

²⁰ Becker, 2005; Dearden and Becker, 2004; 1998; 1995; Aldridge, 2006

²¹ Dearden and Becker, 2004; 1998

²² Parker, 1993; Parker and Seymour, 1996; Olsen, 1996

²³ HM Government, 2008

²⁴ Banks et al, 2002; Early et al, 2006; Pakenham et al, 2007

Stay safe

Not many of the young people interviewed mentioned concerns about their own safety. However, if the person that they are caring for is misusing substances or has severe mental health problems their safety could potentially be put at risk. At the extreme end of cases, this may raise child protection concerns. In its inspection of eight local authority areas' responses to young carers, Ofsted (2009) found that this was sometimes the case.

Enjoy and achieve

The National Carers' Strategy states that 'having the time and space to learn are vital to every child's personal development and well-being'²⁵. However, the young people's school attendance and achievement were often put at risk by their roles as carers and by the social exclusion that often accompanies disability and poor health. Many also found it difficult to enjoy the social aspects of learning as they felt isolated and stigmatised. Many of the young people's teachers did not know about their families' situations

The impacts of the pressures of caring include:

- Not completing homework
- Poor school attendance
- Missing school trips
- Bullying and being bullied
- Poor behaviour in school
- Difficulties mixing with peers
- Lack of shared experiences

It is easy to see how these impacts are all exacerbated by rurality. Increased distances, poor public transport, no access to private transport, no internet access and distance services all make the initial problems much worse.

Make a positive contribution

Rurality was a barrier to participating in social and economic opportunities for the young people. Poor public transport and the expense of travelling, combined with their parent's mobility problems or caring responsibilities, meant that many found it difficult to access leisure or to participate in the labour market, which has a further bearing on their achievement of economic wellbeing.

Achieve economic well-being

The relation between disability, caring, low income and rurality meant that the majority of families were living in or on the margins of poverty. Many young people felt the need to contribute towards their family's finances with their own money.

Although it is usually a parent who leaves their job to look after their partner or child, sometimes it is young adult carers who take time off work, or do not enter employment in the first place. One young woman who did not work in order to care full-time for her mother had difficulty receiving financial support due to the thresholds for eligibility for benefits. Research elsewhere has shown that women who are primary carers are less economically active than other women which has substantial financial implications; they have lower earnings over their working life, are more dependent on welfare benefits, and have less wealthy families.

5. The role of support services in preventing young people from having to act as carers

The amount and quality of external support that is available to families where a person is disabled is critical in determining the amount of care work provided by children and young people.

²⁵ HM Government, 2008:124

Government guidance instructs that children and young people should be protected from taking on inappropriate levels of care work. In most cases, local authorities should ensure that the person with care needs is receiving sufficient services to make certain that the young person is not undertaking substantial or regular caring duties and – where this is a parent – to enable them to fulfil their parenting responsibilities.

Entitlement to community care services

The level of community care services that is provided under national legislation and guidelines and implemented in local contexts often fails to meet the needs of families. This is especially the case in rural areas where the extra costs of service delivery (the ‘rural premium’) affects the level of care local authorities can provide.

The national eligibility framework states that:

‘If, for example, an individual cannot perform several personal care tasks, but can do so without difficulty with the help of a carer, and the carer is happy to sustain their caring role in this way, both currently and in the longer-term, then the individual should not be perceived as having needs calling for community care services.’

Carers’ legislation is aimed at helping the carer sustain their care role, granting rights to assessments of their ability to provide and continue providing care, and allowing payments or services for their needs in relation to the care that they provide. However, in the context of limited resources, service providers were worried that it is often assumed that family members will provide care, especially if they have done so in the past. This assumption means that the resources made available to local authorities to deliver community care services often do not allow individuals to be assessed, and services to be provided, according to independent living principles. Although risks to the individual’s autonomy, health and safety, ability to manage daily routines, and involvement in family and wider community life must be considered, many local authorities only consider providing services when the level of risk is ‘critical,’ that is, the top of four bands of need²⁶.

Furthermore, even when an individual’s need is assessed as ‘critical,’ many local authorities apply ‘cost ceilings’ to care packages that relate to residential care costs. Given the cost ceiling policy it would be difficult for local authorities to fund more care for an individual, who is already receiving their maximum package, even if a young person is assessed as carrying out an inappropriate level of care²⁷.

Assessment for community care services

I don’t think they [adult services] actually, you know, they don’t actually see children. They’re just concentrating on the [person being] cared for and don’t look at the bigger picture.

Front-line service provider, voluntary sector, Eden

All of the service providers interviewed for the study identified that local authorities lacked a consistent whole family approach when assessing adults for community care services. This is consistent with a recent Ofsted inspection of eight local authority areas²⁸, which found that councils were not routinely identifying whether adults were parents and, if they were, whether they had any additional requirements for services that would help them in their parenting role. The Ofsted study found that adults’ and children’s services, operating under separate council directorates, were working to meet the needs of the individual adult or child but responsibility for families was not clear. Separate funding streams as well as limited capacity meant professionals were reluctant to take on work that they perceived as outside their remit. The lack of joint working between adults’ and children’s services was identified as a problem by service providers.

²⁶ DH, DfES, 2005

²⁷ Leece, 2002: 38-39

²⁸ Ofsted, 2009

While this is an issue about the way council departments are structured, the sparsity and size of local authority areas in rural constituencies means that it is considerably more difficult to share information, achieve multi-agency working among adult and child services and other professionals, and build networks across sparse areas

Home care services

In a rural area, [the person with care needs] might need care three times a day, they might need help to get up in the morning, get bathed and get dressed, they might need help again at lunchtime and they might need help again at teatime to get their dinner. They might even then need help again at bedtime so that can be four times that you're back and forward to that one person during the course of a day. It's not economically sound really.

Front-line service provider, adult social care, voluntary sector, Berwick

For many of the young people's families, the extra cost of providing community care services over large, sparsely populated areas led to a lack of choice in the type of services available and inflexibility in the way in which they were delivered. Services are particularly resource intensive when they require home visits in rural areas because of the distances staff have to travel.

The extra distances home care attendants are required to travel in rural areas, in the context of being low paid anyway, has led to particular problems in recruiting and retaining staff in rural areas. One service provider interviewed said that this was particularly the case for agency workers. The shortage of staff makes it difficult to deliver services flexibly and according to the needs of the user. Some young people experienced regular changes in the care professionals who were involved with their families, disrupting the continuity of care provision. High staff turnover makes building relationships with carers much harder.

For the families of the young people in the study, the lack of choice in the type of services available and in the way services were delivered, aggravated by rurality, meant that the young people had little choice but to bridge the gap between the care their family needed and the care they received from formal support.

For one young person the mismatch between her families' needs and the care service that was provided left her no choice but provide manual handling for her mother and cook for her family. Although this was remedied by adult services, they were unable to react quickly enough to the family's changing care needs. For the same young person, until home care services were rescheduled, the rigidity of provision left her the choice of either missing school or leaving her mother unable to get out of bed.

Emotional support

Interviewer: Is there anything you would have liked that you haven't been able to get help with? I think someone for mum to talk to. I know that sounds silly, but for her the only people she gets to see are the carers that go in...but that's it. She can't get out unless we take her somewhere, so something for her, that would be quite useful.

18 year old male, cares for his mother, South Holland

For some young people, service provision focused around the practical needs of their parents, but was unresponsive to their other needs. This left the young people emotionally responsible in sometimes quite difficult situations, for instance when caring for a parent with mental health or substance misuse issues.

Professionals expected one 18 year old to deal with the practical and emotional needs of her mother, who suffered from depression. Community care assistance can also be withdrawn when young people reach the age that is considered appropriate to help. Many of the young people identified a need for further support for their parents. Becoming a young adult carer does not overnight provide individuals with improved capacity or capability for care, and indeed often leads to a spiral of poverty and low-paid employment.

Medical care

I found that they [the Crisis Team] weren't very helpful at all. Because like what you do is ring them up, and they'd like, you'd be on hold for ages, and I'm thinking this is my mum, she's so low, and I can't stay here and stuff. This is like, she just says all sorts of stuff and everything when she is feeling really low. And it's really difficult because I don't know what I'm supposed to do.

18 year old female, cares for her mother, village near market town, North Devon

Lower numbers of service users mean specialist providers do not consider a service viable in rural areas which results in local services having shorter opening hours, or being located further away. As a result, families must travel further for help and there will be longer response times from the emergency services. Many of the family members that the young people cared for had to travel long distances on a regular basis to see specialists or other health care professionals. According to research, only 25 per cent of carers living in rural areas live within five miles of out-patient appointments, compared with 70 per cent of those in cities²⁹.

The refusal to give appointments or make home visits, as well as rigid opening hours and long response times were all mentioned as problems in the case of GP and hospital services. This meant that the young people had to arrange transport or take care of their parents while they waited for professional help.

The lack of transport services meant that individuals had to rely on friends and family to take them to appointments. Sometimes there was no choice but for the young person to take them. Travel costs meant that many families had to pay to access the services to which they were entitled. Many families in rural areas face difficulties accessing services because the alleged high cost of public and private transport adds a premium to their use of community care services³⁰. Some of the young people had to cover the costs of the transport they used for the purposes of carrying out their care role themselves. This means that access to services is conditional.

6. Direct service provision to young people

While inappropriate physical care tasks can and should be delegated to formal provision, young people may also need support in their own right to help them come to terms with the onset of disability or illness in a family member and the associated disadvantages, or to cope with bereavement or the affects of a family member's substance misuse problem.

Two distinct approaches to provision for young people are evident, in theory if not in practice. Young people can receive statutory services under the provision of section 17 of the Children Act (1989) as 'children in need.' Children are taken to be 'in need' if, without services, their health or development would not be of a reasonable standard. Local authorities may then provide services to the child and their family to safeguard and promote the child's welfare.

In practice, local authorities tended to limit interventions to those children where there were clear child protection concerns. Direct service provision was left to the voluntary sector, albeit with local authorities having an increasing role in co-ordinating and funding young carers' projects. However, despite providing highly valued emotional support to young people, by directing their support only at the young person without a view to the care needs of the family as a whole, young carers' projects risked supporting children to maintain their role as carer.

So, rather than envisaging a situation where a young person takes on care work as one of neglect (as a statutory approach risks), young carer provision risked validating a situation where a family is reliant on the care of a child even if the person with care needs does not want to be in a position to have to do so.

²⁹ Carers UK, 1998

³⁰ Carers UK, 2000

Accessing statutory provision: services as ‘children in need’

We’ve got the girl called [social worker’s name] from social services, she helps us, she’s really nice. [...] Before mum’s drinking, it was dad and mum used to fight and dad used to hit mum and then she got depressed.

11 year old female, cares for her mother, Berwick

Only a few of the young people in the study were receiving support through children’s services and the overwhelming majority had parents with alcohol or mental health problems. These young people were more likely to have spent time living away from their parents or to have experienced living with domestic violence. It is unlikely that children receiving support this way were conceptualised as ‘young carers’ but rather as children ‘in need’ or ‘at risk’ of neglect or abuse.

This concurs with other research. The National Survey of Young Carers found that just over a tenth of the 6,000 young carers that they surveyed had been assessed under the Children Act (1989). The authors of the survey hypothesised that, because just under a quarter of those assessed had parents or other relatives with drug or alcohol problems, there may have been child protection concerns that led to children’s services involvement, rather than because of concerns over their vulnerability as carers³¹. Ofsted (2009) also found that, while councils assessed young people when there were clear child protection concerns, they did not consistently consider other ‘young carers’ as meeting the criteria for a social care assessment.

Young carers’ projects: from identification to recognition

We had families who were coming to the attention of children’s services, either top end ‘child in need’ or they were coming to the attention of child protection. And lots of services would come together and say yes we can support the parents with this issues, and we can support little Johnny because he has been identified as possibly having ADHD [...] but the young girl in the family or the older sibling in the family who really was going into school, was trying to get on with things, might be a little bit quieter, but no behavioural problem, not presenting with any issues, but slightly quiet, she got nothing, they got nothing, and that’s the young person that we started to target.

Front-line service provider, statutory sector, Berwick

This gap has been addressed by the voluntary sector, with direct service provision to young people often provided by young carers’ projects. Many of the service providers interviewed pointed out that they were often responding to children who would not normally qualify for services as a ‘child in need.’

Joint working between the statutory and voluntary sectors has meant that service based provision to ‘young carers’ has been able to overcome some of the barriers that are created by delivering services in a rural context. These include in particular the problem of identifying families at risk of relying on the care of a child and tackling the isolation experienced by young people in rural areas. Once young people were identified, however, support tended to focus on the ‘recognition’ of the care that the young person was providing rather than trying to prevent children from inappropriate care work.

Identification and awareness-raising

In large, sparsely populated rural areas that it can be particularly difficult to collect referral data and increase intelligence about the prevalence of families at risk of relying on the care of a child. The increasing move in young carer provision towards service development and co-ordination has led to more systematic efforts. A number of service providers interviewed as part of this study were involved in setting up data collection methods.

The development of young carer provision has meant that many projects are beginning to undertake an increasingly strategic role in their area by co-ordinating multi-agency training and awareness raising directed at adult services and other professionals in order to increase

³¹ Dearden and Becker, 2004

identification of families at risk of relying on the care of a child across universal services. Ofsted found that local authorities that had not developed a written strategy for carers lacked a clear overview of how to improve outcomes for young carers and were likely to have no named professional to lead on developing work in this area³².

The increasing strategic priority of young carers in local authorities and the training of professionals by young carers' projects means that other front line services are more likely to be aware of the issue and have the knowledge and confidence to identify families at risk of relying on the care of a child. Increasingly, young carers' projects had been working together with schools through training and awareness raising activities to help them develop and use protocols to identify young carers.

Many projects made use of children's centres and schools as local information points as they could not always have a service base in remote rural localities. In this way, young carers' projects bring recognition to the issue and allow families to seek help without fear of stigmatisation, which has been seen to be a particular risk in small rural communities.

Recognition and participation

Once families are identified, young people could access youth groups, recreational activities and outings or one to one support from individual support workers. More funding from local authorities increased the sustainability of services in rural areas, allowing projects to reach more young people by subsidising transport and training local volunteers. Most young people in the study valued the support they received from young carers' projects highly. Many commented that it gave them a chance to get away from the emotional impact of caring.

Despite some evidence of good practice in joint working, the projects rarely used their ability to make contact with 'hard to reach' families to assess the unmet care needs of the whole family, either through their own carers' assessment or by signposting families to adult social care to undertake their own assessment. Instead, projects tended only to assess the unmet support needs of the young person.

By considering the young person's needs in isolation of the needs of the whole family, projects were limited in the measures they considered. For example, they often did not consider whether changes in the family's care package could help prevent the young person undertaking care work. Instead, they focused on what could be done to help the young person within their current situation, in order to meet their immediate needs. This was the case even where this meant accepting that the young person may miss out on education or employment opportunities.

Projects supported the young people in their current role as carers through emotional support and respite. But when service provision for the young person does not go hand in hand with the availability of support outside the family for the person with care needs, the projects risked further embedding the reliance of families on children for care.

By not only focusing on the needs of the young people as carers but also on their 'rights' as carers, by providing them with an identity as a young carer, young carers' projects can inadvertently endorse the decision making of a child over their parent's care. By not taking a whole family perspective, there is a risk of seeing the needs of the child and the parent who they care for as antithetical, rather than looking at the needs of the whole family.

Where the person with care needs is a parent, they need recognition as a care giver. Support should focus on taking away the barriers that prevent them from exercising choice and control in their parenting activities, rather than taking for granted that they cannot do so. Children's needs should be met wherever possible through services which empower their parents so that children do not have to care for them in the first place.

³² Ofsted, 2009

Conclusions

Decisions about the balance of economic and caring activity in the family will be made against a background of poverty and social exclusion. Assumptions about who should care based on the young person's gender, or that of the family member with the disability, will also come into play.

Many children who are considered to be 'young carers' live in households where there is a single mother; such young people accounted for more than half of our survey sample. Single mothers sit at the cross section of a particular set of disadvantages, including the increased risks of becoming disabled and of leaving work and entering poverty when they do. These factors and the absence of another adult in the household had a major impact on the level of care the young people undertook. Children in these families may be particularly affected by their new responsibilities, although the impact is sometimes difficult to disentangle from the effects of poverty, unemployment, poor housing and social class.

In our study, the emotional impacts associated with care work, particularly stress and worry were significant. Emotional strain also affected educational achievement and attendance. There is also evidence that caring influences the future economic choices of young people, many of whom chose to continue in a social care profession, which is often low paid and offers limited opportunities for progression.

For many young carers, living in rural areas compounded the limited access to social and economic opportunities because of the lack of public transport and their parent's mobility problems.

Policy and practice for young people in families with a disabled person in their family cannot be considered in isolation from policy and practice aimed at the person with care needs. This is because the extent of the help in place for the disabled family member will have a direct impact on whether or not the young person is required to take on care work. In our study, services often did not take a whole family approach. When assessing adults for community care services, local authorities did not routinely identify adults' additional needs as parents or consider the needs of dependent children. The extra costs associated with providing community care services over large sparsely populated rural areas led to inflexible home care scheduling that did not always fit around needs of the whole family.

Although physical care tasks should be delegated to formal provision, young people often needed emotional support from services. However, many were not considered to meet the threshold for statutory services unless there were child protection concerns. This gap has been addressed by provision from young carers' projects which were increasingly able to overcome the rural premium of service delivery through greater coordination and funding from local authorities.

Projects proved successful in mobilising a multi-agency response to identify families, yet once projects made contact, rather than coming together with other agencies to protect children from inappropriate care work, projects focused on demanding 'recognition' for the young people's rights as carers.

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