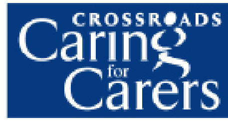

ECONOMIC EVALUATION OF YOUNG CARERS' INTERVENTIONS

CROSSROADS CARING FOR CARERS
AND
THE PRINCESS ROYAL TRUST FOR CARERS

NOVEMBER 2008

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1. EXECUTIVE SUMMARY

This project assesses the economic impact of young carers' interventions that are targeted on young carers affected by parental substance misuse and parental mental health problems.

We estimate that for every pound invested in a young carers' project the saving to the Exchequer and wider society is £6.72.

In order to arrive at this conclusion we needed to estimate the cost of delivering young carers' interventions, the impact of such interventions and the value of the savings made when such an impact was achieved. Of these three estimates, the estimate of the impact made by young carers' interventions was the least robust estimate that we had to make. An alternative way of presenting the information from this project without estimating the impact made by young carers' interventions is to say that a project working with 50 young carers each year would have to do one of the following to justify its funding (ie 'break even'):

- prevent truancy occurring or the taking into local authority care of three young carers who would otherwise have been at risk; or
- prevent one young person at risk of becoming a teenage parent from becoming a teenage parent.

The project consisted of a number of stages that provided us with the various estimates we needed to reach this conclusion.

UNDERSTANDING THE INTERVENTION

The first stage of the project was to develop a clear understanding of the interventions being assessed. As well as documenting the kinds of inputs, processes and outputs required to deliver a young carers' intervention that was targeted on young carers affected by parental substance misuse and parental mental health problems, we also identified the types of outcomes such interventions achieve. We grouped these into the following categories:

- caring, in particular reducing the burden of care on the young carer
- education and training, in particular reducing truancy and improving school attendance;
- mental and physical health, in particular reductions in teenage pregnancy;
- child protection, in particular reducing the probability of a young carer being taken into local authority care;
- reductions in offending;
- reduced substance misuse; and
- behavioural, in particular improved self-esteem.

ESTIMATING THE VALUE OF THE INPUTS REQUIRED TO DELIVER A YOUNG CARERS' INTERVENTION

A number of young carers' projects working with young carers whose parents / guardians experience either mental / physical health or substance misuse problems were chosen to represent a range of different project types. Each of these projects was visited or interviews were undertaken over the telephone. A range of data on the inputs required to run the project and the value of those inputs was gathered.

The average cost of an intervention per capita is £2,500.

ESTIMATING THE IMPACT OF YOUNG CARERS' INTERVENTIONS

A substantial portion of the resource for this project was devoted to undertaking a review of available evaluations of young carers' projects, with the intention of developing a robust estimate of the impact of young carers' interventions. However, we found very few evaluations of young carers' interventions that were sufficiently methodologically robust for our purposes. We therefore constructed estimates of impact for various key outcomes delivered by young carers' projects from a range of different data sources.

Taking all of the evidence into consideration we have assumed that young carers' projects have an 11% impact on reducing truancy among the young carers they work with.

Taking all of the evidence into consideration, it is reasonable to estimate young car ers' projects have a 1% impact on reducing the risk of the young carers with whom they work being taken into local authority care.

Taking all of the evidence into consideration we have assumed that young carers' projects have a 2.5% impact on reducing the risk of the young carers they work with from becoming teenage parents.

ESTIMATING THE SAVINGS DELIVERED BY YOUNG CARERS' INTERVENTIONS

The main per capita savings delivered by young carers' interventions working with young carers whose parents / guardians experience either mental / physical health or substance misuse problems are as follows:

Avoiding a young carer being taken into local authority care: £50,574
Improving a young carer's schooling: £47,931
Avoiding a teenage pregnancy: £130,405
Supporting a young carer to undertake appropriate caring: £7,827

2. CONTEXT

This project assesses the economic impact of young carers' interventions that are targeted on young carers affected by parental substance misuse and parental mental health problems.

Research has established some of the implications of being one of the UK's 175,000 known young carers, including the risk of truancy, underachievement, isolation, mental and physical ill health, poverty and stress. These risks are particularly acute for young people affected by parental substance misuse (250,000 young people in the UK[1]), parental alcohol misuse (1.3 million young people[2]) and parental mental health problems (4.2 million parents[3]). Anecdotally, young carers' services regularly receive referrals of young people who are missing most or all of their schooling in order to care for someone. These young people may well be some of the 13,000 UK children found by the 2001 census who care for 50+ hours per week. This relatively small group of persistent absentees is nevertheless a significant one: in England, just less than 3% of all pupils account for 50% of truancy statistics, and the Department for Education and Skills (now the Department for Children Schools and Families) has identified that 13,000 pupils in 200 schools in England are the young people whose needs are most acute.

Crossroads Caring for Carers and The Princess Royal Trust for Carers have the largest network of young carers' services in the UK and jointly have a range of around 100 services which are used by 15,000 young people and their families.

The range of support needs for children most affected by their parents' substance misuse and mental health problems is well established. Young people affected by parental substance misuse and mental health problems have traditionally been supported through children's services. Some adults' mental health and substance misuse services now recognise that they should support adults in the context of their parenting roles. In some areas, "whole family" support is being offered. This can include the mixture of targeted youth work and parental support offered by some voluntary sector young carers' services. More rarely, it means joint working and whole family assessment carried out by statutory children's and adults' services working across the structural divides between their agencies.

Relatively little is known about the economic costs and benefits of the range of interventions offered to the most vulnerable young carers.

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[1] Home Office (2003) Hidden Harm: Responding to the needs of children of problem drug users, London: Home Office

[2] Cabinet Office (2004) Alcohol Harm Reduction Strategy for England, London: Cabinet Office

[3] Crossroads Caring for Carers / The Princess Royal Trust for Carers (2008, unpublished) Invitation to tender

3. METHODOLOGY

The stages in undertaking this project are set out in Figure 3-1.

Theories of change
Working with stakeholders at a national, regional and project level the project team map out the logic model(s) underpinning the intervention ie what outcomes it is expected to achieve and how is it expected to achieve them.

Costing the interventions
Visits to case study sites will be undertaken to undertake a bottom-up costing of the interventions.

Evidence review
Existing research and evaluation evidence is then reviewed using agreed criteria that defines how robust evidence must be to be included and allows for the review process to be replicated if it is repeated in the future.

Modelling
A model is constructed that is shaped by the logic model and populated with data from the review process.

Stakeholder validation
Key assumptions in the model can be tested and validated with stakeholders to ensure that there is a high degree of 'sign-up' to the outputs from the project.

Figure 3-1: Methodology

4. THEORIES OF CHANGE

The first stage of the project was to develop a clear understanding of the interventions being assessed. This section sets out that understanding using the conceptual model in Figure 4-1.

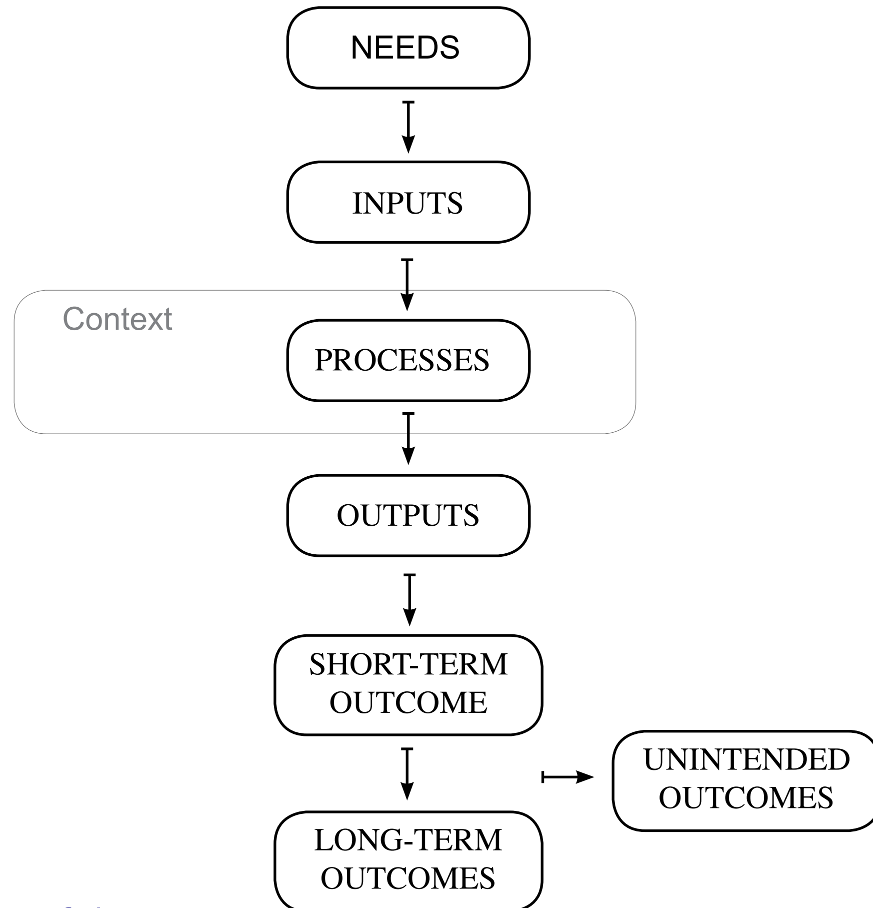

Figure 4-1: Theory of change

This exercise was important for two main reasons:

1. The economic model that we developed was based on the theories of change that we outlined. In particular the theories of change helped us to understand the links between the inputs, outputs and outcomes that go to make up the young carers' interventions.

2. The search terms we developed for searching for relevant impact studies was based, in part, on the theories of change.

OVERVIEW

It seems that there are probably two theories of change to consider, one that operates for young carers whose parents experience mental health issues and one for those whose parents are substance misusers. However, the key inputs, processes and outputs for both theories will be the same. The outcomes intended in both models will also be the same, but the level of outcomes achieved may be different for the two groups. More details on the theories of change are provided below.

NEEDS

Both young carers whose parents have mental health issues and young carers whose parents have substance misuse needs may have significant caring roles and may experience poor parenting and a lack of emotional warmth from parents. The services offered to both groups of young carers and the outcomes sought are similar.

INPUTS

Inputs cover set-up costs and running costs. Set-up costs include the purchase of equipment, securing accommodation and recruiting staff. Running costs include costs associated with employing staff and supporting volunteers, management costs, accommodation, staff training, publicity and the costs associated with working with a range of partner organisations.

PROCESSES

Key elements in the process of delivering services are as follows:

- Referral: Most referrals are from other agencies: self-referrals are relatively unusual for these client groups.
- Assessment: Most projects use a standardised assessment process that normally includes putting the client into a tier based on need.
- Care plan: This will be agreed with the young person and the family.
- Case work: This is one-to-one work.
- Group work: These include activity-based groups, the primary aim of which is to provide respite for young carers, and peer support groups that involve structured, facilitated sessions with a focus on problem-solving.
- Advocacy work: This will not be relevant in all cases, but might include advocacy with a school where a young person is having difficulties or with an organisation providing caring services to the family.
- Mentoring: Some projects use volunteers to offer mentoring, although this is not the norm.

CONTEXT

A range of contextual factors were identified that might shape the service offered. These included:

- government policy, in particular the Every Child Matters agenda;
- statutory requirements such as the Children's Act;
- data protection and data sharing requirements; and
- fundraising opportunities.

However, none of the contextual factors identified seemed to be unique to young carers' services and so have not impacted upon the development of the model.

OUTPUTS

Outputs included:

- Number of referrals received

- Number of assessments
- Number of young carers case-managed
- Number of groups held
- Number of advocacy episodes
- Presentations to other services
- Training sessions delivered to other agencies

OUTCOMES

Ultimately the aim of the interventions is to improve the young person's well being. However, no specific and measurable definitions of well being were identified. Rather, a range of outcomes, all of which contributed to well being, were identified and are described in Figure 4-2.

Outcome domain	Short-term manifestations	Long-term manifestations
Caring	Reducing burden of care on young person Improved care provision for the family from statutory services	
Education and training	Reduced truancy from school Improved school attendance Reduced school exclusion Attendance of vocational training	Increased qualifications Increased chance of employment Less benefit claims More tax paid
Mental health	Reduction in incidence of self-harming	Reduction in incidence of poor mental health
Physical health	Reductions in injuries or chronic conditions associated with heavy lifting	Reductions in teenage pregnancy Reductions in teenage fatherhood
Child protection	Reductions in 'looked after' children	Social exclusion
Offending	Reduction in offending	Reduction in offending
Substance misuse	Reduced substance misuse	Reduced substance misuse
Behavioural	Improved personal hygiene Improved anger management Improved social skills	Improved self-esteem as manifest by ability to form and sustain successful relationships with friends / partners / spouses

Figure 4-2: Short and long-term outcomes

These outcomes were incorporated into the economic model we developed.

WHAT MAKES THE YOUNG CARERS' INTERVENTIONS DISTINCT?

Many of the young people who experience the young carers' interventions will also receive services from other statutory and non-statutory service providers. What makes the young carers' interventions unique? Key points of distinction include the following.

- The interventions provide young carers with recognition of their particular situation, something that other services they come into contact with do not do consistently.
- A caring role can be socially isolating. The interventions are designed to reduce isolation.
- Young carers may experience erratic parenting and do not always receive the emotional warmth that might be expected from a parent. The interventions provide stable adult contact and positive role models for young carers.
- The services are provided by voluntary sector organisations that have a degree of independence; this helps the young carer develop a trusting relationship with workers and helps workers perform an advocacy role with other (statutory) services when one is required.
- Attempts to work with the whole family across children's and adults' services.

THEORIES OF CHANGE: CONCLUSION

The theories of change outlined have been used in developing the search criteria for the review of evidence and the economic model, both of which are described below. While there is some evidence to suggest that there are probably two theories of change to consider, one that operates for young carers whose parents experience mental health issues and one for those whose parents are substance misusers, as will be seen below, there was insufficient data available to make a distinction between these two theories during the modelling exercise.

5. ESTIMATING THE IMPACT OF YOUNG CARERS' PROJECTS

A substantial portion of the resource for this project was devoted to undertaking a review of available evaluations of young carers' projects, with the intention of developing a robust estimate of the impact of young carers' interventions. This review used a 'rapid evidence assessment' methodology (described below). However, the rapid evidence assessment identified only limited evidence of the impact of young carers' interventions and therefore additional work was undertaken to 'triangulate' the estimates of impact against other sources of evidence.

WHAT IS A RAPID EVIDENCE ASSESSMENT?

An alternative to expensive and time-consuming primary research is to take advantage of the body of evidence that already exists on many interventions by undertaking a systematic review or a rapid evidence assessment (REA). The Government Social Research website describes an REA as:

" . . . a tool for getting on top of the available research evidence on a policy issue, as comprehensively as possible, within the constraints of a given timetable. . . . REAs provide a balanced assessment of what is already known about a policy or practice issue, by using systematic review methods to search and critically appraise the academic research literature and other sources of information." [4]

The rapid evidence assessment comprised two separate structured searches of the research literature and a review of grey literature. The second search of the research literature was undertaken because the first failed to produce a paper which could be used in the later modelling phase of the research.

FIRST SEARCH

The first search identified 1329 studies. The titles and abstracts of these studies were reviewed. The first aim of this initial review was to identify whether the study met the project's theoretical criteria (see Figure 5-1.)

A study meets the theoretical criteria if:

- the study group are young people who are either explicitly defined as young carers or are young people whose parents have a mental health and / or a substance misuse problem.

AND

- there is an investigation of the effectiveness of a service or support intervention targeted on either the young person or their family.

Figure 5-1: Theoretical criteria

All studies classed as '1 – accept' and '2 – possible' were also subject to an initial assessment of methodology. The limited information available in some abstracts meant that it was not always possible to identify clearly the methodology that had been adopted. Where this was the case the study was retained for the next stage of the review.

[4] www.gsr.gov.uk/new_research/archive/rae.aspm

Eighty one studies were retained at the end of the review of titles and abstracts and the full papers were retrieved. A small number of papers could not be retrieved either because the paper was not available from electronic sources or accessible libraries (including the British Library) or because an incomplete reference made it impossible to identify the source of the study.

Once retrieved the full articles reviewed for relevance. Initially the same categorisation used during the review of titles and abstracts was used with the intention that papers originally classified as a '2' would be reclassified as either a '1' or a '3', with a further detailed assessment of papers classified as '1' to follow. However, on the basis of the review of the full papers, all on the short-list were ultimately classified as a '3'.

OUTCOME OF FIRST SEARCH

It was clear that no paper reported on our theoretical questions with the methodological rigour we required for the modelling. Of the papers reviewed, the majority were studies of the needs of young carers or the prevalence of caring by young people. A few studies also included a survey or audit of young carers' services[5], but these were not evaluations of the effects of interventions. While many papers commenced with some reference to or summary of relevant government policy on caring, another category of paper consisted entirely of analyses or discussions of government policy on young carers. Finally, some papers were primarily discussions of research methodology where a young carers' research study was included as an example of a particular research strategy. A large minority of papers were studies of adult carers, most often family members caring for relatives with Alzheimer's, some form of dementia or multiple sclerosis. Of these the majority were studies of the impact of caring upon carers and / or the needs of carers. Some studies were evaluations of interventions, most of which were educational interventions whereby adult carers were either provided with information or attended classes about the condition of the person that they were caring for. The most promising paper was by Arksey[6] titled 'Scoping the Field: Services for Carers of People with Mental Health Problems'. This was a report of a literature review undertaken in 2002 for the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NHS SDO)[7] titled Services to Support Carers of People with Mental Health Problems. While the Arksey paper did not itself include relevant material, the much fuller report upon which it was based was retrieved from the NHS SDO website[8]. This document reported that the research team undertook a scoping review of evaluation studies of interventions and services to support carers of people with mental health problems. One of its findings was that:

> '[C]hildren and young people who take on caring responsibilities are singled out in UK legislation and policy documents. . . . . [W]e found no studies looking at the effectiveness or cost-effectiveness of interventions and services for this specific group of carers.

[5] *For example, K Tisdall, H Kay, V Cree and J Wallace (2004) 'Children in need? Listening to children whose parent or carer is HIV positive', Br J Social Work 34, 1097 - 1113*

[6] *H Arksey (2003) 'Scoping the Field: Services for Carers of People with Mental Health Problems'. Health and Social Care in the Community 11:4, 335 – 344*

[7] *NHS SDO (2002) Services to Support Carers of People with Mental Health Problems. NHS*

[8] *retrieved 06/08/08*

SECOND SEARCH

Our first search showed that parallel studies with young carers of parents with problems not related to mental health or drug use were relatively common. Having not identified a study with sufficient methodological rigour for our theoretical concerns, we developed a second set of search terms which did not seek to directly identify young carers' interventions, but instead sought to identify a wider range of studies that examined interventions for the children of adults with mental health or substance misuse issues. Our assumption was that, even if the children receiving these interventions were not explicitly identified as young carers, many of them would, in fact, be undertaking caring roles. This second search identified 528 new studies and they were reviewed using the same process described for the first search.

OUTCOME OF SECOND SEARCH

We were unable to locate a paper which was of direct relevance to our study. One paper had some relevance. It provided a reasonably close parallel in theoretical terms and scored highly in methodological terms. Rotheram-Borus et al[9] undertook a six year long study of intervention outcomes for adolescent children whose parents had HIV. The package of interventions evaluated had some similarities to those delivered by Crossroads Caring for Carers and The Princess Royal Trust for Carers. The intervention was based on social learning theory and cognitive behavioural principles (Rotheram-Borus et al 2004: 743). Three modules were delivered: the first to parents, the second (and much longer module) to young people and parents; and a third to young people whose parents died during the study. The second module was delivered in group settings. Some sessions were just for young people and in some parents also attended. The evaluation, which was a randomised control trial, followed up young people for six years. Main outcomes measured were employment and school enrolment, receiving public welfare support, early parenthood, mental health symptoms and the quality of young people's romantic relationships. Key limitations to the usefulness of the study to this project include it being a US study (the study setting was New York), delivered primarily to black and minority ethnic groups (Black Americans and Latinos) and the parents' primary need being related to their HIV diagnosis.

Key findings were that significantly more young people in the intervention group than the control group:

- were employed or in school (82.58% vs. 68.94%) (a difference of 13.64%);
- were less likely to receive public welfare payments (25.66% vs. 36.65%);
- were less likely to have psychosomatic symptoms (mean, 0.24 vs. 0.31);
- were more likely to report better problem-solving and conflict resolution skills in their romantic relationships (mean score, 4.38 vs. 4.20);
- expected to have a partner with a good job (mean, 4.57 vs. 4.19) and
- expected to be married when parenting (mean 3.05 vs. 2.40).

[9] M Rotheram-Borus, M Lee, Y Lin and P Lester (2004) 'Six-year intervention outcomes for adolescent children of parents with the Human Immunodeficiency Virus', Arch Pediatr Adolesc Med 158, 742

GREY LITERATURE

We also undertook a review of grey literature – in order to determine whether there was any further literature available that met our theoretical and methodological criteria. This search differed from the initial two searches in that rather than consulting the electronic databases mentioned above our starting points were internet search engines' websites for relevant UK government departments and large UK charities known to have an interest in young carers. From these starting points various types of material – websites, web pages, books, online reports and so on were identified and examined for their relevance.

The review of grey literature followed many of the same principles of the previous two database searches. Following the testing of various keywords, search terms and search phrases – which took place prior to the first database searches being carried out – certain keywords, search words and search phrases were established as being helpful for producing relevant material. Following searches of engine searches and relevant websites, the initial results were reviewed for relevance to this project. Any websites, papers and so on that on first inspection appeared useful were noted. Links were found from various papers and websites to other potentially relevant sources and these too were also inspected. After the initial inspection of results, we began to build up our own database of potentially useful sources: grey literature, websites, books and so on. As was the case with previous searches, a small number of papers could not be retrieved because the paper was not available from either electronic sources or accessible libraries. Once we had gathered all the obtainable literature, we then scored these sources using the same criteria that had been used to score sources found in the database searches. Following this review of the search engine results 17 sources were identified that appeared theoretically and methodologically relevant for the purposes of this project. These 17 papers were retrieved so that they could be reviewed in greater detail. Following this review, 11 papers appeared promising and were reviewed. Somepapers were strategies or reviews relating either directly to young carers or to social care more generally. Others were reports of local evaluations of young carers' projects, but none were robust efficacy studies.

ESTIMATES OF IMPACT

The rapid evidence assessment provides only limited estimates of impact. Further, relevant research evidence was also considered to develop estimates.

ESTIMATING THE IMPACT OF TRUANCY

Of those young carers who are identified as such, it is known a significant proportion experience educational difficulties. Dearden and Becker[10] estimated the figure to be 22% in 2003. The equivalent figure in 1995 was 33%. Dearden and Becker[11] attributed the improvement in educational prospects to the fact that "Many project staff now work within schools to raise awareness of the issues and to work with teachers and others to improve young carers' educational experiences and outcomes." It is not unreasonable to conclude, therefore, the improvement in educational prospects which may be attributed to young carers' interventions is at least 11%.

[10] C Dearden and S Becker (2004) "Young carers in the UK: the 2004 report", London: Carers UK. Table 11

[11] C Dearden and S Becker (2004) "Young carers in the UK: the 2004 report", London: Carers UK. Table 11, Page 11

There have been several other analyses of the effect of general (ie not specifically targeted at young carers) interventions in reducing truancy. For example Brookes et al found a success rate in truancy interventions for students who required extra help to be 34%; this accords very closely with the figures identified by Dearden and Becker. If we take the survey results of 1995 to be indicative of the proportion of young carers having difficulties before specific help was given, (ie 33%) we might apply the "success rate" found by Brookes et al[12] (ie 34%). Thus we would expect to see a reduction in schooling difficulties of 33% × 34% = 11%. This is exactly the improvement found by Dearden and Becker.

Rotheram-Borus et al[13] found that the US intervention they evaluated increased by 13.64% the number of young people who were in school or employment.

Taking all of the evidence discussed above into consideration we have assumed that young carers' projects have an 11% impact on reducing truancy among the young carers they work with.

ESTIMATING THE IMPACT ON REDUCING THE RISK OF LOCAL AUTHORITY CARE

Following the introduction of the Carers (Recognition and Services) Act, Deardon and Becker included a question on social services' assessment in their survey of young carers (Deardon and Becker 2004). In the most recent survey (reported in Deardon and Becker 2004) they found that 18% of young carers had been assessed. However, for children caring for a relative with drug or alcohol problems this figure was 28%. The majority of these were assessments under Section 17 of the Children Act (1989), as children in need. We do not have data on the proportion of young carers who are the subject of a Child Protection Plan (on the 'at risk' register). However, data published by the Department for Children, Families and Schools shows that for the year ending 31st March 2008 there were 319,000 Initial Assessments completed and 34,000 children became subject to a Child Protection Plan (placed on the 'at risk' register). This means that approximately 10.7% of children who received a Core Assessment were subject to a Child Protection Plan. We therefore assume that 28% × 10.7% = 3% of young carers caring for a relative with drug or alcohol problems are at risk of being taken into local authority care. We have not been able to identify an estimate of the impact that young carers' projects or similar projects have on reducing the risk of a child or young person being taken into care. However, it is not unreasonable to assume the impact of projects on reducing the risk of children and young people being taken into care is the same as for a project's impact on truancy: 34%.

Taking all of the evidence discussed above into consideration, it is reasonable to estimate young carers' projects have a 1% impact on reducing the risk of the young carers with whom they work being taken into local authority care.

[12] M Brookes, E Goodall and L Heady (2007) Misspent youth: The costs of truancy and exclusion, New Philanthropy Capital, available at *http://www.philanthropycapital.org/research/research_reports/education/truancy%20and%20exclusion/* (accessed 27 March 2008)

[13] M Rotheram-Borus, M Lee, Y Lin and P Lester (2004) 'Six-year intervention outcomes for adolescent children of parents with the Human Immunodeficiency Virus', Arch Pediatr Adolesc Med 158, 742

ESTIMATING THE IMPACT ON TEENAGE PARENTHOOD

As will be discussed below, evidence on both the health needs of young carers and the associated costs for society have been difficult to identify. However, one area of young carers' health it has been possible to include in the model is teenage parenthood.

Levels of educational attainment have a major impact on the likelihood of becoming a teenage parent, as noted by Wellings et al[14] (quoted in Dennison[15]), "29% of sexually active young women who left school at 16 without any qualifications had a child before the age of 18, compared with ... 1% of those who left at age 17 or over". Considering Bonell et al[16] report at least 50% of young women who are ambivalent to – or dislike – school expect to be sexually active by age 16, it is not unreasonable to suppose approximately 15% of young women who experience educational difficulties are at risk of teenage parenthood.[17]

Clearly not all young carers are young women, although, as noted by Dearden and Becker, the majority of caring tasks are carried out by women. Thus, a lower bound estimate of the probability a young person facing educational challenges becoming a teenage mother is 7.5%. As we have already seen, young carers' interventions are likely to reduce the impact of poor educational experience by 34%, this will reduce the likelihood of teenage motherhood by 7.5% × 34% = 2.55%.

Taking all of the evidence discussed above into consideration we have assumed that young carers' projects have a 2.5% impact on reducing the risk of the young carers they work with from becoming teenage parents.

To develop an economic model we need to estimate the typical per capita cost of young carers' interventions.

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[14] K Wellings, K Nanchahal, W Macdowall, S McManus and R Erens (2001) Sexual behaviour in Britain: early heterosexual experience. Lancet 358: 1843-50

[15] C Dennison (2004) Teenage pregnancy: an overview of the research evidence, NHS Health Development Agency

[16] CP Bonell, VJ Strange, JM Stephenson, AR Oakley, AJ Copas, SP Forrest, AM Johnson and S Black (2003) Effect of social exclusion on the risk of teenage pregnancy: development of hypotheses using baseline data from a randomised trial of sex education, J Epidemiol Community Health 57: 871-876 Table 4 available at http://jech.bmj.com/cgi/search?andorexactfulltext=andandresourcetype=1anddisp_type=andsortspec=relevanceandauthor1=andfulltext=andvolume=57andfirstpage=871 (accessed 5 November 2008)

[17] This is likely to be an under-estimate. Bonell et al (Table 4) report 20% of young women ambivalent to or disliking school expect to become parents before the age of 20.

6. PROJECT COST

TYPICAL PER CAPITA COSTS OF YOUNG CARERS' INTERVENTIONS

Typically, young carers' charities are staffed by professionals, and also make use of suitably trained and equipped volunteers whose services, though provided without cost to the charity, are of a professional standard. In calculating the cost of interventions, we include the value of volunteers' time – in essence treating an hour of volunteer's time as the financial equivalent of a cash donation sufficient to purchase an hour's intervention at market prices.

A number of young carers' projects working with young carers whose parents / guardians experience either mental / physical health or substance misuse problems were chosen to represent a range of different project types. Project types include:

- large and small projects;
- recently established and long-term projects; and
- projects in different parts of England.

Each of these projects was visited or interviews were undertaken over the telephone. A range of data on the inputs required to run the project and the value of those inputs was gathered. These included running costs and, where possible, set-up costs. Set-up costs include the purchase of equipment, securing accommodation and recruiting staff. Running costs include costs associated with employing staff and supporting volunteers, management costs, accommodation, staff training, publicity and the costs associated with working with a range of partner organisations.

Information was also collected on throughputs of young carers.

Using information on the range of inputs and the throughput of young carers the per capita cost of an intervention was calculated.

The average cost of an intervention per capita is £2,500. The cost of delivering an intervention was remarkably consistent across different projects ranging from approximately £2,400 – £2,600 per capita.

7. SAVINGS

INTRODUCTION

We consider the benefits of young carers' interventions may be classified in four main areas:

- Improved school attendance / reduction in the probability of exclusion or persistent truancy
- Reduction in the probability of the carer being taken into local authority care
- Improvements in health / self-esteem
- Enabling the young carer to move from inappropriate to appropriate caring

In each of these categories we determine potential savings which may be made by society in supporting young carers. Generally, a range of cost figures are indicated and in such cases we consider a lower bound estimate. Thus actual savings are very likely to be in excess of those we estimate here.

Although it is acknowledged that young carers' interventions, especially advocacy services, may contribute to keeping at "at risk" family together, we do not consider directly the costs of family breakdown, although these comprise a significant economic burden to society. Indeed, the cost to the nation of family breakdown is well over £20,000 million per annum.[18] However, the majority of these costs arise through increased benefits claimants, reduced educational outcomes, health etc. which are covered in one of the four domains of the model listed above. To include them as separate domains runs the risk of double counting.

Similarly, we do not consider the potential of a reduction in offending and the increase in employment opportunities as a result of young carers' interventions. The primary focus of interventions is not in these "symptomatic" areas, but in the causal areas of youth support in their caring role, and in social and educational outcomes.

The model that we attempt to populate is represented diagrammatically in Figure 7-1.

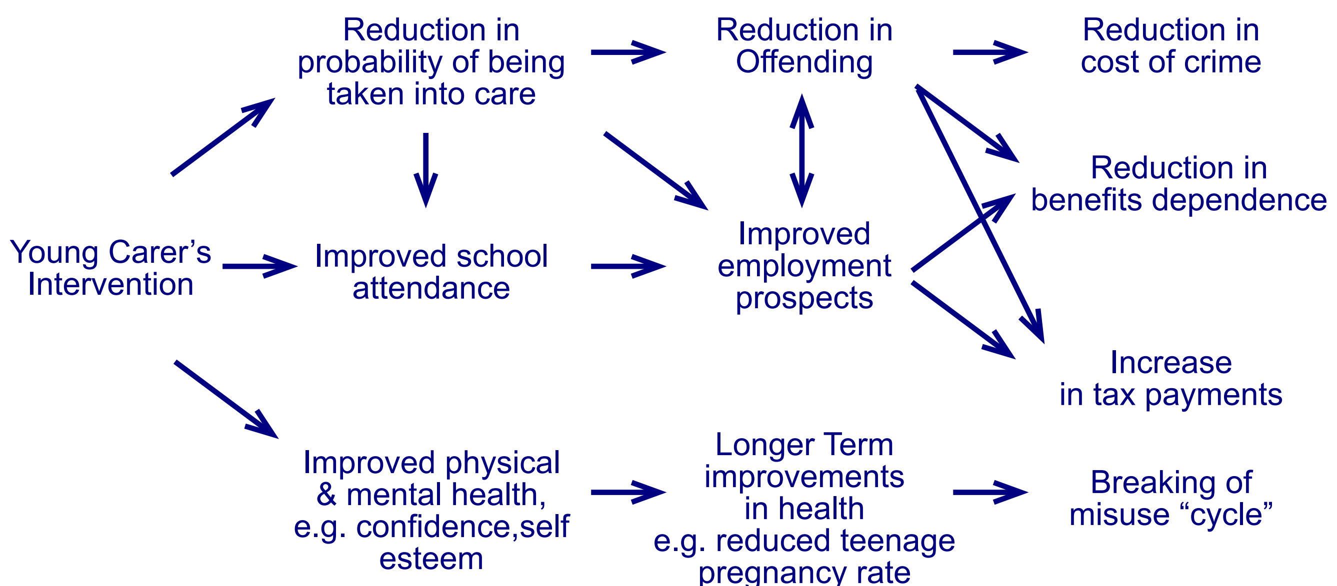

Figure 7-1: The model

[18] H Grant (2006) Fractured Families: The state of the nation report, Social Policy Justice Group available at http://www.centreforsocialjustice.org.uk/client/downloads/BB_family_breakdown.pdf (accessed 19 September 2008)

IMPROVED SCHOOL ATTENDANCE / REDUCTION IN THE PROBABILITY OF EXCLUSION OR PERSISTENT TRUANCY

Truancy and associated reduced educational outcomes are a major problem in the UK today. It is clear, even for those young carers who are not at risk of being taken into LAC, may require extra help with school work in order to achieve their academic potential. The results of poor educational attainment are very similar to those associated with being taken into LAC. These are costs both to society and the young person. For example poor education may result in reduced earnings potential for the young person and the increased likelihood of costs to society in terms of increased future expenditure arising from criminal activity, reduced health, increased benefit requirements and increased social services needs.

A recent study[19] found the average child excluded from school costs society £63,851 (in 2005 prices). More than three quarters of these costs fall on society at large. Brookes et al also showed the average cost of a persistent truant is £44,468. This figure splits roughly equally between costs to the individual and costs borne by society in general[20]. In today's prices the savings arising from preventing an exclusion are £68,823; the saving arising from preventing persistent truancy is £47,931 per capita.

REDUCTION IN THE PROBABILITY OF THE CARER BEING TAKEN INTO LOCAL AUTHORITY CARE

One of the primary concerns in supporting young carers is the maintenance of the family unit, and the reduction in the carer's vulnerability; reducing the need to take the young carer themselves into LAC. The cost of LAC may be considered to be the sum of the cost of the care itself, and the "cost" in reduced life outcomes for a young person in care.

Actually, it is generally not the taking into LAC per se that causes reduced life outcomes for young people. There is a simultaneity issue where the very problems which lead to the need to take young people into care also lead to reduced life outcomes. It is not unreasonable to regard a reduction in the probability a young carer is taken into care as being indicative of an increase in the probability of improved outcomes.

The cost to local authorities of LAC is reasonably straightforward to determine. For example Scott et al[21] estimated this is £408 per week (in 1998 prices), equivalent (in today's prices) to £27,300 per year[22]. Jackson et al[23]calculated the annual cost of LAC in 2001 was £1,340 million, (ibid p.4) divided by 58,900 young people in their study[24], giving £22,750

[19] M Brookes, E Goodall and L Heady (2007) Misspent youth: The costs of truancy and exclusion, New Philanthropy Capital, available at http://www.philanthropycapital.org/research/research_reports/education/truancy%20and%20exclusion/ (accessed 27 March 2008)

[20] ibid, Table3 and Table5

[21]S Scott, M Knapp, J Henderson and B Maughan (2001) Financial Cost of Social Exclusion: Follow-Up Study of Anti-Social Children into Adulthood, Br Med J, 323, 1-5. Table 2

[22]Assuming 2.5% price inflation. Note, Scott et al assume an average time in care of 26 weeks.

[23]S Jackson, L Feinstein, R Levacic, C Owen, A Simon and A Brassett-Grundy (2002) The costs and benefits of educating children in care, Centre for Longitudinal Studies, Working Paper 4.

[24]ibid p.34

per capita per annum in 1999 prices or £28,490 in 2008 prices. We use the lower of these figures. We consider the cost of one year's LAC, although, if a young carer's vulnerability is reduced so they are not taken into care, there may be further savings in subsequent years.

In addition to the direct cost of care, it is well known that children who are taken into LAC have reduced life outcomes compared to those who are not. See, for example, Social Exclusion Unit (2003)[25], Richardson and Lelliott[26] and Jackson et al[27].

The extra tuition cost of nursery and compulsory education for children in LAC – over and above the cost of their education had they not been in LAC – was estimated by Jackson et al (p.5) to be £114 million. This is equivalent to £2,424 per person in current prices. However, despite the extra amount spent on education, a young person in care has a much greater probability of becoming "Not in Education, Employment or Training" (NEET) on their leaving school.

Jackson et al (p.94) considered the probability of a young person in care becoming NEET is 50–70%. In the general population, an estimated 20% of young people are NEET[28]. Conversely, Godfrey et al[29] estimated 8.5% of the young labour force were NEET in 1999. In circumstances where a young person is sufficiently vulnerable to be taken into LAC, they suffer an increased risk of becoming NEET. This increased risk is between 30% and 60%.

The cost of being NEET is considered by Godfrey et al[30]. Becoming NEET impacts on a young person's life in many ways, for example reduced educational attainment; reduced employment prospects; increased likelihood of becoming involved in crime; and reduced physical and / or sexual health. The conclusion reached by Godfrey et al (Table 8) is the overall cost to society of an individual becoming NEET (at 2000/2001 prices) is £97,000 – equivalent to £115,000 in today's prices. Thus society may expect a young person in care to attract between £34,500 and £69,000 extra costs, because of the increased risk of becoming NEET.[31]

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[25]Social Exclusion Unit (2003) A better education for children in care, available at http://www.cabinetoffice.gov.uk/~/media/assets/www.cabinetoffice.gov.uk/social_exclusion_task_force/publications_1997_to_2006/abefcic_fs_3%20pdf.ashx (accessed 15 July 2008)

[26]J Richardson and P Lelliott (2003) Mental health of looked after children, Adv Psychiatric Treatment, vol. 9, 249–251

[27]L Jackson, R Feinstein, C Levacic, A Owen, A Simon and A Brassett-Grundy (2002) The costs and benefits of educating children in care, Centre for Longitudinal Studies, Working Paper 4.

[28]The Prince's Trust (2007) The Cost of Exclusion: Counting the cost of youth disadvantage in the UK, available at http://www.princes-trust.org.uk/main%20site%20v2/downloads/Cost%20of%20Exclusion%20apr07.pdf (accessed 27 March 2008)

[29]C Godfrey, S Hutton, J Bradshaw, B Coles, G Craig and J Johnson (2002) Estimating the Cost of Being "Not in Education, Employment or Training" at Age 16-18, Department for Education and Skills, Research Report RR346, page 14 available at http://www.dcsf.gov.uk/research/data/uploadfiles/RR346.pdf (accessed 19 September 2008)

[30]Ibid.

[31]If the increase in the probability of becoming NEET as a result of being in LAC is 30%, the increase in the cost to society is £115,000 × 0.3.

If a young person, at risk of being taken into care or actually in LAC, benefits from interventions which return their life expectations to those of the general population, a cost to society of at least £34,500 has been avoided.

IMPROVEMENTS IN HEALTH / SELF-ESTEEM

Godfrey et al (2002) acknowledged it is extremely difficult to estimate the health costs of social exclusion. This is particularly difficult in the case of young people where some chronic conditions particularly associated with social exclusion will be less prevalent among young people. Further, no work we know of has been done on whether young carers are at greater risk of ill health compared with the general population.

All young carers' projects had, as one of their aims to raise the self-esteem of carers. Increased levels of self-esteem may manifest themselves in a number of ways but, for young people, one manifestation is likely to be in the avoidance of sexual ill health and teenage parenthood. Several young carers' charities coordinate direct intervention in the areas of general and sexual health for the members of their client group. If we assume the costs of sexual ill health are the same regardless of background, we may use Godfrey et al's estimates as an indication of the potential savings which may be made through a young person's increase in awareness of sexual health. Based on the opportunity costs of health care professions, subsequent benefits payments, and the opportunity cost borne by young parents looking after children, Godfrey et al estimated the cost of pregnancy and birth is £32,815 with further (discounted) medium-term costs totalling £76,890[32]. The total cost per capita, in current prices, is £130,405.

MOVING FROM AN INAPPROPRIATE TO AN APPROPRIATE CARING ROLE

Generally, the aim of young carers' projects is not to stop young people from taking on caring roles. Young people and their families value these roles. Thus the aim of these projects is to ensure that young people move from inappropriate caring roles to roles appropriate to their age and circumstances, that these roles are recognised and that appropriate support is provided to the young carer.

Clearly, if the young carer were not able to provide any support for their family member, the state would have to provide this support. Taking, as an example, Wokingham Borough Council[33], the cost of council provision of care support is £15.00 per hour, with a maximum cost of £360 per week.

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[32]Per capita costs are total costs (taken from Godfrey et al Table 7) divided by the number of teenage pregnancies (taken from Appendix 2).

[33]Wokingham Borough Council (2008) Charges for services, available at http://www.wokingham.gov.uk/health-social-care/social-care/finance/charges (accessed 26 September 2008)

The number of hours per week of direct care given by a young carer will vary with their situation. As HM Government (2008:33)[34] note, while "there is no average profile of a carer", the majority of carers, both youth and adult, provide less than 19 hours per week. (ibid: 35 Figure 2). However, an assumption about replacement care would not necessarily apply to people with substance misuse and not to all people with mental health problems. In some cases a more likely scenario is family breakdown and children being taken into care. Therefore it is appropriate to take a lower-bound estimate and assume that caring will take at least one to two hours per day, ie ten hours per week.

In sum, it is not unreasonable to suppose young carers are saving statutory services at least £150 per week; £7827 per year. If a young person is able to continue in a properly supported and appropriate caring role, the state will save further amounts in subsequent years. However, we consider only the saving in a single year.

The main savings considered in the model are set out in Figure 7-2. It will be seen from Figure 7-2 that the cost of LAC is roughly equivalent to the return on improved schooling. To avoid double counting, we assume either one or the other saving may be actualised, rather than both. Note the impact of poor schooling is already a part of the cost to a young person of being taken into LAC.

SUMMARY OF SAVINGS

Cost base		**Potential saving per capita**	
Appropriate caring			£7,827
Cost of local authority care	Direct Cost	£13,650[35]	
	Extra tuition	£2,424	
	Risk of becoming NEET	£34,500	£50,574
Improved schooling			£47,931[36]
Reduced risk of teenage pregnancy			£130,405

Figure 7-2: Summary of main savings

[34] HM Government (2008) Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own, available at http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345 (accessed 17 June 2008)

[35] Following Scott et al (op cit.), we assume an average 26 weeks of direct care costs.

[36] We assume few schools would "exclude" a young carer, hence the cost of persistent truancy is used.

In calculating the savings accrued by a young carers' project we can identify three areas where savings may occur: reducing the probability of being taken into local authority care, truancy and becoming a teenage parent. However, it is not straightforward to estimate the potential savings to society. This is because there is an overlap between the costs incurred when a child is taken into local authority care and when a child is a persistent truant – some of the costs associated with local authority care are the costs of providing additional education support for such young people. To calculate the savings accrued by a young carers' project we therefore use the following steps:

1. We estimate that a young carers' project results in a 1% reduction in the probability of a young carer being taken into local authority care. Therefore the cost saving to society is 1% × £50,574 = £50.74.

2. Now, we have shown above, it is not unreasonable to suppose 2% of young carers are taken into LAC, interventions notwithstanding. This implies 98% are not taken into care. To avoid double counting, we consider only the cost savings arising from reducing truancy amongst this group. We estimate a young carers' intervention re sults in an 11% reduction in the likelihood of having a carer's life expectations reduced due to truancy. However, to avoid 'double counting' we only apply this to 98% of young carers (ie we exclude the 2% taken into local authority care). The cost saving to society is 98% of (11% × £47,931) = £5,166.96.

3. We estimate that the saving to society from reduced teen pregnancy is 2.55% × £130,405 = £3,325.33.

4. Thus, the lower bound total saving to society achieved by a young carers' project is therefore 50.74 + 5,166·96 + 3,325.33 = £8,543.03 per capita.

8. CONCLUSION

INTRODUCTION

We assume the cost of intervention per capita is £2,500. The main savings considered in the model are set out in Figure 7-1.

The rapid evidence assessment has not provided us with an estimate of the different impacts of a young carers intervention in a form where we can be confident of the accuracy and robustness of those impacts. Nevertheless, studies such as Rotheram-Borus et al (2004) and evidence from a range of other sources have allowed us to estimate the likely impact of a young carers project on three key outcomes.

- We estimate that young carers projects have a 1% impact on reducing the risk of the young carers they work with being taken into local authority care.
- We estimate that young carers' projects have an 11% impact on reducing truancy among the young carers they work with.
- We estimate that young carers projects have a 2.5% impact on reducing the risk of the young carers they work with from becoming teenage parents.

COST-BENEFIT ANALYSIS

If a young carers' intervention allows a young person to continue providing appropriate and properly supported caring when otherwise they might not, and results in either a 3% reduction in the likelihood of being taken into local authority care or a 11% reduction in truancy, together with a 2.5% reduction in the risk of being a teenage parent, the saving to society is of the order of £8,543.03. In addition, there are savings of approximately £7,000 which arise from supporting appropriate caring. Using these assumptions we estimate that for every pound invested in a young carers' project the saving to society is £6.72.

BREAK EVEN ANALYSIS

We assume the cost of intervention per capita is £2,500. Therefore a project working with 50 young carers a year would have to do one of the following to justify its funding (ie 'break even'):

- prevent truancy occurring or the taking into LAC of three young carers who would otherwise have been at risk; or
- prevent one young person at risk of becoming a teenage parent from becoming a teenage parent.

FURTHER RESEARCH

More research needs to be done in the area of efficacy of interventions, and it is plausible that the improvements in young carers' life chances are greater than the estimates we have used in this report. Throughout the report we use conservative or 'lower-bound' estimates merely to show how great the potential savings are, even with a conservative estimate of effectiveness.

Such research should involve a long-term evaluation of a number of different young carers' projects. The selection of projects should include projects using a range of different approaches in a range of different settings.

The evaluation should, at a minimum, use a rigorous experimental or quasi-experimental research design (minimum of Level 3 on the Maryland Scale) namely one of the following research designs:

- Random assignment and analysis of comparable units to programme and comparison groups.
- A comparison between multiple units with and without the intervention; or using comparison units that evidence only minor differences.
- A comparison between two or more comparable units of analysis, one with and one without the intervention.

9. APPENDIX 1: THEORIES OF CHANGE

This document sets out the 'theories of change' for interventions for young people affected by parental substance misuse and / or mental health problems.

WHAT IS A THEORY OF CHANGE?

Carol Weiss who is closely associated with the development of the 'theories of change' approach argued that a key reason why complex programmes are hard to evaluate is because the assumptions that underpin them are sometimes poorly articulated[37]. A theory of change explains both the 'mini-steps' that are required to achieve a long-term outcome and the connections between the mini-steps. The theories of change we develop need to include a number of components:

- **An understanding of need**: This will elaborate the needs that each service is designed to meet.
- **A process theory**: This will need to include a description of how the intervention will be delivered to the target population and an organisational plan that details the resources (funding, personnel, facilities, etc) that will be used to deliver the programme and how these are organised in a way that will result in the intended delivery of the intervention.
- **An impact theory**: This will describe the process by which the programme brings about change. It is likely to include both short and long-term outcomes and show how these are causally linked to each other and how both are causally linked to programme outputs.

HOW WAS THE THEORY OF CHANGE DEVELOPED?

The primary source of information for developing the theory of change was a workshop with representatives from Crossroads, the The Princess Royal Trust for Carers and local projects delivering front-line services to young carers. At this workshop the key question asked was:

> "What is the conceptual link from an intervention's inputs to the production of its outputs and, subsequently, to its impacts on society in terms of results and outcomes?"[38]

Some documents were also supplied to the research team. These included annual reports from young carers' projects and the results of local evaluations / research.

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[37] CH Weiss (1995) 'Nothing as practical as good theory: exploring theory-based evaluation for comprehensive community initiatives for children and families'

[38] United Kingdom Evaluation Society Glossary of evaluation terms http://www.evaluation.org.uk/Pub_library/Glossary.htm

The following Figure was used to help participants conceptualise a theory of change.

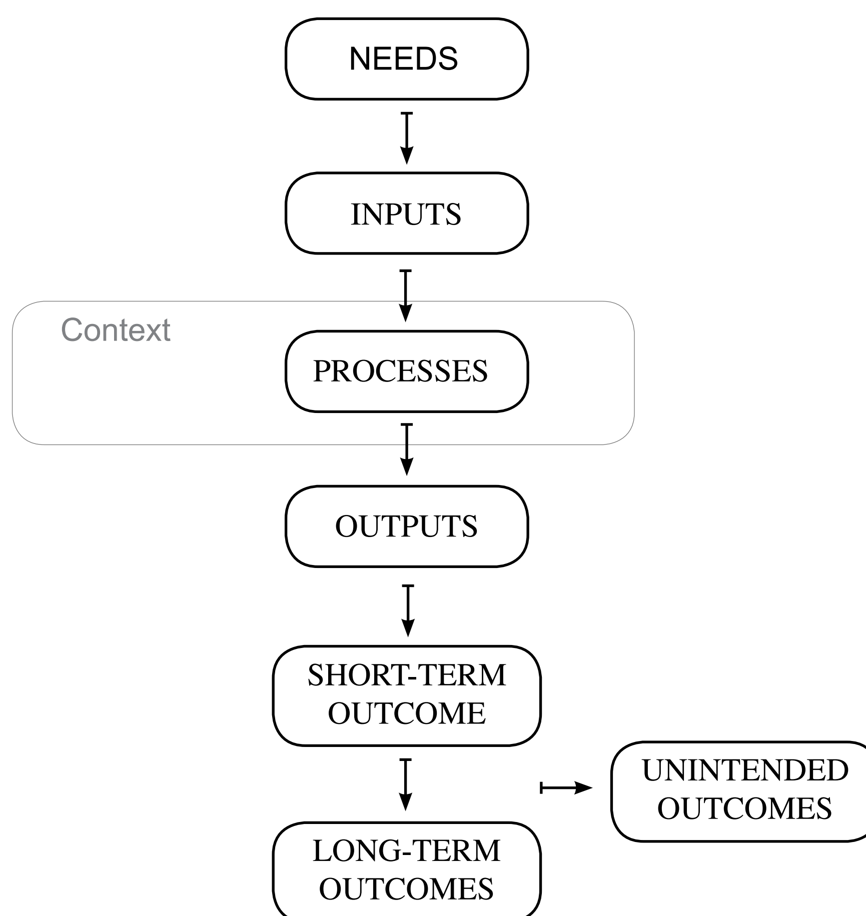

Figure 9-1: Theory of change

NEEDS

Both young carers whose parents have mental health issues and carers whose parents have substance misuse needs will have significant caring roles and experience poor parenting and a lack of emotional warmth from parents. However, the two groups of young carers also have some needs that are distinct. Although the services offered to both groups of young carers and the outcomes sought are similar, these different needs suggest that there are two distinct theories of change that need to be taken account of.

SUBSTANCE MISUSE

Young carers whose parents are substance misusers are more likely to be 'streetwise', spend more time out of the home and will engage in 'riskier' behaviour. They will be more conscious of, and have greater experience of, stigma associated with substance misuse. This group is more likely to witness or experience domestic violence.

MENTAL / PHYSICAL HEALTH

Young carers whose parents have mental health issues are more likely to spend time in the home and more likely to be socially isolated.

INPUTS

Inputs can be divided into set-up and ongoing running costs as follows:

- Set-up costs (one-off costs incurred to set up the intervention)
    - Equipment (eg computers, photocopiers, activity equipment, mini-bus)
    - Purchase of accommodation
    - Staff recruitment costs (advertising, etc)
- Running costs
    - Capital expenditure
    - Staff (FTEs)
    - Staff travel
    - Volunteers (FTEs)
    - Publicity
    - Steering group
    - Accommodation (rent)
    - Activities (cost of trips, subsistence, etc)
    - Utilities
    - Service charges (telephones, office equipment, serviced offices, etc)
    - Training costs

Some projects use home-based workers and do not have central accommodation. This will influence the cost base of these kinds of projects.

PROCESSES

Key elements in the process of delivering services are as follows:

- **Referral**: Most referrals are from other agencies; self-referrals are relatively unusual for these client groups.
- **Assessment**: Most projects use a standardized assessment process that normally includes putting the client into a tier based on need.
- **Care plan**: This will be agreed with the young person and the family.
- **Case work**: This is one-to-one work.
- **Group work**: There are different types of group work including:
    - Activity-based groups ranging from regular activity sessions one evening a month through to residential activities / holidays. The primary aim of activities is to provide respite for young carers in an environment where they are with other young people with similar experiences; and
    - Peer support groups that involve structured, facilitated sessions with a focus on problem-solving.
- **Advocacy work**: This will not be relevant in all cases, but might include advocacy with a school where a young person is having difficulties or with an organisation providing caring services to the family.
- **Mentoring**: Some projects use volunteers to offer mentoring.

The intensity of services delivered to young carers varied depending on need.

The people delivering services come from a mixture of backgrounds including:

- social work,
- teaching, and
- youth work.

Many also have counselling qualifications. Most are women, although there seemed to be anecdotal evidence that volunteers were more likely to be men.

CONTEXT

A range of contextual factors were identified that might shape the service offered. These included:

- government policy, in particular the Every Child Matters agenda;
- statutory requirements such as the Children's Act;
- data protection and data sharing requirements; and
- fundraising opportunities.

However, none of the contextual factors identified seemed to be unique to young carers' services.

OUTPUTS

Outputs included:

- number of referrals received
- number of assessments
- number of young carers case-managed
- number of groups held
- number of advocacy episodes
- presentations to other services
- training sessions delivered to other agencies

OUTCOMES

Ultimately the aim of the interventions is to improve the young person's well being. However, no specific and measurable definitions of well being were identified. Rather, a range of outcomes, all of which contributed to well being, were identified. They can be grouped under the broad headings of:

- education and training;
- mental health;
- physical health;
- child protection;
- offending;
- substance misuse; and
- behavioural.

In Figure 9-2 short and long-term manifestations of these broad outcomes are set out.

Outcome domain	Short-term manifestations	Long-term manifestations
Caring	Reducing burden of care on young person Improved care provision for the family from statutory services	
Education and training	Reduced truancy from school Improved school attendance Reduced school exclusion Attendance of vocational training	Increased qualifications Increased chance of employment Less benefit claims More tax paid
Mental health	Reduction in incidence of self-harming	Reduction in incidence of poor mental health
Physical health	Reductions in injuries or chronic conditions associated with heavy lifting	Reductions in teenage pregnancy Reductions in teenage fatherhood
Child protection	Reductions in 'looked after' children	None identified
Offending	Reduction in offending	Reduction in offending
Substance misuse	Reduced substance misuse	Reduced substance misuse
Behavioural	Improved personal hygiene Improved anger management Improved social skills	Improved self-esteem as manifest by ability to form and sustain successful relationships with friends / partners / spouses

Figure 9-2: Short and long-term outcomes

Another dimension of well being that was discussed was 'resilience'. However, it was not clear if this was something that the interventions were designed to develop or whether it was a positive pre-condition by which one could differentiate young carers more or less likely to achieve positive outcomes.

While many of the outcomes identified have a family dimension to them, outcomes were firmly focused on the young carers.

Relatively few unintended outcomes were identified. One area might be advocacy leading to changes in policies of organizations in contact with young carers.

DISCUSSION

Above we describe the detailed ‘mechanics’ of how the young carers’ interventions work. In this section we discuss the overall theories.

IS THERE MORE THAN ONE MODEL?

It seems that there are probably two theories of change to consider, one that operates for young carers whose parents experience mental / physical health issues and one for those whose parents are substance misusers. The key inputs, processes and outputs for both theories will be the same. The outcomes intended in both models will also be the same, but the level of outcomes achieved may be different for the two groups.

WHAT MAKES THE YOUNG CARERS’ INTERVENTIONS DISTINCT?

Many of the young people who experience the young carers’ interventions will also receive services from other statutory and non-statutory service providers. What makes the young carers’ interventions unique? The workshop participants suggested the following:

- The interventions provide young carers with recognition of their particular situation, something that other services they come into contact with do not do consistently.

- A caring role can be socially isolating. The interventions are designed to reduce isolation.

- Young carers experience erratic parenting and do not always receive the emotional warmth that might be expected from a parent. The interventions provide stable adult contact and positive role models for young carers.

- The services are provided by voluntary sector organisations that have a degree of independence; this helps the young carer develop a trusting relationship with workers and helps workers perform an advocacy role with other (statutory) services when one is required.

10. APPENDIX 2: RAPID EVIDENCE ASSESSMENT

The rapid evidence assessment comprised two separate searches. The second search was undertaken as the first failed to produce a paper which could be used in the later (modelling) phase of the research.

FIRST SEARCH

SEARCH STRATEGY

The first search was conducted between 24 and 30 June 2008 using 'young' AND 'carer*' and where possible, limiting the findings to those published from 1995 onwards. These search criteria were arrived at after an initial testing stage where alternative words, formulations, supplementary inclusions and exclusions were used to identify both the quantity and potential relevance of references achieved. Given the nature of SR's we needed to ensure that the analysis of the abstracts obtained was largely in relation to studies which had the potential of inclusion in the very broadest sense. Our concern was therefore to avoid as far as possible the inclusion of studies of animal caring, though inevitably a number of these did figure in the sources. Specifically, the inclusion of search terms 'mental' 'child' 'parent' 'intervention' 'autis*' and 'family' in various combinations of inclusion and exclusion alongside 'young' and 'carer*' was tested. We found that this greater level of specificity narrowed the searches and excluded sources that may have been of relevance. These tests were carried out in such a way as to observe how they might impact on searches already undertaken and for which we knew there were potentially relevant sources. Hence we carried out tests on the new search terms and excluded 'young' AND 'carer*'. For each such search between 10% and 20% of the resulting list was examined for relevance. No relevant sources were identified: hence we felt that it was safe to conclude that 'young' AND 'carer*' could robustly be used for this project. The results of our first search are shown in Figure 10-1.

Database	Sources found*
ISI Web of Science (all three major databases: SSCI, AHCI, SCI-EXPANDED)	212
ASSIA: Applied Social Sciences Index and Abstracts	305
CSA: Social Services abstracts, Sociological abstracts, Sociology full text collection	551
Psychinfo	258
SCOPUS: bibliographic references provided by Elsevier	425
IBSS: International Bibliography of the Social Sciences	49

*These numbers are not mutually exclusive so the total sum does not represent the number of unique sources.

Figure 10 1: Results of the first searches

RESULTS OF THE FIRST SEARCHES

The 1800 sources listed in Figure 10-2 were entered into an Endnote database and subsequently whittled down to 1329 on the basis of excluding duplicates and other categories of inclusion (non-English text, pre-1995). This database was then analysed and each abstract was scored in terms of its potential relevance to our review in terms of theory and methodology using the criteria in Tables 2 and 3.

We used a broad classification of theoretical relevance with just three categories:

1 = ACCEPT (meets criteria in Table 2)

2 = POSSIBLE (meets criteria in Table 2)

3 = REJECT (does not meet criteria in Table 2)

A study meets the theoretical criteria if:

- the study group are young people who are either explicitly defined as young carers or are young people whose parents have a mental health and / or a substance misuse problem.

AND

- there is an investigation of the effectiveness of a service or support intervention targeted on either the young person or their family.

Figure 10-2: Theoretical criteria

All studies classed as ‘1 – accept’ and ‘2 – possible’ we also graded using the scale in Table 3. For a study to get classed as a ‘1’ it should meet the theoretical criteria and be A–E on the methodological scale. Thus a relatively low threshold was set (by normal review standards) as typically the threshold would be set at D. To be classed as a ‘2’ the study should meet theoretical criteria and be F–X on the methodological scale.

Numeric code	Alpha code	Methodology	Risk of bias
1	A	Meta-analysis or systematic review of RCTs and strong quasi-experimental designs	Very low risk of bias
1	B	Random assignment and analysis of comparable units to programme and comparison groups	Very low risk of bias
1	C	A comparison between multiple units with and without the intervention; or using comparison units that evidence only minor differences	Selection bias
1	D	A comparison between two or more comparable units of analysis, one with and one without the intervention	Confounding factor; selection bias
1	E	Temporal sequence between the intervention and the measure (time series analysis or before / after)	History; confounding factors; selection bias
2	F	Correlation between an intervention and a measure at a single point in time	Causal direction; history; confounding factors; selection bias
2	G	Well-conceived non-analytical studies (for example case studies with clearly defined research questions, coherent sampling strategies, well structured analysis, clear reporting)	
2	H	Poorly conceived non-analytical studies	
2	I	Expert opinion	
2	X	Methodology cannot be ascertained	

Figure 10-3: Hierarchy of methodological rigour

Six ‘1’s and 75 ‘2G’ to ‘2X’s were identified and the full papers were retrieved. A small number of papers could not be retrieved either because the paper was not available from electronic sources or accessible libraries (including the British Library) or because an incomplete reference made it impossible to identify the source of the study.

Once retrieved the full articles reviewed for relevance. Initially the same categorisation used during the review of titles and abstracts was used with the intention that papers originally classified as a ‘2’ would be reclassified as either a ‘1’ or a ‘3’ with a further detailed assessment of papers classified as ‘1’ to follow. However on the basis of the review of the full papers, all on the shortlist were ultimately classified as a ‘3’.

OUTCOME OF FIRST SEARCH

It was clear that no paper reported on our theoretical questions with the methodological rigour we required for the modelling. Some papers were reports of some form of literature review, generally a structured review using some or all of the methods associated with a systematic review. There were, however, no meta-analyses reported.

Of the papers reviewed, the majority were studies of the needs of young carers. Of these most used some form of non-random sampling (typically a purposive or convenience sample) and qualitative research methods such semi-structured or unstructured interviews or some form of focus or discussion group. Many papers also included a summary of recent government policy on young carers, some contrasting the policy of the government in the country where research took place with policy in other countries. A few studies also included a survey or audit of young carers' services[39] but these were not evaluations of the effects of interventions. While many papers commenced with some reference to or summary of relevant government policy on caring another category of paper consisted entirely of analyses or discussions of government policy on young carers. Finally, some papers were primarily discussions of research methodology where a young carers research study was included as an example of a particular research strategy.

A large minority of papers were studies of adult carers, most often family members caring for relatives with Alzheimer's, some form of dementia or multiple sclerosis. Of these the majority were studies of the impact of caring upon carers and / or the needs of carers. Some studies were evaluations of interventions, most of which were educational interventions whereby adult carers were either provided with information or attended classes about the condition of the person that they were caring for. An exception was Schneider and Carpenter (2001), who evaluated different configurations of health and social care services on the well being of carers. The main outcomes examined tended to be to reduce carer stress, burden and depression.

The most promising paper was by Arksey[40] titled 'Scoping the Field: Services for Carers of People with Mental Health Problems'. This was a report of a literature review undertaken in 2002 for the National Coordinating Centre for NHS Service Delivery and Organisation Research and Development (NHS SDO)[41] titled Services to Support Carers of People with Mental Health Problems. While the Arksey paper did not itself include relevant material the much fuller report upon which it was based was retrieved from the NHS SDO website[42]. This document reported that the research team undertook a scoping review of evaluation studies of interventions and services to support carers of people with mental health problems and that[43]:

[39]For example, K Tisdall, H Kay, V Cree and J Wallace (2004) 'Children in need? Listening to children whose parent or carer is HIV positive', Br J Social Work 34, 1097 - 1113

[40]H Arksey (2003) 'Scoping the Field: Services for Carers of People with Mental Health Problems'. Health and Social Care in the Community 11:4, 335 – 344

[41]NHS SDO (2002) Services to Support Carers of People with Mental Health Problems. NHS

[42]retrieved 06/08/08

[43]NHS SDO (2002) Services to Support Carers of People with Mental Health Problems. NHS. page 16

'Given that children and young people are known to care for people with mental health problems (young carers Research Group (YCRG), 2001) [44], it was also necessary to collect evidence concerning services specifically targeted at this group.'

The scoping study included a literature review (reported in the paper) and a consultation exercise (reported elsewhere). The literature review included searches of electronic databases, hand searching, searching the websites of key organisations, contacting librarians of key organisations and checking bibliographies of studies. One of its findings was that[45]:

'[C]hildren and young people who take on caring responsibilities are singled out in UK legislation and policy documents. . . . . [W]e found no studies looking at the effectiveness or cost-effectiveness of interventions and services for this specific group of carers.'

SECOND SEARCH

Our first search showed that parallel studies with young carers of parents with problems not related to mental health or drug use were relatively common. Having not identified a study with sufficient methodological rigour for our theoretical concerns, we conjectured that we could further specify the theoretical parameters while keeping the methodological hierarchy as before. Our hope was to identify studies which were close enough to our interests and which could be used to inform the modelling exercise.

SEARCH STRATEGY

We used the same data bases as for the first search and the same testing procedure using the terms 'substance misuse' 'support' 'child*' 'mental illness' 'mental health' 'family intervention' 'intervention' 'systematic review' 'parent*'.

Our final search criteria involved four terms which were: 'children' 'parent*' 'intervention' 'substance misuse OR mental illness'.

RESULTS OF THE SECOND SEARCH

Results of the second searches are set out in Figure 10-4

Database	**Sources found***
ISI Web of Science (all three major databases: SSCI, AHCI, SCI-EXPANDED)	91
ASSIA: Applied Social Sciences Index and Abstracts	4
CSA: Social Services abstracts, Sociological abstracts, Sociology full text collection	29
Psychinfo	502
SCOPUS: bibliographic references provided by Elsevier	78
IBSS: International Bibliography of the Social Sciences	11

*These numbers are not mutually exclusive so the total sum does not represent the number of unique sources.

Figure 10-4: Hierarchy of methodological rigour

[44] Young carers Research Group 2001. Children caring for family members with severe and enduring mental health problems. YRCG Bulletin. Loughborough:young carers Research Group, Loughborough University

[45] NHS SDO (2002) Services to Support Carers of People with Mental Health Problems. NHS. Page 89

The 715 sources listed in Table 4 were entered into an Endnote database and subsequently whittled down to 528 using the same exclusions described above. This database was then analysed using the methodology described above and the criteria in Tables 2 and 3.

OUTCOME OF SECOND SEARCH

While we were unable to locate a paper which was of direct relevance to our study we did find one which provided a close enough parallel in theoretical terms and which scored highly in methodological terms.

Rotheram-Borus et al[46] undertook a six year long study of intervention outcomes for adolescent children whose parents had HIV. The package of interventions evaluated were similar in nature to those delivered by Crossroads Caring for Carers and The Princess Royal Trust for Carers. Key limitations of the study include it being a US study (the study setting was New York) and the parent's primary need being HIV related. Nevertheless we believe this study is robust enough to suggest the extent of the impact of the intervention on education / employment outcomes. Given that we are concerned with such outcomes in our model this paper allows us to use their findings, albeit with care, to estimate the positive effects of skill based interventions of young carers. Conservative use of their findings will help us to establish a baseline figure that we would expect to be a realistic, and probably an under-representation of interventions with young carers of parents with mental health or substance misuse problems.

GREY LITERATURE

We also undertook a review of grey literature – in order to determine whether there was any further literature available that met our theoretical and methodological criteria. This search differed from the initial two searches in that rather than consulting the electronic databases mentioned above - ISI Web of Science ASSIA, CSA, Psychinfo, SCOPUS and IBSS – our starting points were the use of two internet search engines (www.Google.co.uk and www.Yahoo.co.uk) and a number of websites. Websites included those for relevant UK government departments and large UK charities known to have an interest in young carers. From these starting points various materials – websites, web pages, books, online reports and so on – were identified and examined for their relevance.

The review of grey literature was conducted between the 7 August and 22 September 2008 and followed many of the same principles of the previous two database searches. Following the testing of various keywords, search terms and search phrases (which took place prior to the first database searches being carried out) certain keywords, search words and search phrases were established as being helpful for producing relevant material. Thus, words such as 'young', 'carer' 'intervention*' and 'evaluations' which had been identified as effective for producing relevant results in previous searches were used again for the grey literature search. These keywords and combinations of them were used on the two internet search engines and (where possible) on the search engines of individual government websites.

[46] M Rotheram-Borus, M Lee, Y Lin and P Lester (2004) 'Six-year intervention outcomes for adolescent children of parents with the Human Immunodeficiency Virus', Arch Pediatr Adolesc Med 158, 742

To give an example of the breadth of the search, the phrase 'Evaluations of interventions to support young carers', when used on www.Google.co.uk resulted in 76,300 'hits'. The great difference between the results obtained from this Google search – and other internet searches like it – and the previous two database searches was that the search engine results were not necessarily journal articles, reports, books, book reviews, or chapters in edited books. Instead a range of material was identified, including, for example, websites, unpublished documents, advertisements and video sources. In short, there is the potential for a search engine to produce a greater variety of sources and results. Consequently there was a need to approach the search engine results with a different level of scrutiny than that which had been used for the previous two database searches. Many results were dismissed outright, such as advertisements or websites where the content was not relevant for the purposes of this project. Due to the vast number of results it was decided that the results would be reviewed until it was clear that the law of diminishing returns was applying, and few or no new results were being obtained. At this point we decided it was safe to assume that we had observed and reviewed any literature that would have been relevant and that there would have been little if anything of interest amongst the subsequent results which we did not have time to review.

Following searches of engine searches and relevant websites, the initial results were reviewed for relevance to this project. Any websites, papers and so on that on first inspection appeared useful were noted. Links were found from various papers and websites to other potentially relevant sources and these too were also inspected. After the initial inspection of results, we began to build up our own database of potentially useful sources; grey literature, websites, books and so on. As was the case with previous searches, a small number of papers could not be retrieved either because the paper was not available from electronic sources or accessible libraries. Once we had gathered all the obtainable literature, we then scored these sources using the same criteria that had been used to score sources found in the database searches (ie If a source was given a 1 = we would accept it, if it was given a 2 = we considered it a possibility and if it was given a 3 = we would reject it).

Following this review of the search engine results 17 sources were identified that appeared theoretically and methodologically relevant for the purposes of this project. These 17 papers were retrieved so that they could be reviewed in greater detail. Initial review suggested that 11 documents were of some relevance (see Figure 10-5).

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1. Working with young people: A profile of projects funded by the Partnership Drugs Initiative (Scottish Executive) (2004)

2. Evaluation and Description of Drug Projects working with Young People and Families funded by Lloyds TSB Foundation Partnership Drugs Initiative (Scottish Executive) (2006)

3. Evaluation of the Aberlour Dundee Outreach Service (2008)

4. How good are our services for young carers and their families? How good can we be? (Scottish Govt 2008)

5. Meeting young carers' needs: An evaluation of Sheffield Young Carers' Project (2000) – Becker and Dearden Young Carers' Research Group

6. Effective Interventions Unit. Supporting families and carers of drug users: A review (Macdonald et al University of Edinburgh) c2002 –

7. A Review of Effective Carer Interventions. Appendix B. Developed for the Caring for Carers Project. Department of Disability, Housing and Community Services ACT Government September 2003 (Australian Govt)

8. Early intervention and prevention in Bedfordshire. How to access services for children, young people and families through Multi Agency Allocation Groups (MAAGs), the Common Assessment Framework and the Lead Professional Children and Young People's Strategic Partnership

9. Hidden harm Next Steps Supporting Children – Working with Parents Scottish Exec 2006

10. The Children's Counselling Service at Family Care: An Evaluation. A report prepared for Family Care by Chris Dearden. Department of Social Sciences, Loughborough University, April 1998

11. Joint Area Review Self Assessment Targeted Early Intervention and Prevention. Notts 2008

Figure 10-5: Relevant documents retrieved via a review of the grey literature

The Effective Interventions Unit, set up by the Scottish government, conducted a review in 2002 which synthesised literature, evidence and practice experience with a view to improving the services and interventions for families and carers in Scotland. This was followed by reports commissioned by the Scottish Executive (2004, 2006) which used similar methodology to draw together the findings from a range of projects across Scotland elements of which relate to young carers of parents with drug / alcohol misuse problems. Additionally a report in greater depth of the Aberlour Dundee area was carried out in 2008. In 2008 the Scottish government also produced a guide to carers of young people in Scotland which is informed by findings from some of these projects. The focus throughout, however, is generally on (i) the risks for young people living in such families in developing drug / alcohol habits themselves with a view to identifying policies and measures which will reduce these risks and (ii) interventions with the parents with drug / alcohol misuse problems. These reports are largely qualitative, based on interviews with project workers and supplemented by (i) statistical data on the case loads and interventions and (ii) aggregated secondary data which identifies the extent of young people at risk. These reports are collations of summaries of projects which are wide ranging through not being part of a systematic programme. Rather, they are local initiatives fulfilling specific objectives and hence provide a rich source of information on experience and practice. A recurrent theme is a perceived need to understand the broader context of family life when dealing with any client group such that there is a suggestion that bespoke solutions are generally required. The potential for a lack of clarity in the ultimate aims of any particular intervention is,

however, also acknowledged. No economic analysis of the effectiveness of any particular project is undertaken nor is there a systematic analysis of the relative importance of different measures using a quasi-experimental design. In addition, the 2006 Scottish executive report 'Hidden Harm' covers a range of issues surrounding the effects on families and children of parents with drug / alcohol addiction. Measures to support children as carers are an aspect of this report.

In England there have been evaluations of projects whose aims are closer to ours. Some of this has been reported in the academic press but the evaluations have also been prepared for the funding bodies, for example the Sheffield Young Carers' Project (Dearden and Becker 2000) and Dearden's 1998 report for Family Care. Here the focus is on young carers though not restricted to young carers of parents with drug / alcohol misuse problems. Similar to the work in Scotland the methodology is qualitative and aims to understand the kinds of interventions which are positively regarded by the young carers themselves and/ or which are regarded by the project workers as being effective in improving the lives of the young carers.

The general area of child support services covers elements which relate to young carers. In Bedfordshire, for example, Multi Agency Allocation Groups (MAAG) seek to coordinate the activities of a number of agencies in order to provide a coherent, joined up approach to supporting children and families on a number of fronts. While there is nothing of direct relevance in this literature, it is clear that young carers of parents with drug / alcohol misuse problems would be a target group in the delivery of these services. Again, the focus is not on what is known to work, but what sort of assistance is available. The aim is, therefore, to have a more effective and holistic advocacy model. In Nottinghamshire, Joint Access Teams serve a similar function as the MAAGs.

The Australian government have also conducted a review in regard to how best to support carers (2003) though this focussed largely on the academic literature albeit with a view to developing recommendations for further research and practice.

OUTCOME OF GREY LITERATURE REVIEW

While none of the papers outlined in the grey literature review were of direct relevance to the later stages of the project they did provide some useful context that informed the team's thinking in developing the subsequent analysis.