

## The positive outcomes of developing a research bid with young carers

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### Abstract

*This article reports on the positive outcomes of developing a funding application with nine young service users to undertake participative research about young carers' assessments. Through a series of intensive workshops, using children and young people's participation methods, young carers were involved in the complex planning of a research proposal, developing the statement of aims and designing the methods for data collection, analysis and dissemination. The paper explores the outcomes of this process, focusing in particular on the knowledge developed about statutory assessments of young carers' needs, their experiences of assessment practices and their perceptions of the value of participating in bid development. The author concludes that, whilst time consuming, young carers' involvement in the early stages of bid development is important in ensuring the development of research that is more robust and which has greater relevance, by reflecting the issues and experiences of those people most affected by its outcomes.*

**Keywords:** Young carers, assessment of need, children's participation, service user involvement in research bid development

### Introduction and background

The participation of children and young people in social work research, policy and practice is a relatively new phenomenon. Historically, adult interpretations of children's wishes and needs have determined service development, and influenced research and policy (Franklin & Sloper, 2004). Children have been perceived by adult researchers as vulnerable, in need of care and protection, and as incompetent and, consequently, incapable of understanding the research process or of being able to give trustworthy, reliable accounts of their experiences (Christensen & Prout, 2002).

For many years, the disparities in power and status between adults and children, which derive from historical attitudes and assumptions about the nature of childhood, were reinforced in legislation, policy and practice (Lansdowne, 1994). Perspectives on children's status in UK society shifted, however, following the implementation, in

England and Wales, of the Children Act 1989 (and parallel legislation in Scotland and Northern Ireland) and the ratification of the United Nations Convention on the Rights of the Child (United Nations General Assembly, 1990; see also Kellett *et al.*, 2004; McLaughlin, 2006), which increased awareness of children's rights and "paved the way for children's involvement" (Alderson, 2001, p.141) in research as both participants and co-researchers. The momentum for child focused research has been intensified in the UK, moreover, in the wake of the government's *Every Child Matters* initiative (HM Government, 2003) and the Children Act, 2004. Children's participation is now central to a range of UK health and social care policies which place emphasis on the need to listen to, and consult with, children and young people in decisions that affect their lives (see Warren, 2007).

This article seeks to add to the emerging debate concerning the participation of young service users in the development of

research proposals, and to add to the ongoing debate about the value of assessment processes and practices in preventing children and young people who provide care, assistance or support to another family member, friend or neighbour who has care needs (commonly referred to as 'young carers') from undertaking inappropriate levels of care. Despite a growing body of research which explores the needs and experiences of young carers and their families, very few studies focus on young carers' experiences of assessment, and there are no studies to date which examine how the different assessment practices that have developed in England and Wales since the transformation of Children's Services set out in the *Every Child Matters: Change for Children* programme (HM Government, 2004) impact on the lives of young carers and their families. The findings presented here are based on discussions and group work undertaken by the author, during a five months sabbatical, with a group of nine young carers to develop a collaborative research proposal that would investigate the similarities and differences in the assessment experiences of young carers. It is not my intention to explore here the issues associated with the process of involving young service users in the writing of the bid, but to focus, instead, on the outcomes of that process and its impacts in terms of knowledge development.

### **Young carers as researchers**

There are currently very few studies in which young carers have been able to demonstrate their abilities as participative co-researchers rather than research subjects, and where young carers have been active participants able to demonstrate, through each stage of the research project, their capacity "to shape, change and challenge the research process and knowledge development" (McLaughlin, 2006, p.1399; see also Jones *et al.*, 2002; Moore & McArthur, 2007). Although the idea for the

research proposal was initiated by academics, the involvement of young people in the complex planning, design and development of the proposal was important in reflecting their real experiences rather than academics' own perspectives or perceived priorities. During the development phase, young carers brought unique and important perspectives and insights to the partnership, making all key decisions about the design and development of the research, including its aims and methods for data collection, analysis and dissemination. The author acted as a conduit to this process.

Of the nine young carers who participated in the workshops, two were male and seven were female. Their ages ranged from 15-19 years, the majority (eight) falling within the secondary school/post 16-education band, with an average age of 17 years. Whilst most were white British, one young person described her ethnic origins as Pakistani and another as dual heritage. All of the young people provided care to at least one or both of their parents, the majority (seven) providing care to their mothers. In addition, two young people also provided care to one or more siblings.

### **Methods underpinning the development of the research proposal**

As little is known about the extent and nature of current assessment practices, a scoping exercise was undertaken by the author to generate baseline information that could inform the development of the bid, through the distribution of a short questionnaire to two young carer project networks (The Princess Royal Trust for Carers and The Children's Society), reaching an estimated 350 projects based in both the voluntary and statutory sectors. In addition, a series of eight workshops were held with nine young carers, drawn from two young carer projects in contrasting local authority areas of the West Anglia region

(The Hub in Bedfordshire and West Anglia Crossroads in Cambridgeshire) between April-May 2009. The two local authorities were chosen on the basis that they were known to have adopted diverse ways of assessing young carers' needs: in one area, young carers' assessments were commissioned by the local authority and undertaken by the Young Carers' Project staff whilst, in the other authority, approximately twenty five miles away, assessments were undertaken by statutory agencies, with support from the Young Carers Project Manager. We were interested to learn more about young carers' perceptions of these different assessment practices and how their experiences might inform the development of the research proposal.

## **Key Findings**

The findings are discussed in two parts. The first part focuses on the preliminary evidence that emerged from the scoping exercise which provided some sense of the assessments taking place currently and which, together with young carers' own experiences, was used to inform the development of the research proposal. The second part focuses on the outcomes of the work undertaken with young carers, in particular, what has been learnt about their needs and assessment experiences, and their experiences of participating in developing a research proposal.

Preliminary evidence from the scoping exercise revealed a broad diversity of assessment practice with regard to the number of assessments undertaken, the approach adopted and the assessment frameworks in use nationally. Thirty six of the estimated 350 specialist young carer projects across the UK responded to the request for information; 32 were located in locally governed areas in England, three in Scotland and one in Wales. Of these, 34 provided statistical information on the numbers of young carers known to their

project and 31 provided additional statistical information about assessments completed with these young people. Of the five respondents (located in England) who gave no information on young carers' assessments, one no longer had a role as a direct service provider working with young people and four had not been advised of any assessments undertaken and, therefore, held no statistical information on young carers' assessments. Thus, of the 28 specialist projects located in England (27) and Wales (1) that were in a position to offer information about young carers' assessments, the response rate was 100%. Whilst, no claims are made that the findings reported on here can be generalised more widely, they do point to the need for further investigation.

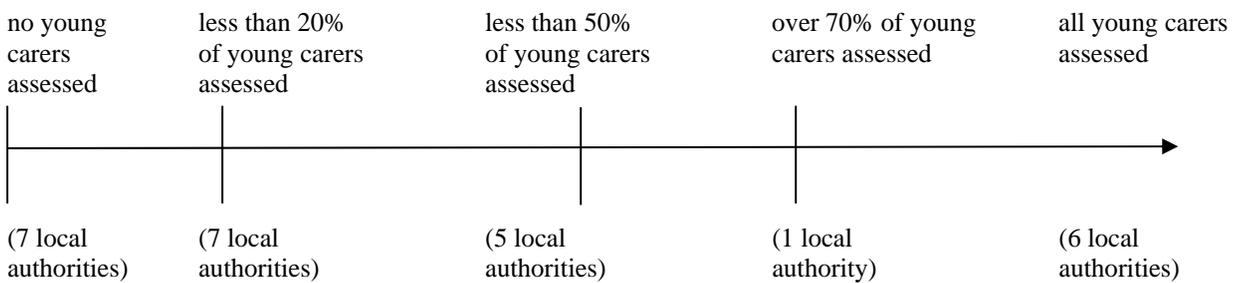
Overall, the emerging data from this study suggests that, over the past five years, there has been an increase in the number of young carers receiving a statutory assessment of need. Of 4,884 young carers known to the 31 projects in 29 local authorities in England and Wales who returned statistical data, 1,685 young carers (34.5%) had received a needs assessment prior to April 2009, compared with 18% (885) in 2003 in a study conducted across the UK by Dearden and Becker (2004). As can be seen in Figure 1, the scale of assessments completed ranges from local authorities in which there are no assessments taking place to authorities where all young carers receive an assessment of need. The data show that, whilst in 6 authorities all young carers received a formal assessment of need, in 12 authorities less than half of known young carers had been assessed and in 7 authorities no young carers had received a formal assessment. This suggests that the likelihood as to whether a young carer receives an assessment of need in England and Wales is dependent primarily on geographical location rather than familial circumstance. When viewed in this way, assessment (and intervention) appears to be based on a 'postcode lottery' which pays little or no

regard to young carers' legal rights and entitlement. This is particularly concerning given that the legislative framework provided for by the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and the Carers Act (Equal Opportunities Act) 2004 very clearly outlines young carers rights to an assessment and the duty of local authorities to inform carers of their right to an

assessment in certain circumstances (see Frank & McLarnon, 2008).

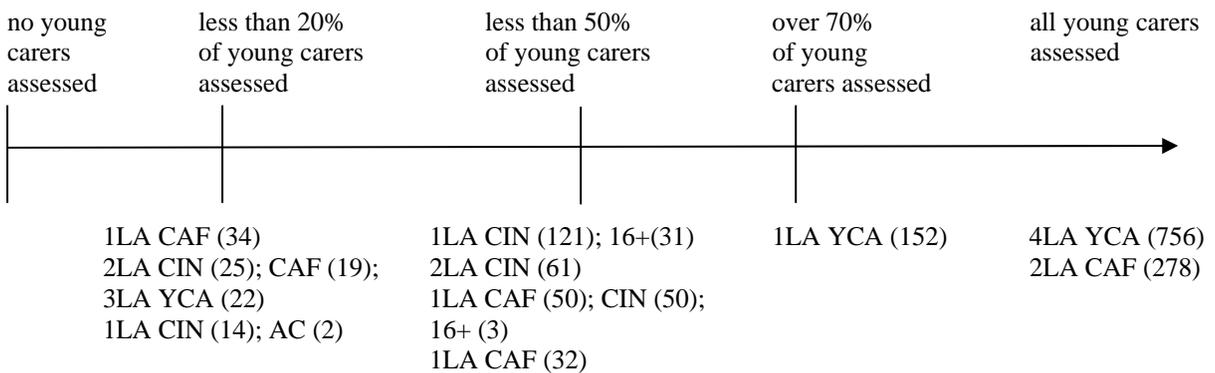
The emerging data also show that those local authorities in England and Wales that are undertaking formal assessments of the needs of young carers are doing so under different pieces of legislation, using a diverse range of frameworks as shown in Figure 2.

**Figure 1** Assessment completions



NB. In 3 local authorities, project staff were unaware whether young carers had received a statutory assessment  
 Number of assessments: 1685  
 Total number of local authorities: 29

**Figure 2** Assessment completions and types (n=1650)



Type of assessment:

YCA = specially designed in-house young carer assessment

CAF = common assessment framework

CIN = child in need assessment under Children Act 1989

16+ = assessment of young carers aged 16 or over under Carers and Disabled Children Act 2000

AC = adult carer assessment (legislation not identified)

Figure followed by LA denotes number of local authorities using type of assessment

Figures in brackets denote number of each type of assessment

(NB. data missing on 35 assessments)

The data show that authorities where approximately 70–100% of all known young carers have been assessed, use either a specially designed in-house young carers assessment framework or the Common Assessment Framework (CAF) (a shared assessment tool, designed to help early identification of need and promote co-ordinated service provision), which was implemented in all local authorities between April 2005 – March 2008. This may be a sign that some authorities have shifted their thinking and systems of assessment for young carers towards active prevention. In contrast, however, as shown in Figure 2, some authorities undertaking substantially less numbers of assessments relative to the number of young carers known to them (under 50%) are assessing young carers as either *children in need* under the Children Act 1989, or as *carers* (16+ or over) under the Carers and Disabled Children Act 2000 or the Carers (Recognition & Services) Act 1995. Whilst these local authorities are, quite rightly, acting within the parameters of the legislation, some commentators (see Frank & McLarnon, 2008) have expressed concern that the very act of labelling children as ‘in need’ is a sign that support for a parent and their family has already failed and that parents need to be able to access support at a much earlier stage so that their children are prevented from having to take on caring roles.

There are indications from the data, however, of a change towards a more preventative, proactive approach by some authorities, positioned at the lower bands on the continuum, to the assessment of young carers’ needs. In line with the Government’s Carers Strategy (HM Government, 2008), a number of projects responding to the scoping exercise, who are undertaking fewer assessments (less than 50% of known young carers), are using the Common Assessment Framework alongside other assessment frameworks, as can be seen in Figure 2. What is not clear from this data, however, is how many of these assessments pre-date the

implementation of CAF in these particular authorities and whether, overall, more assessments have been undertaken since the implementation of CAF. Also not known is the extent to which the common assessment information may have been fed into the specialist assessments identified or prevented some children from needing to be assessed as ‘in need’ at some future point.

The scoping exercise has highlighted the need for further research that will provide more robust statistical data on the extent, nature and outcomes of statutory assessments of young carers, and the reasons why it is that some authorities are undertaking substantially more assessments than others when, in theory, all authorities should be operating under the same pieces of legislation. We are aware that local authorities have all been at different stages with regard to introducing and embedding the Common Assessment Framework and the findings from the scoping exercise may, in part, reflect the extent to which these changes have been embraced in different regions nationally. In Figure 2, for example, both the lower and upper bands of the assessment completions continuum suggest that a number of authorities may not be using the Common Assessment Framework routinely to assess young carers’ needs. Whilst a recent small-scale survey (involving 50 young carers and staff from 8 councils) undertaken by Ofsted (2009) to examine the assessment and delivery of services for young carers and their families found that, where the Common Assessment Framework was most developed, “it had proved effective in the identification and assessment of young carers’ needs” (Ofsted, 2009, p.14), the study also found that, in children’s social care services, there was no consistent pattern with regard to assessments of young carers who were not suffering, or likely to suffer, significant harm and that, in practice, resource constraints meant that assessments tended to be only carried out if there were clear child protection issues.

The scoping exercise has also highlighted the need for research that will examine the quality of the different assessment approaches currently in use and explore how assessment processes and practices are perceived, both by those on the receiving end – the young carers – and by those who conduct the assessments. Currently, little is known about how and by whom young carers' needs are best assessed. The scoping exercise revealed a diverse range of approaches to assessment practice which has been useful in informing the development of a research proposal that will enable us to understand better the implications of young carers' experiences of assessment, through an examination of the relationship between the content, process and outcomes of assessment for children and young people, so that those interventions most likely to result in positive outcomes for young carers may be identified.

### **Outcomes of Young Carers' Bid Development Group**

The involvement of young carers in the writing of the research proposal resulted in a number of positive outcomes. First, the young carers' insider knowledge of assessment practices, and of the needs of the community that we proposed to research, was highly valuable in confirming for us both the need for a piece of research about young carer assessments and the value of involving young carers in that research as a way of enabling them to take action for themselves. The desire to inform other people, such as service providers and policy makers, about young carers' views and experiences, and to effect change in assessment practices and service provision for other young carers and their families, were strong motivators for the young carers both to join and maintain their membership of the Bid Writing Group and provided us with a clear indication of the young people's commitment to act upon the findings of any

future research that we might undertake together.

Second, involvement in the project also resulted in both the facilitator and the young people developing greater awareness and understanding of the quality (and quantity) of individual assessments and their impact on individuals and their families. As a starting point for developing the research proposal, young carers explored their own views and experiences of assessment, to help identify similarities and differences between the experiences of the two project groups and to identify key areas and issues that could be explored further in the research study. The differences between the assessment experiences of the two project groups were striking. Young carers, whose assessments had been undertaken by their own project staff, described their experiences of the process and its outcomes in positive terms:

*When the young carer's worker did it [the assessment] – ok – more comfortable; less pushy.*

*I didn't think my words would be twisted by the young carers' project.*

*The help that I got after the assessment made a big difference! I was offered respite and I found out I was eligible for funding to help me get a break from home life and I got more regular one-to-one meetings.*

However, for the majority of young carers, whose assessments had been undertaken by social workers in children's or adult social care services, their experiences of both the process of assessment and its outcomes appeared negative:

*When it happened it went on for a long time.*

*Unannounced visits are awkward and uncomfortable for a young carer.*

*Interviewed at their [social workers'] convenience.*

*Forms are too formal – it looks like an exam paper.*

*Boring – questions were pointless.*

*When the social did it – noseey.*

*Not listening and interrupting. Just the opinion of the person cared for are listened to as they are the ones who have an assessment.*

*Copies of assessment received weeks after the interview.*

Whilst in this regard a palpable sense of anger dominated our early workshops, the process of talking about these experiences was important in building a group identity and in enabling the young people to develop a shared understanding of the issues to be researched. As one young carer commented:

*I learnt that some of the other carers had assessments which either did or did not benefit them for one reason or another. It was an opportunity for those, such as myself, who did not have an individual assessment or could not remember them, to learn what they were all about; it was also nice to hear the different experiences - even if they were not particularly positive.*

For many young carers, the realisation “that other people have had the same experiences as me” was notably cathartic. As one young carer wrote:

*I really felt as though I was part of a community talking about how I have had problems with the crisis team ... and having trouble with trying to get a home assessment. I thought the project was a huge success especially when we talked about the good and the bad experiences about assessment and what they did when they got to the home of the carer.*

As can be seen in Figure 3, the young people’s views about the purpose of assessment were closely associated with the outcomes that they wanted to see, and whether the assessment had led to improvements for themselves and their family as a whole – in particular, the introduction of, or increase in community services, specific support for themselves (and for the person with care needs) or equipment in the home. For those young carers in the group whose assessments had been undertaken by statutory agencies, the lack of action or noticeable outcomes resulting from their assessment had left them feeling angry. Young carers were particularly concerned about the gaps in support around the family and the person they provided care to, so much so that, for them, the primary outcome of assessment, i.e. better support for their parent and family, was a priority.

**Figure 3** Young carers’ views of the purpose of an assessment

Young carers were asked about the purpose of assessment and what it meant to them. Their responses included:

- Being asked lots of questions.
- Getting your point across.
- Helps you to know where you stand.
- Helps you to plan and know who to turn to, what they [social workers] can do.
- Getting decent help - giving help to people in our situation.
- Improving support that we would have liked if had more money.
- Making things better for young carers in the future.
- Being able to deliver what they [assessors] promise.

**Figure 4** Young carers' perceptions of the assessment process

Young carers from both projects contributed their experiences of the assessment process:

- Assessments are a waste of time unless something is done after the process.
- When assessments do happen, they go on for a long time or are never ending and lack action.
- Assessors do not care. They visit unannounced, interview at their convenience and never arrive on time.
- Young carers are not fully informed or prepared for assessment.
- Assessors ask too many questions. The process is boring and pointless. Some questions are personal and unimportant.
- Assessors don't listen. They interrupt and jump to conclusions.
- The assessment forms are too formal. It looks like an exam paper.
- Professionals don't see young carers as a priority – they ignore others in the family.
- Young carers are not asked but told what is happening.
- Copies of the assessment are received weeks after the interview.
- The responsibility (for care) is transferred back onto the carer.

The young carers welcomed the opportunity to have their views heard and discussions which focused on their own experiences were helpful in confirming the immediate relevance of our proposed research in focusing not only on the outcomes but also the content and process of young carers' assessments. This resulted in a proposal that was firmly rooted in the reality of their experiences. As can be seen in Figure 4, the young carers explored and reflected on aspects of their own assessment experience which was helpful, not only in terms of identifying the key areas and issues to explore in the research study, but also in enabling the young people "to find out their own standpoint and any biases that they may hold" (Kirby, 1999, p.80). These experiences provided some insight into the challenges and complexities that we faced together, both in designing the research approach and in supporting the young carers as researchers, if our funding application was successful.

Outcomes were also evident in other contexts. A third outcome of the Bid Development Group was its effect in increasing young carers' knowledge of, and access to, decision making structures which might enable them to take action for themselves (see Kirby, 1999). User-informed research, particularly involving

children and young people, is still very much in its infancy. Indeed, few studies exist which highlight the value of young carers' participation as collaborators or peer researchers in the development of research parameters and in conducting and analysing research interviews (Jones *et al.*, 2002; Moore & McArthur, 2007). The starting point for this project was the desire to involve a group of young carers in the development of a research proposal about young carer assessments but also, subsequently, to enable those same young people to participate in undertaking the research, if the application for funding was successful. It is not my intention to explore here the process by which the project moved from a user-informed to a user-led research bid but, as has been discussed elsewhere, it is important to acknowledge that, through the life of the project, the young carers did develop ownership of both the process and outcomes of the research proposal. Through a process of intensive discussion and group work, using children and young people's participation methods, the young carers developed the statement of research aims and designed the methods for data collection, analysis and dissemination. One important identifying element of their ownership of the research, towards the end of the development phase, was the young carers' decision to maintain control of the

research, if the bid was successful, by undertaking all of the required research tasks themselves (designing and conducting the research, analysing the data, and disseminating the findings) with support from the author, rather than buying in the services of a researcher to undertake some or all of these tasks.

It was essential to evaluate young carers' experiences of the workshops and, in particular, how this influenced their views of user participation. As can be seen from the reflections below, the project did impact on both young carers' awareness and understanding of the development of a research proposal as well as their perception of the value of user participation.

*I have learnt the importance of allowing others to have a voice so that their confidence has grown in a strange environment. Participation in helping to write the bid has helped me to understand that young people should be able to be involved, as it is, after all, about their experiences and how to make things better. ... Overall, I felt that we have been able to compile a set of information from different experiences we have had in the past which has helped me to realise that things do differ from place to place and are not set in stone. Things can always be changed so long as views are treated with sensitivity and used appropriately within the research project to express thoughts and feelings. The facilitator was able to listen and also explain why our views were important in getting the funding for the bid itself. (Female young carer, 17)*

Similarly, another young person observed that:

*I learnt overall from this whole experience that we could make a big difference if we really tried and put our point across to everyone. I also learnt that I could work in a group and maybe*

*would want to work for this kind of work in the future. I also learnt that we can help one another with the kind of problems that young carers face in life and professionals do not take any notice of what we got to say and do not help us with our problems. This project had a big advantage because by us doing this, we could maybe get young carers' points across and make our... future better, and get things done quicker, and could also help ... future young carers. ... Overall, I enjoyed the experience. (Female young adult carer, 18)*

Young people can benefit substantially from taking part in research projects, particularly in regard to their own personal development (see Precht, 1998). Motivated at the outset by a desire to write about the project in a future employment, college or university application, a number of the young people indicated that this had been a major incentive for joining the group. Whilst the nature of the group would help to improve personal confidence in that all the young people would be involved in working with some people who they did not know, there were also opportunities for the young people to develop knowledge about research methodology, assessment policy and information, group work and understanding of themselves in relation to others, as well as particular skills such as building relationships and interpersonal communication. Structures were put in place to enable the young people to reflect on their own learning and development throughout the life of the group and, by the end of the development phase, most of the young people could identify several areas of personal growth and development. The development of interpersonal, group work or team building skills was frequently mentioned in workshop feedback forms. One young carer commented:

*My knowledge of group work and team building has increased and how to conclude all of our decisions together. It*

*has also given me a stronger passion to help as well as changing the way things are run and improving the lives of many young carers. I now have higher confidence and determination to continue helping this research project as it has done so much for me and others, and will also increase people's awareness.*  
(Female young carer, 15)

Another young carer, reflecting on what he or she had learnt about working with others, commented:

*It is important to note what others say as they have valuable points to contribute.*

There was general acknowledgement of the value of working together on issues with others in the group and recognition of the importance of listening to others and being listened to. As one young carer poignantly commented:

*If you co-operate you can do anything.*

## **Conclusions**

This bid writing process has been just one stage in what is hoped will be a long term development process, and not just a means to an end, or an end in itself. Whilst time consuming, involving young carers in the development of the bid has, without doubt, brought us closer to the reality of young carers' lives. As a result, the research proposal is quite firmly grounded in their experiences. The research aims and objectives now have greater relevance, the data collection methods and analysis are appropriate, sensitive and inclusive, and the dissemination strategy will ensure that the key messages from the research will inform the development of future research-based policy and practice with young carers and their families as shown in Figure 5 below.

It is acknowledged that the context for developing this bid was unusual, in that the conventional barriers to the participation of service users and carers, namely the provision of financial support for their time and expenses, and funding of the facilitator's time, did not exist. Whilst it is not uncommon for such barriers to prohibit researchers from involving service users or carers at this most crucial stage of the research process, this article has focused on some of the positive outcomes of service user participation in bid development. As the project here has highlighted, participation presents important opportunities for ensuring the development of research that is more robust and has greater relevance, by reflecting the issues and agendas of those people most affected by its outcomes, rather than the perspectives or perceived priorities of academics. In presenting opportunities for personal growth and development, involvement in research also has the potential to promote further opportunities for young service users and carers, improving employment, educational or community orientated opportunities.

Many of the young people involved in this project were formerly, like other young carers throughout the UK, unaware of their rights and entitlement to ask for an assessment of their needs (see Becker & Becker, 2008; Frank & McLarnon, 2008). Whatever the outcome of this bid application, it is hoped that, at the very least, the process of participation has helped to increase young carers' access to local assessment processes which will, in turn, enable them to fulfil their rights as young people, carers and citizens to participate more fully in the decision making processes that affect their lives.

**Figure 5** Overview of the research proposal

<p><b>Research Aim</b> To explore the similarities and differences in the assessment experiences of young carers, to understand better the different assessment practices undertaken in statutory social care authorities in England and to explore the impacts/outcomes of these practices for children, young people and their families.</p> <p><b>Research Design and Methodology</b> The study will combine quantitative and qualitative methods in two phases of data collection and analysis:</p> <ul style="list-style-type: none"> <li>• a UK-wide e-survey to generate descriptive statistics on the nature, extent and outcomes of young carers' assessments.</li> <li>• individual in-depth telephone interviews conducted with 20 young carers and their respective assessors by a team of young carer researchers.</li> </ul> <p>All research instruments and information leaflets will be developed, with support, by a team of young carer researchers.</p> <p><b>Data Analysis</b> Young carers will maintain a high level of control over these processes through:</p> <ul style="list-style-type: none"> <li>• choice of which frequency counts and percentages to calculate, which relationships and comparisons to investigate, and by working together to build a thematic analysis.</li> <li>• reviewing interviews to identify key themes, writing analytic summaries of each interview and collating data to assist with writing the final report.</li> <li>• making decisions about the key messages that should be taken from the research.</li> </ul> <p><b>Writing up and Dissemination</b> Young carers will contribute to the design, content and production of a research report and supportive practice guide about good assessment practice. They will help launch both documents at a seminar for researchers, policy makers and practitioners.</p>
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