

All Work and no Play? Understanding the Needs of Children with Caring Responsibilities

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This article draws on research with children who provide care for parents with serious mental health problems and signals ongoing research that uses photographic participation methods with these groups of vulnerable children. The intention of this article is to highlight the need to move away from popular and simplistic representations of children with caring responsibilities (young carers) as victims of their parents' illnesses, as 'little angels' whose caring work is condoned through rewards or as (exploited) informal domestic workers whose childhoods are inevitably compromised by the caring activity they undertake. Recommendations are made for generating deeper understanding about the lives and needs of children who are affected by parental impairment that is congruent with the thrust of current UK policy, Every Child Matters and the 2004 Children Act. © 2007 The Author(s). Journal compilation © 2007 National Children's Bureau.

Introduction

Children who undertake domestic caring responsibilities for parents who are ill or disabled are more commonly referred to as young carers¹. Indeed, these vulnerable children and young people are now recognised and included in both health and social care policy and practice in the UK, and increasingly are being identified internationally, for example in Germany, Spain, Australia and more recently in North America (see Aldridge and Becker, 2003; Baago, 2005; Horwath, 2000). The focus of the research studies undertaken in the Young Carers Research Group (YCRG) at Loughborough University, has been on those children and young people who undertake long-term and disproportionate caring responsibilities for (often lone) parents who have long-term illness or disabilities. It is important to point out here that the YCRG has always prioritised this subgroup of vulnerable children in its work, and not those children and young people who undertake domestic duties that are congruent with their age and level of maturity.

The reasons why children care and the impact that caring activity has on children's development and childhood, as well as on adult experiences, are well documented. The impacts of caring can include restricted access to social networks, school absenteeism, truanting, educational under-performance, psychological and emotional problems as well as compromised transitions to adulthood (Dearden and Becker, 2000, 2004; Frank and others, 1999; Thomas, 2001). It is important to note that, for children, these are not inevitable consequences of living with a parent who has a chronic illness or disability. Indeed, in the YCRG we have emphasised consistently the importance of recognising the potential trigger for caring (the

onset of parental illness or disability) combined with other significant factors, such as lone parenthood, low income or poverty, lack of adequate parental and family services and lack of available informal support. These factors together mean that children and young people are more susceptible to being drawn into the type of caring responsibilities that may be inappropriate to their age and level of maturity.

The contradiction of caring

However, the more complex consequences of caring for children are reflected in the contradiction they represent in both political and epistemological terms. From a political perspective, the government confirmed its commitment to addressing the issue of young caring when early studies first pointed to the potential numbers of young carers in the UK and the impacts of caring on childhood development (Aldridge and Becker, 1993, 1994; Bilsborrow, 1992; Dearden and Becker, 1998; Meredith, 1991). An Early Day Motion in parliament immediately followed the launch of Children Who Care (Aldridge and Becker, 1993) and, 2 years later, young carers were included in policy for the first time in the Carers (Recognition and Services) Act 1995 (HM Government, 1995).

Nonetheless, the duality of children's roles when they cared posed a challenge to both policy and practice simply because these were children who were still essentially in the phase of *childhood* but were, at the same time, undertaking *adult*-type responsibilities. This tension also polarised associations between childhood (lack of responsibility) and caring (responsibility and work). These conflicts, or contradictions, could not be fully reconciled in UK policy or practice, to a large extent because of the disjuncture between the necessity for a needs-based approach to young caring and one that had its roots firmly in a children's rights paradigm. This was not helped by the fact that in some of the early studies young caring was often described and understood in terms of role reversal and, in psychiatric terms, as evidence of attachment disorder, or parentification (see Chase, 1999).

History tells us that children have always undertaken some degree of domestic and caring responsibility (DeMause, 1976), but what is clear is that in the current context of young caring, and the necessary policy responses to it, children also represent a conflict between the private sphere of the family and the political sphere that requires government interventions based on child protection. Even in the context of current children's policy in the UK, young carers continue to pose a challenge to the principles both of protection and prevention.

Epistemologically, the issue of young caring has also represented a polarity between a children's rights paradigm that is about liberalism and empowerment (giving children a voice) and the rights-based approach of the disability movement, with its emphasis on the needs and rights of disabled people as parents. The academic debate that resulted from this apparent contrariety has moved on and some common ground has been reached in recent years. Nonetheless, a disability rights approach emphasises the role and needs of disabled parents, and not the identity or agency of children. As Wates argues:

Labelling children of disabled adults as young carers and focussing on them as a distinct service user group deflects attention from the underlying issue.... Many parents feel that their parental role is

undermined and their families disadvantaged by social services systems that routinely leave parenting tasks and roles out of account when assessing a disabled adult's needs. (Aldridge and Wates, 2005, p. 81)

On the other hand, a children's rights approach to young caring has emphasised the importance of recognition, identity and agency:

The classification of children as young carers attests fundamentally to a children's rights philosophy. Put another way, young caring emphasises the perspective of children as opposed to an adult-based definition and understanding of what is meant by the phase of childhood, and informal care. It sees children as young people with agency and expertise through experience. (Aldridge, in Aldridge and Wates, 2005, p. 86)

Children's agency and parental mental illness

The aim of the mental health study² was to extend the idea of children's agency in an area that we knew was largely neglected, that is, children living with, and caring for, parents with serious mental health problems. The study was also both timely and relevant given the number of young carers' practitioners (young carers' project workers) who were reporting increasing numbers of children's referrals from community mental health teams across the UK.

The mental health research was, and is, important for a number of other reasons. Firstly, methodologically its three-way, qualitative approach (where children, parents and key workers were interviewed), enabled us to provide a more comprehensive picture of parental impairment, its impact on children and the nature and extent of professional interventions. Thus, the study provided us with greater insight into the needs of children and families in these contexts. Statistically it also allowed us to reconfigure data on the prevalence of mental illness in the adult population in the context of parenting and young caring.

Secondly, theoretically it enabled us to challenge the disability rights critique whose commentators had continued to assert that if adults with disabilities were provided with adequate services children would not have to care (see Keith and Morris, 1995). Adopting a children's (and family) rights perspective, the study demonstrated that even when parents have access to multidisciplinary services and support, children continue to provide care. On the one hand, children do so out of a sense of love and duty and the close interdependency that often typifies the caring (parent-child) relationship (Aldridge and Becker, 2003) and, on the other, children's availability through co-residency means that children are able to provide consistent and flexible support.

Thirdly, analytically and in its recommendations, the mental health study endorsed a number of key findings and messages for policy-makers and practitioners.

- In some cases, the primacy of parent-child relationships (as well as relationships with significant others) negates the inevitability of adverse outcomes for children when they care for parents with serious mental health problems.

- Caring can help alleviate the worries and concerns that children have, thus supporting psychiatric evidence that caring, in some circumstances, can help children emotionally (see Göpfert and others, 1996).
- Professionals (including mental health practitioners) often assume an inevitability of risk to children of harm or developmental delay when they live with, or care for, parents with serious mental health problems. This risk association is often made without talking to children or families themselves.
- Mapping and monitoring children's and parents' experiences and needs should be done conjointly in order to fully understand the support needs of children, parents and families as a whole.

Not only do the findings from the mental health research both mirror, and add new dimensions to, other studies in the field but, importantly, its messages find resonance with research conducted outside the area of young carers' research, for example, in population studies and, in particular, child-centred population geography. The patterns of care-giving highlighted in the mental health study are replicated in (and are synchronous with) the study of children in sub-Saharan Africa who care for parents with HIV/AIDS (Robson and others, 2006). In this respect, there is also a cultural synchronicity between these two studies, even though they were conducted in very different contexts. In Lesotho, Tanzania and Zimbabwe, children experience similar outcomes to those of other children in the UK, and elsewhere when caring for their physically ill parents. Robson and colleagues found that children in these areas of sub-Saharan Africa undertake household, caring and nursing responsibilities and, as a result, experience school absenteeism (and dropout) and emotional and physical problems and are information poor.

In addition, there are some striking similarities between findings from this study and the mental health research. In particular, for example, Robson and others (2006) noted that the nature and extent of responsibility among children fluctuates according to their parents' state of health:

Care for a sick relative is likely to be an irregular demand on children's time – one that the household calls on in times of severe need, or temporary crisis brought about by the sickness of a household or family member. (p. 101)

In addition, caring can help to accentuate close parent-child relationships, 'Some youngsters in Zimbabwe appear to develop intimate bonds and deeper knowledge of the ill person through caring' (p. 104).

We can compare this readily with the findings from the mental health study:

All the young carers in our study undertook practical, domestic duties at some time, to a lesser or greater degree, depending on the condition of their parents at the time. Therefore, the need to undertake more household chores arose when parents became incapacitated by their illness. (Aldridge and Becker, 2003, p. 70)

Furthermore, our evidence would point to the fact that caring may serve to offset some of the negative consequences of other external dynamics and may indeed strengthen parent-child relationships. (Aldridge and Becker, 2003, p. 84)

All work and no play

One of the ways in which the duality, or contradiction, of young caring (*children* who undertake essentially *adult*-type responsibilities) has been approached has been in attempting to reconstruct or reconceptualise caring responsibility as evidence of children's work or, child 'labour'. Zelizer (2005) argued that children's work (including care work) is divided between the production of goods or services and the creation of personal capital, whether this be material, human, social or cultural in nature. She also argued that

Permissible and forbidden forms of children's work vary strikingly with the social relations to which they are attached ... children themselves create well marked boundaries between appropriate and inappropriate forms of work as well as between appropriate and inappropriate rewards for that work. (p. 185)

Zelizer also described children's care work in the context of an incessant negotiation between 'the matching of meaningful relations and forms of work' (p. 187).

However, there are a number of problems with this reassignment of children's caring responsibility simply as work. Not least is the tension that lies in an approach that at once confers choice where often there is none and, at the same time, fails to give credit where it is due. To explain, much of the evidence from studies on young caring refutes the idea that children have any choice in either creating boundaries between what is acceptable and unacceptable work or in negotiating the form care responsibility takes (Aldridge and Becker, 1993, 1994; Meredith, 1991). What has been a dominant feature of much of the young carers' research is that children often have little choice in the onset, type and extent of their caring duties, not because of poor relationships between parents, but because of the lack of adequate support services and interventions and because of the failure to recognise the importance of children's caring contributions and their need for such recognition and inclusion *on their own terms* (and in their own words).

Furthermore, there is a somewhat regressive aspect to the idea of reconstructing young caring simply as work in that it could be seen to be endorsing a relapse position that, once again, centre-stages parental culpability. Some of the early criticisms of the research and campaign work on young caring focused on the fact that if children are defined as care workers, their ill or disabled parents are inevitably implicated in the exploitation of their own children through such work (see Keith and Morris, 1995). Any regression to this position, whether intentional or not, not only unfairly inculcates parents in this exploitation, but also negates the views of children (and does a disservice to them), who often do not view caring as a labour of various toils but a labour of love. It also overlooks the fact that parents often feel guilty about involving their children in care routines.

In a broader context, a clear association is also made between young carers and work – that deserves recompense or reward – in media representations of young caring in the UK. This is evidenced in the media's (particularly the print media) reliance on oversimplified narratives about children's caring responsibilities. Here, young carers are 'little angels' undertaking unacceptable burdens that are, nonetheless, deserving of public reward.

Franklin (2002) has noted a 'growing tendency for news media to report children in ways which are negative and damaging to their interests' (p. 16). With specific reference to young

carers, Deacon (1999), argued that media representations of young carers proffer only two narrative permutations: that of the 'little angel' or the 'little victim'. Citing numerous examples from the print media where children's caring activities are described, for example, as, 'unaided, unpaid, unsung' (*Guardian*, 9 September 1994), Deacon (1999) suggests, 'these sorts of examples reveal how journalists have misinterpreted and exaggerated aspects of the debate in ways that are potentially unhelpful ... with their disinterest in care recipients' perspectives and ready characterisation of the caring relationship as one of 'dependency' and inherent exploitation' (p. 10).

Today, the media, and particularly the print media, continue to portray young carers in similar ways, with an emphasis on the unpaid, burdensome work that they do. The *Daily Mail* recently conferred its National Carer of the Year Award on a 14-year-old girl (*Daily Mail*, 7 October 2005, front page, and pp. 40–41). Kirstie King, *The Mail* reports, cares for her autistic sister and their mother who has severe arthritis. *The Mail* describes Kirstie's duties thus:

[She] gently encourages [her sister] to come and sing pop songs with her in the immaculate kitchen while she unloads and reloads the washing machine, makes beans on toast and washes up the breakfast things. By 7 am it's time to help her mother into her clothes. "It's like dressing a big doll, Mummy," Kirstie smiles.

The obvious message of the article was that Kirstie should be both applauded and rewarded for her courage and resilience in the face of adversity; less overt is an underlying commendation for Kirstie's dogged adherence to the work ethic. With no attempt to address issues of accountability or policy and practice oversights, nor, importantly, Kirstie's needs, *The Mail* legitimises her care 'work' by rewarding her with a national award and a family holiday:

Now [Kirstie's] years of selfless hard work have been recognised. She was named Carer of the Year ... In an age when thousands of teenagers are mired in binge-drinking, drugs and casual sex, Kirstie's quiet courage is humbling ... 'I don't think my life is so bad. It's hard work but there are plenty worse off than me.' (p. 40)

The child labour reconstruction of young caring inevitably, then, aligns itself, not only with popular media narratives, but also with the legitimisation of children's work and exploitation and thus associates the social issue of young caring with production and capital. Young carers are not paid for the 'work' that they do, but in constructing their caring activities simply as work implies the need for some form of reward through payment. However, we are then forced into a position that condones and legitimises caring work in childhood, when in fact most would argue that this is something that should only be undertaken (legitimised and thus paid for) in the realm of adulthood (see Meredith, 1991).

Interestingly, and more broadly, Robson and colleagues noted that it is the intention of the International Labour Organisation to eliminate children's work. In this context, it would be naïve to think that reconceptualising young caring as evidence of child labour would simply lead to its eradication; it is much more likely that children's caring contributions would be even more sequestered and overlooked because they do not fit with contemporary constructions of childhood or current international objectives.

An over-emphasis on children's caring *work*, both in academic debate and media representations of young caring, for children fails to address fully the complexity of their relationships

with parents, as well as the issue of children's agency through choice. In one sense, then, an emphasis on children's work here diverts attention from children's needs, rights and capacity to choose whether they care or not. It also fails to recognise or give credence to the significance of parental impairment as a crucial and distinguishing factor in influencing the type and extent of children's domestic and caring responsibilities. As said, there is no recognition in the child labour approach that children and young people often have little choice (whether through duty, love or lack of adequate services) in taking on responsibilities that are also a direct consequence of (and are distinguished by) the nature and extent of their parent's illness or disability.

Evidence from the UK has shown over and over again that what young carers do is distinct from the responsibilities of other children whose parents are not ill or disabled, simply because young carers have little choice in terms of the onset of caring. They do not gradually assume responsibilities congruent with their age and level of maturity and there are few interventions that recognise the significance of children's caring contributions (nor that children may sometimes want such recognition), while at the same time offering timely and appropriate support.

Robson and colleagues' geographical study on young carers in Africa is significant in that it does recognise these important distinctions and dimensions of caring, and it does so in a very different cultural context where children are expected to undertake more domestic and caring responsibility than would perhaps be expected of children in the west:

As caregivers, young people do more domestic work and have greater responsibility for tasks like cooking, fetching water and wood than other young people, *because* they live in a household with a sick grandmother, parent or sibling. (p. 100, my emphasis)

And:

It is the intimate care (giving the recipient medication, bathing, massaging and dressing them) that most clearly distinguishes the labour of young caregivers from the usual work young people do in Africa with respect to household chores. (p. 100)

Every child does matter

Ultimately the message from both the sub-Saharan research and the mental health study in the UK is, like the intention of this article, to promote a sea change in the way children with care responsibilities are conceptualised and represented, and to confer on them agency – also a 'central tenet of child-centred (population) geographies' (Robson and others, 2006, p. 106). In this case, what is needed is more distinct emphasis on listening to what children have to say and consulting with them about their needs and feelings as a more constructive way of helping them attain social, material and cultural capital.

This approach is concurrent both with an international children's rights perspective and with the thrust of the UK government's recent children's policy initiatives. The fundamental objectives of the recruitment and appointment of the new Children's Commissioner (<http://www.everychildmatters.gov.uk/strategy/childrenscommissioner/>) were based on listening

to children and conferring on them both advocacy and agency. Furthermore, these same principles form the basic tenets of Every Child Matters (<http://www.everychildmatters.gov.uk>) and the 2004 Children Act (<http://www.dfes.gov.uk/publications/childrenactreport/>).

That said, it is not difficult to perceive how the five principles that underpin Every Child Matters (<http://www.everychildmatters.gov.uk>; and that also inform the objectives of the role of the new Children's Commissioner: <http://www.everychildmatters.gov.uk/strategy/childrenscommissioner/>) are, once again, challenged when considered from the perspective of young carers. Hence, caring can at times threaten or undermine children's safety and physical health and well-being – either when a parent experiences a serious deterioration in their mental health condition or when children suffer physical injuries as a result of lifting a disabled parent for example. Obviously, economic stability and well-being can be compromised when parents experience chronic illness or disability, especially when its onset can result in lone parenthood, loss of employment and the need for families to subsist on benefits.

Children's enjoyment and achievement can be both enhanced and compromised by their caring activity. In a number of research studies, children have said that they gain a sense of well-being, a feeling of being needed and having achieved something positive through their caring roles (Aldridge and Becker, 2003; Becker and others, 1998; Robson and others, 2006). However, they also report the obverse in circumstances where caring becomes long term, disproportionate and unsupported (Aldridge and Becker, 1993, 1994). Lack of recognition (for caring), however, can also undermine children's need and capacity to make a positive contribution. It is here that we must be careful not to place too much responsibility on children while at the same time understanding the politics of recognition (see Aldridge and Wates, 2005; Fraser, 1995) that require awareness of, and insight into, children's contributions as well as their needs. As Marlowe (1996) has argued

To think of myself as having been a young carer helped me to realise how much I had done to support my family. Previously this role had been unrecognised, taken for granted and undefined. (p. 103)

Furthermore, the principles of prevention and early intervention that underpin the 2004 Children Act (<http://www.dfes.gov.uk/publications/childrenactreport/>) are also potentially compromised when considering the position of young carers and their families. Because of children's availability through co-residency and their need to contribute in some way, preventing them from caring becomes an almost insurmountable problem and one that, if we accept and acknowledge their wishes and feelings, is sometimes contrary to what children want and say they need. Early intervention in these children's lives is also problematic for a number of reasons that are not simply about professional oversight or neglect. Mistrust of strangers, intentional secrecy, loyalty to parents and fear of the consequences of any interventions that might potentially lead to family separations, are key obstacles to successful early interventions in young carers' lives. Until children feel able to talk openly about their caring experiences without fear of the consequences of such openness, effective early interventions that could make a difference to their lives (i.e. at the onset of parental illness or disability when children are more susceptible to being drawn into caring) will continue to be problematic.

Show and tell

In their sub-Saharan study, Robson and others (2006) argue that it is important to give young people, 'the opportunity to give voice to their lives and experiences using their own words and means of expression' (p. 98). Furthermore, Doran and others (2003) have said that what has been missing from research on young carers has been deeper insight about children's experiences of caring which should 'be used to develop policy'.

While we have mainly adopted qualitative approaches in our research methods among children who care, the deeper insight Doran and colleagues call for cannot always be gained through talking with children and allowing them to express themselves verbally. Indeed, one of the difficulties with the new children's policies and initiatives that aim to give voice to children and young people is the underlying assumption that they necessarily want or feel able to speak out.

One of the serendipitous outcomes of the mental health study was that it highlighted the fact that some children and young people simply feel unable or unwilling to participate in conventional research methods that require their verbal contributions (through interviews). This can mean that certain groups of vulnerable children simply are not represented in research outputs. Such lack of representation inevitably means that children's views and insights are not helping to shape and inform either policy or practice when, in fact, this has been proposed as an important and necessary element in promoting inclusion and participation among children. In a report by Hill and others (2004) on strategies for moving the participation agenda forward for children and young people, the authors state:

It has been argued (for example, Brown, 1998) that the absence of the authentic voice of children themselves in the public discourses about childhood is one of the reasons why they occupy such a marginal and vulnerable position in society. (p. 84)

If children do not wish – or feel unable to – participate in conventional research procedures (that ultimately help to inform both policy and practice and promote a rights-based framework), it is important to identify other more appropriate ways in which children can contribute and express themselves. Research currently underway in the YCRG uses photographic participation and elicitation methods³ among children who live with, and help to care for, parents with serious mental health problems. In the study, children are given cameras in order to provide photographic diaries of their lives. So, what in essence becomes difficult to capture verbally, we can understand and distil visually through the images that children themselves present.

Crucially, this type of research, which has a long visual ethnographic history, helps us to move away from the idea of young caring as all work and no play for children. Preliminary findings indicate that not only do they enjoy the active participation in the research process, but the photographic approach also provides them with the opportunity to illustrate, not just their caring experiences, but also other meaningful aspects of their lives (for example, the importance of friendships, hobbies, even family pets) that can help them cope emotionally. Furthermore, allowing children's visual contributions to enter policy, practice and even media debates should help us to move away from popular representations of young carers as little victims or little angels.

It is perhaps only by seeing these children's lives through their eyes that we can begin to understand more fully their caring and childhood experiences (when parents have illness or disability) and only then can we truly begin to address the issue of how best to intervene and support them on their terms. As Radley and Taylor (2003) have argued, using photographs that have been taken by respondents provides 'a direct entry into [respondents'] point of view' (p. 79). They add:

The technique of photography is a culturally fashioned extension of the senses (Lury, 1998) so that it provides a potential 'to question, arouse curiosity, tell in different voices, or see through different eyes from beyond'. (p. 79)

Conclusion

It is true that 'the phenomenon of young carers challenges us to re-conceptualise our understanding of the experiences of childhood' (Robson and others, 2006, p. 96). Furthermore, young caring has always presented a challenge to a protectionist approach to childhood and youth, and health and social care interventions aimed at supporting children in need. Young carers' researchers and campaigners have addressed this challenge by promoting a children's rights-based approach and by recognising the importance of identity and agency in young carers' lives.

Policy initiatives, in particular more recent ones, are based on the sound principles of listening to what children and young people have to say. While this approach is to be applauded, it is also true that some children will always be excluded from the processes that allow their voices to be heard, simply because they do not want, or feel unable, to participate verbally. Far from addressing the complexities and duality young caring poses by reconstructing young caring as evidence of child labour, we should continue to promote a rights-based approach that is also congruent with current children's policy and initiatives. In this way we would ensure that *every* child has a voice or can explicate their feelings, wishes and needs in whatever way that is appropriate to them, either verbally, visually or via other methods that allow us deeper insight into their lives.

Notes

¹Young carers are 'children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult' (Becker, 2000, p. 378).

²Children caring for parents with mental illness: perspectives of young carers, parents and professionals (Aldridge and Becker, 2003) was a 2-year study that used qualitative methods among three respondent groups: 40 young carers, parents and key workers. The study was conducted in partnership with Rethink and was funded by the National Lotteries Charities Board.

³Twenty children and young people who help to provide care for parents with mental illness are participating in the study, which is for one year and funded by the Economic and Social Research Council (ESRC). Further details are available on the Young Carers Research Group (YCRG) website: <http://www.ycrg.org.uk>.

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