**QUEEN'S
UNIVERSITY
BELFAST**

Using Adverse Childhood Experience scores to better understand the needs of young carers

Spratt, T., McGibbon, M., & Davidson, G. (2018). Using Adverse Childhood Experience scores to better understand the needs of young carers. *British Journal of Social Work*. <https://doi.org/10.1093/bjsw/bcy001>

Published in:
British Journal of Social Work

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

Publisher rights

© The Author 2017. Published by Oxford University Press on behalf of The British Association of Social Workers. All rights reserved.
This work is made available online in accordance with the publisher's policies. Please refer to any applicable terms of use of the publisher.

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

Using Adverse Childhood Experience scores to better understand the needs of young carers

Trevor Spratt, Marlene McGibbon and Gavin Davidson

Accepted by the British Journal of Social Work 07.11.17

Abstract

We report results of **research** into the experiences of young carers in **Barnardo's Young Carers and Action for Children Young Carers projects**. The study involved **in-depth interviews with young carers, with the aim of better understanding, from their perspective, the impact of caring on their lives. We employed the 10-item Adverse Childhood Experiences questionnaire in secondary analysis of the data**. Results reveal that numbers of ACEs range from 0 to 6, with only 4 children out of 22 having a score of zero. The subgroup (16) with a parent with a mental illness had a mean ACE score of 2.375. Further dividing this group into those with additional ACEs (10) and those with one (6), offered a mean of 3.2 for the first group and 1 for the **latter**. By contrast, the mean for the group (6) caring for those with physical disability/illness was 0.5. Actual ACE scores are likely to be higher. These results merit further research involving larger numbers. Implications for practitioners and policy makers include screening for ACEs in assessments and development of bespoke services to meet the needs of those with high ACE scores, in this case, young carers with a parent with a mental illness.

Introduction

As society has become more aware of the particular challenges facing young people who find themselves in caring roles, so responses have been developed at a number of levels, legislative, policy, service provision and professional practice, to seek to better meet their needs. The focus of the research reported in this paper involves the analysis of qualitative data drawn from a series of interviews with 22 young carers in receipt of supportive services in Northern Ireland. The aim being to detect possible indication of

cumulative adversities, which if present, provide probabilistic indication of impact upon future wellbeing, mandating in turn, a revision of current assessment practices to involve measures of adversities so as to further inform prioritisation of service provision.

Background to the research

It is important to note that whilst the term ‘young carer’ is widely used in the UK and increasingly internationally (Leu and Becker, 2017), it is neither universally adopted nor regarded as unproblematic as a concept. As Olsen has observed, ‘...a child of a disabled single parent ... is typically included in the definition of young carer, whilst a child having significant housework duties in a so-called ‘normal’ family is excluded’ (2000, p. 391). Such distinctions between caring for disabled and non-disabled parents are not made in all countries. Within the UK, ‘young people who are from black, Asian or minority ethnic communities are significantly more likely to be a young carer.... [but] are less likely to self-identify as young carers’ (The Children’s Society, 2013, p. 8), in part because they perceive such responsibilities as normative within their communities. In this paper the population of young carers are characterised by having caring responsibilities for disabled or ill parents and having had requirements for assessment and provision of services recognised by referrers and agreed by service providers.

There is a growing interest in the experiences of young carers. In part this is reflective of the increasing numbers of young people with caring responsibilities, yet remaining under the radar of provision. The Guardian reports that; ‘The most recent census puts the number at 166,000 while figures sourced by the BBC in 2010, which are used by charities and government, estimate that there are 700,000 throughout the UK’ (the Guardian, 11/11/14). Evason (2007), notes that numbers of young carers may be increasing as a consequence of the boundaries of informal care being pulled back and redrawn more tightly around the immediate family – which may mean that young carers, who in the past could have relied on the support of friends or wider family network, may now find themselves as the sole carer for a disabled or ill person. **In addition, the restrictions placed on access to adult social care as a result of budget**

cutbacks have served to increase pressures on families to provide care for adult members (the Guardian 13/07/16).

Becker and Becker (2008) argue that the true prevalence of young people caring in the UK is underestimated because of a reliance on parents' self-reporting their children's caring roles. As a consequence, the data are not likely to adequately identify or include young people in many caring situations, especially where there is associated stigma, particularly with respect to alcohol and drug misuse or enduring parental mental ill health. There is also some evidence that young carers can themselves participate in ensuring their invisibility, fearing that requests for help may result in family break up due to initiation of care proceedings or the institutionalisation of the care recipient (Thomas *et al.*, 2003). Research also indicates that some young carers may fail to identify themselves as such for fear of ridicule or being regarded as different by their peers, especially in school (Morgan, 2006). Young carers also point to the stigma surrounding disability and illness (particularly mental illness and alcohol and drug use) as a factor contributing to maintenance of secrecy with respect to caring roles (Moore and McArthur, 2007).

Whilst research has helped identify the wide range of variables which may impact on specific aspects of young carers' lives (Becker and Becker, 2008), it remains unclear why some children and young people appear to experience emotional, relationship or other psycho-social problems which may be attributable to their caring roles, while others do not manifest any outward signs of such difficulties. Becker (2007) suggests that if the focus of research turns away from the vulnerability of young carers to concentrate instead on their resilience, then researchers may be better equipped to explain differential outcomes. Some commentators have also noted positive results of caring, such as gaining a sense of wellbeing and feeling needed. In addition, studies have highlighted young carers' accounts of the close and loving relationships they have developed with their families as a result of caring (Thomas *et al.*, 2003; Earley *et al.*, 2007; Moore and McArthur, 2007).

A number of studies have sought to examine the particular impact on young carers of providing care for a parent with mental illness. Thomas and colleagues (2003) found that there was a tendency for young carers to face the most difficult

circumstances where they were supporting a parent with drug and/or alcohol problems or mental illness. Aldridge (2006) notes that young carers who are monitoring the emotional health and well-being of, and providing crisis support to their parents (including the administration of medication), have responsibilities which are beyond their years and for which there has been little or no preparation. Roberts and colleagues (2008) suggest that the need for high levels of emotional support are often associated with mental health problems and that the sometimes episodic and unpredictable nature of such illnesses can generally compromise young carers' lives, particularly in relation to educational attainment.

The policy response to the needs of carers in England has seen the introduction of the Care Act 2014 and the Children and Families Act 2014, both containing provisions for young carers. The **latter** piece of legislation mandates local authority social workers to carry out assessments of the needs of young carers, at their or their parents' request. In addition, local authorities must take reasonable steps to identify young carers who live in their area and undertake assessments, even if there has been no request for an assessment. As part of the assessment process there is a duty to consider the needs of the young carer, this potentially involving the direct provision of services to them in order to prevent a negative impact on their well-being.

A particular challenge facing both policy makers and service providers is how best to differentiate the large population of young carers in the UK in order to help target resources towards those with the most pressing of needs. Such differentiation is largely driven by assessment processes and may be crudely divided into two branches, one focusing on the nature of caring responsibilities, including the numbers and types of tasks associated with caring for an adult with limited capacity, often as a consequence of physical disability/illness, and the other on the impact caring may have on the well-being of the young carer. The issues regarding impact on wellbeing include both contemporaneous exposures to adversity and long-term effects. This means that it is important to measure both the full number of exposures (not simply the impact of providing care) as well as the range of possible future expressions that collectively are encompassed by the concept of *well-being*. For the professional undertaking an assessment, any comprehensive understanding of the present must therefore be

informed with an eye to the future, with probabilistic outcome calculations being principally informed by epidemiological research (Author's own, 2012).

The study

The research reported here is part of a wider project involving an examination of protective and risk factors with respect to young people providing care for family members (Authors own, 2016). **The aim of the study was to generate knowledge with regard to such factors to further inform policies and practices designed to promote the resilience of young carers. Objectives included an examination of cultural and family contexts of young carers' lives; their perceptions of illness and disability; the importance of multiple role identities; resources and systems of support, and interdependence and reciprocity in relationships.**

The two research partners facilitating the study were Barnardo's Young Carers and Action for Children Young Carers projects. Young people were referred to the projects by parents, social workers, general practitioners and schools on the basis that they required additional help and support in coping with the caring role. Each young person's needs were then individually assessed with projects seeking to support young carers and their families in various ways, including provision of individual counselling, group activities and advocacy. The aims of both services were to recognise the additional stresses placed on children who were carers and provide a range of service provision to offer both practical and emotional support.

Methodology

Young carers are recognised as a 'hard to reach' population and can be difficult both to identify and engage (Kennan *et al.*, 2011). Consequently, it was important to undertake the project in partnership with both policy makers and organisations currently providing services for young carers. The research was conducted by one of the authors based at Queen's University Belfast, in partnership with Barnardo's Young Carers

Project and Action for Children Young Carers Project, along with the Health and Social Care Board (NI). The research was given approval by the Research Ethics Committee of the School of Sociology, Social Policy and Social Work and the Office for Research Ethics Committees Northern Ireland.

With regard to the recruitment and data collection processes, the two projects approached both the young people and their parents to provide information and seek permission for the researcher to contact them. Permissions were then sought by the researcher from young people and parents to initially spend time with the young people within the project settings, before conducting individual interviews with them, usually in the familiar facilities of the projects.

In total 22 interviews were conducted. The rich qualitative data emerging from these interviews is reported elsewhere (Author's own, 2016). **Of the 22 young carers in the study, 18 were female and 4 were male. The age range was from 8 to 18 years. Twelve of the young people were living in households where both parents resided, with the remainder living in single parent households, predominantly with mothers. The participants were drawn from both rural and urban communities and were all from white Northern Irish backgrounds.**

Adverse childhood experiences research

The analysis of the data was based upon the adverse childhood experiences research model. The extensive ACE literature details the multiparous nature of how adversities experienced in childhood find expression in later life. The model demonstrates that the greater the number of adversities experienced, so the probability for poor health and social circumstance outcomes in later life, exponentially increase. These include the domains of physical (Felitti and Anda, 2009) and mental (Read *et al.*, 2005) health and a myriad of social circumstances from early pregnancy to imprisonment (Bellis *et al.*, 2014). In recent years the ACE questionnaire has been adapted to help better understand the needs of diverse populations whose outcomes are of particular concern for social work service professionals, including children who experience domestic violence (colleague and Author's own, 2016) and young people who commit suicide

(colleagues and Author's own, 2014), (for a comprehensive account of ACE research and implications for social work practices, see Author's own, 2012 and colleagues and Author's own, 2010).

One aspect of the analysis of the qualitative data (interviews transcribed from digital recorders) employed the ACE questionnaire as a research tool to record specific adverse experiences where participants mentioned them in the course of the interviews. This instrument has the advantage of being used both in large population surveys and specific population studies, providing data of sufficient weight to establish probability for a range of outcomes (including health and social circumstances), associated with an ACE score. While the instrument was originally designed for self or interviewer completion for over 18 year olds, it has increasingly been adapted for use as a tool for secondary data analysis (colleague and Author's own, 2014). The strength of its use as research tool in this way has been to provide a systematic means of analysing data, bringing to light previously hidden or oblique patterns, which may then provide a basis for a theoretical bridge to help link experiences to outcomes. Its major disadvantage is that, used in this way, it is only possible to compile partial scores – with these being inevitably lesser than the actual. Its use here is intended to examine to what extent indicative patterns might be discernable and, if so, how these might inform both current assessment practice and future research.

Exposure to a parent with a mental illness constitutes a measure of adversity (each factor on the 10 point series of factors constituting a score of either 0 or 1). Combined affirmative (the adversity has been experienced) and negative (it hasn't) responses with respect to each factor results in a final ACE score, ranging from zero, where the individual has experienced no adversities, to ten, where the full range have been experienced. Each additional factor exponentially increases the probability of an individual experiencing negative impacts upon their wellbeing, as measured across a range of health and social circumstances across their life-course.

The ACE Questionnaire, asks, *Prior to your 18th birthday:*

1. *Did a parent or other adult in the household often or very often... Swear at you, insult you, put you down, or humiliate you? or Act in a way that made you afraid that you might be physically hurt?*

2. *Did a parent or other adult in the household often or very often... Push, grab, slap, or throw something at you? or Ever hit you so hard that you had marks or were injured?*
3. *Did an adult or person at least 5 years older than you ever... Touch or fondle you or have you touch their body in a sexual way? or Attempt or actually have oral, anal, or vaginal intercourse with you?*
4. *Did you often or very often feel that ... No one in your family loved you or thought you were important or special? or Your family didn't look out for each other, feel close to each other, or support each other?*
5. *Did you often or very often feel that ... You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? or Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?*
6. *Was a biological parent ever lost to you through divorce, abandonment, or other reason?*
7. *Was your mother or stepmother:
Often or very often pushed, grabbed, slapped, or had something thrown at her? or Sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something hard? or Ever repeatedly hit over at least a few minutes or threatened with a gun or knife?*
8. *Did you live with anyone who was a problem drinker or alcoholic, or who used street drugs?*
9. *Was a household member depressed or mentally ill, or did a household member attempt suicide?*
10. *Did a household member go to prison?*

(The ACE study <http://www.acestudy.org/the-ace-score.html>)

Results

In the following tables, the numbers in the top row represent the 10 ACE questions, with the pseudonyms of the participants indicated in the first column. The intersections record affirmative answers to the questions. Negative responses have not been entered (these would normally be signified by a zero), as a secondary data analysis of this type does not allow for such values to be established. Table 1 presents the data in 'raw' form i.e. alphabetically, whilst Table 2 reorders the presentation in line with the finding that

young carers who have a parent with a mental illness indicates that this factor is a proxy indicator for elevated ACE scores for this sub group of participants.

Table 1 here

Table 2 here

Analysis

A majority of the participants (16) had responsibilities for caring where a parent had a mental illness. As this provides an affirmative answer to question 9 on the ACE questionnaire, these participants all had an ACE score of at least 1. By contrast, only 2 of the 6 participants who had responsibilities for caring for a parent with a physical disability or illness had an ACE score – 2 and 1 respectively. The reordering of the data in Table 2 to reflect high to low scores, demonstrates an almost perfect diminution pattern, with higher scores associated with having a parent with a mental illness and lower scores with having a parent with a physical disability/illness, with Lana (who has an ACE score of 2 and a parent with a physical disability/illness), being the only outlier. The group (16) with a parent with a mental illness have a mean ACE score of 2.375. However, a more incisive examination is evident if this group is subdivided into those with additional ACEs (10) and those who have not (6), this resulting in a mean of 3.2 for the first group against 1 for the **latter**. By contrast, the mean for the group (6) caring for parents with physical disability/illness is 0.5; in line with the general population ACE score norm, where approximately half the population have an ACE score of zero (Bellis *et al.*, 2014). Independent measures of current health and functioning were not used in this study, however it is of note that one participant (Lisa), mentioned that she had previously attempted to take her own life, whilst two others (Grace and Orla) indicated that they had self harmed. All three participants were in the group who were caring for mentally ill parents and had ACE scores of more than 1.

Assessment

The findings from this research add some weight to the indication in the research literature that young carers who have parents with mental illness face additional challenges. Whilst research in this area has tended to locate the source of such challenges in the nature of mental illness and risks associated with the caring role, the findings reported here indicate that this is too simple a reading of where threat to future well-being may emanate. The finding that young people with mentally ill parents have higher ACE scores than do their peers whose parents have solely physical disability/illness demonstrates that challenges to future well-being are not solely located in the exposure to the mental illness of the parent, but is also is a product of experience of additional adversities. The three predominant additional ACEs (see Table 2) are loss of a biological parent (8 participants), exposure to someone using alcohol or drugs (5) and neglect (3). In keeping with findings from the general ACE literature we might speculate that parents with mental illness are more likely than are parents with solely physical disability/illness to experience partner loss, to self medicate using alcohol or drugs and neglect their children's needs, although the interactions between these factors may be complex.

These multi-factorial adverse experiences of young carers may go quietly unobserved in the assessment process. Thomas and colleagues (2003) observe that such circumstances may not be sufficiently dramatic or so obvious as to attract the attention of children's services unless it is suspected that the young people reach the child protection threshold of likely or actual suffering of significant harm. Colleague and Author's own (2009, pp. 1581-2) note that focusing on child protection issues has the potential to '...miss entirely the quieter majority of 'Children in Need' whose circumstances fail to meet child protection thresholds and [who] consequently may receive few, if any, services.' The current legislative and policy intent has been motivated, in part, to avoid tragic cases, such as the death of Madeline O'Neill and her daughter Lauren; Monds-Watson and colleagues (2010, p. 46) observing that despite repeated recognition as to the potential vulnerability of children where parents have mental health difficulties, 'not a single professional spoke with Lauren about how she was experiencing or interpreting her mother's difficulties, or tried to find out what she needed.' Given the concerns generated by such tragedies it is entirely understandable

that practitioners may focus on the direct impact to the young person's well-being caused by exposure to their parents mental illness, together with any attendant immediate risks. In doing so, however, a systematic assessment of the number of adversities experienced by the young person, with their predictive indication of negative impact on well-being across their life-course, may be missed. The danger of occluded assessment practices which are too narrow in focus and prioritise more immediate needs is that range of adversities experienced by the young person are not fully captured and consequently not fed into calculation of impact so as to inform design of service provision. The Children and Families Act 2014 mandates assessment of the young persons needs, but does not offer guidance on the content of such assessments. The findings reported here indicate that incorporating the ACE questionnaire into assessment may offer a way to weigh the data so as to inform service provision. This brings us to the question of what such services should look like.

Informed interventions

With the factors known to be harmful to children, together with associated outcomes cast over the life-course, being now well understood, the public health response has been to seek to develop a range of strategies to promote awareness of the impact of ACEs, together with a range of evidence based programmes, often targeted specifically towards new parents (Bellis *et al.*, 2015). Other types of intervention are required, however, where children have already experienced adversities in childhood. Here, two distinct foci of intervention are discernable. One involves actions to promote cessation of an on-going adversity (for example physical abuse) and the other concentrates on efforts to ameliorate the effects of already experienced adversities. Whilst social work professionals currently work in both preventative and cessation/amelioration services, it is the **latter** sphere in which they predominately operate.

Factor informed interventions have a number of advantages over interventions, which seek to reinforce naturally occurring qualities or characteristics of the individual. As Gilligan (2009) notes, children who demonstrate resilience are not invulnerable, they cannot withstand unscathed, ever increasing levels of stress and pressure and, past a certain threshold of increasing adversity, any child is likely to buckle and succumb to

excessive strain. It is therefore important to locate the spheres of resilience building beyond the individual, principally in the relational spheres of family friends and community. The problem here is that resilience is often equated with having a secure base and predictable routines of care (Daniel and Wassell, 2002), which are precisely the kinds of conditions rarely found in situations where young people have mentally ill parents. There is, however, some evidence that positive relationships located outside the immediate sphere of the parental home can make significant differences in the lives of young people. For example, Bellis and colleagues draw our attention to the positive measureable impact on well-being for those with high ACE scores who have experience of at least one consistent and positive adult during their developmental years (2015). Somewhat less compelling is the evidence supporting the impact of cessation of adversity. Anda and Brown refer to the efforts of child protection services as a 'dressing on a greater wound' (2010, p. 9). Whilst the objective of child protection services has been to identify maltreatment, ensure cessation and put in place measures to prevent reoccurrence, these short-term interventions are seldom calibrated in response to measures of cumulative adversities predicting poor future outcomes (colleague and Author's own, 2016). Nor do they properly account for and address the deep-seated causation of such adversities, which is both intra-generational in nature and sensitive to socio-economic conditions (Bywaters, 2015). Ideally, of course, the two types of interventions should complement and support each other, with conditions of cessation being usually necessary before individual support services can have effect. Such joined up thinking is not yet, however, a normative feature of contemporary interventions.

Implications for practice and policy

For social workers, the primary challenge lies in the realm of assessment. The point in time and category directed nature of young carers assessments means that the wider range of adversities experienced by children are not routinely considered. Our evidence would suggest that where a young carer has a parent with a mental illness, this provides a proxy indicator for elevated ACE scores. A secondary challenge is the design of services that go beyond provision of help to share the tasks of caring (essential as this is), to target the needs of the young person in order to achieve stress reduction and

buffering against adversity so as to reduce probability of poor outcomes associated with exposure to high levels of adversity. Meeting such challenges would inevitably involve changes in how the needs of young carers are prioritised by social workers and other professionals. Research indicates that young carers have found services to be intrusive, lacking in continuity, untimely, inflexible and unresponsive in crisis situations (Morgan, 2006; Moore and McArthur, 2007).

In relation to policy, the findings presented here, lay added weight to the argument that needs are not a straightforward product of category, with the population of children and young people who are deemed 'carers', being further differentiated by a range of factors which may serve to make their requirements very different from one another. Policy makers require nuanced information (generated both by aggregated assessment data and research) to enable targeting of services to maximise effective impact. The research reported here is in line with current research in the area of young carers in suggesting that some groups of young carers may have more compelling needs than others and should be prioritised for interventions that may include immediate protective services directed toward adverse experience cessation alongside services to ameliorate the effects of adversity and shore up resilience.

Limitations and further research

The research reported here has a number of limitations, which render it not generalizable. Firstly, the small sample size (22) is not sufficient for the type of quantitative analysis required in order to establish the sub groups so described, consequently these subdivisions are indicative in nature. Secondly, the use of an ACE questionnaire as a secondary data analysis tool means that data pertaining to a number of questions was not sought in the interviews. As has been the case in other studies using this methodology in this way, it is acknowledged that mean ACE score values are reduced, with reported mean scores likely to be substantially lower than actual mean scores. Thirdly, a further limitation of the tool is that it is designed to capture adversities experienced during the first 18 years of life. Earlier application will compound the mean score diminution effect. Fourthly, the sample size renders it insufficient to detect more sensitive differentiating features; for example, a large data

set would enable analyses to examine both demographic and diagnostic categories. Finally, because the sample is drawn from a population of young people who are already seeking services, it may be that they are atypical.

The research reported here does, however, provide indication that children who have caring responsibilities for parents who are mentally ill are experiencing significantly greater numbers of adversities than their peers who are caring for parents with physical disability/illness. To test if these indications hold true for the population of young carers, a large-scale study would be required, designed to establish ACE scores and identifying any sub population features.

Acknowledgements

Out appreciation is extended to our research partners, Barnardo's Young Carers Project and Action for Children Young Carers Project, along with the Health and Social Care Board (NI) and the Office for Research Ethics Committees Northern Ireland, without whose support, guidance and facilitation the research project would not have been possible.

References

Colleague and Author's own (2009)

Author's own and colleagues (2010)

Colleagues and Author's own (2014)

Author's own (2012)

Colleague and Author's own (2016)

Author's own (2016)

Aldridge, J. (2006) 'The experiences of children living with and caring for parents with mental illness', *Child Abuse Review*, **15**, pp. 79-88.

Anda, R. and Brown, D. (2010) *Adverse Childhood Experiences and Population Health in Washington: The Face of a Chronic Public Health Disaster*, Report for the Washington State Family Policy Council, Washington.

Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M. and Tisdall, K. (2002) 'Does the covert nature of caring prohibit the development of effective services for young carers?', *British Journal of Guidance and Counselling*, **30**(3), pp. 229-246.

Becker, S. (2007) 'Global Perspectives on Children's Unpaid Caregiving in the Family: Research and Policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa', *Global Social Policy*, **7**(1), pp. 23-50.

Becker, S. and Becker, F. (2008) *Service needs and delivery following the onset of caring amongst children and young adults: evidence based review*, Nottingham, Commission for Rural Communities Tackling Rural Disadvantage, Prepared for the Commission for Rural Communities by Young carers International Research Evaluation, University of Nottingham.

Bellis, M., Lowey, H., Leckenby, N., Hughes, K. and Harrison, D. (2013) 'Adverse childhood experiences: retrospective study to determine their impact on adult health behaviours and health outcomes in a UK population, *Journal of Public Health*, **36**(1), pp. 81-91.

Bywaters, P. (2015) 'Inequalities in Child Welfare: Towards a New Policy, Research and Action Agenda, *British Journal of Social Work*, **15**(1), pp. 6-23.

Eley, S. (2004) "'If they don't recognise it, you've got to deal with it yourself': Gender, young caring and educational support', *Gender and Education*, **16**(1), pp. 65-75.

Evans, R. and Becker, S. (2009) *Children caring for parents with HIV and AIDS: Global issues and policy responses*, Bristol, The Policy Press.

Evason, E. (2007) 'Who cares now? Changes in informal caring 1994 and 2006', ARK Research Update 51, Belfast, ARK. www.ark.ac.uk/publications/updates/update51.pdf [Accessed 12/11/09]

Felitti, V. and Anda, R. (2009) 'The relationship of adverse childhood experiences to adult health, well-being, social function and healthcare', in R. Lanius and E. Vermetten (eds), *The Hidden Epidemic: The Impact of Early Life Trauma on Health and Disease*, Cambridge, Cambridge University Press, pp. 1-18.

Gilligan, R. (2009) *Promoting Resilience: Supporting children and young people who are in care, adopted or in need*, London, British Association for Adoption and Fostering (BAAF).

Keenan, D., Fives, A. and Canavan, J. (2012) 'Accessing a hard to reach population: reflections on research with young carers in Ireland', *Child and Family Social Work*, **17**, pp. 275-283.

Leu, A. and Becker, S. (2017) 'A cross-national and comparative classification of in-country awareness and policy responses to 'young carers', *Journal of Youth Studies*, 20(6), pp. 750-762.

Monds-Watson, A., Manktelow, R. and McColgan, M. (2010) 'Social work with children whose parents have mental health difficulties: acknowledging vulnerability and maintaining the "Rights of the child"', *Child Care in Practice*, **16**(1), pp. 35-55.

Moore, T. and McArthur, M. (2007) 'We're all in it together: supporting young carers and their families in Australia', *Health and Social Care in the Community*, **15**(6), pp. 561-568.

Morgan, R. (2006) *Being a Young Carer: Views from young carers'*, Newcastle upon Tyne, Commission for Social Care Inspection.

Moore, T. and McArthur, M. (2007) 'We're all in it together: supporting young carers and their families in Australia', *Health and Social Care in the Community*, **15**(6), pp. 561-568.

Olsen, R. (2000) 'Families under the Microscope: Parallels between the Young Carers Debate of the 1990s and the Transformation of Childhood in the Late Nineteenth Century', *Children and Society*, 14(5), pp. 384-394.

Read, J., van Os, J., Morrison, A. and Ross, C. (2005) 'Childhood Trauma, Psychosis and Schizophrenia: A Literature Review with Theoretical and Clinical Implications', *Acta Psychiatrica Scandinavica* **112**(5), pp. 330-350.

Roberts, D., Bernard, M., Miska, G. and Head, E. (2008) *Experiences of children and young people caring for a parent with a mental health problem*, SCIE Research Briefing, 24. <http://www.scie.org.uk/publications/briefings/briefings24/index.asp> [Accessed 29/11/08]

The ACE Study <http://www.acestudy.org/the-ace-score.html> [Accessed 27/06/17]

The Children's Society (2013) *Hidden from view: The experiences of young carers in England*.

https://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf [Accessed 10/09/17]

Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S. and Webb, A. (2003) 'Your friends don't understand': invisibility and unmet need in the lives of young carers', *Child and family Social Work*, **8**(1), pp. 35-46.

The Guardian (11/11/2014) 'Hidden army of young carers to be uncovered under new legislation', <https://www.theguardian.com/society/2014/nov/11/hidden-young-carers-get-break-new-legislation> [Accessed 27/06/17]

The Guardian (13/07/2016) 'Vulnerable adults at risk as councils face £1bn shortfall', <https://www.theguardian.com/society/2016/jul/13/vulnerable-adult-social-care-risk-england-councils-face-1bn-shortfall> [Accessed 18/09/17]