

Critical Social Work

School of Social Work University of Windsor 401 Sunset Avenue Windsor, Ont. Canada N9B 3P4

Email: cswedit@uwindsor.ca

Publication details, including instructions for authors and subscription information can be found at: http://uwindsor.ca/criticalsocialwork

Link to article:

http://www1.uwindsor.ca/criticalsocialwork/youngcarerIreland

Critical Social Work, 2013 Vol. 14, No. 1

Why we still need the term 'Young Carer': Findings from an Exploratory Study of Young Carers in Ireland

Critical Social Work 14(1)

Allyn Fives, ¹ Danielle Kennan¹, John Canavan¹, and Bernadine Brady¹

¹ National University of Ireland, Galway

Author Note

Funded by Office of the Minister for Children and Youth Affairs, Ireland

Abstract

Previous research on young carers has provided data on prevalence, the tasks performed, the impacts on the carer, and the supports they require. However, some in the disability rights movement argue that the numbers of young carers and the negative impacts of caring have been exaggerated, and that the children's rights approach serves to undermine the rights of disabled and/or ill parents. The findings from exploratory research in Ireland suggest that it is not parental illness and/or disability that is a cause for concern, but instead levels of support to and awareness of young carers. It is argued that the term young carer should continue to be used and that services should be developed in Ireland specifically for young carers.

Keywords: awareness, disability, parents, resistance, rights, support, young carer

There has been increasing interest over the past two decades in the provision of informal care by children and young people. Researchers have explored ways in which to identify young carers (Gray, Robinson, & Seddon, 2008), estimated the numbers of young carers and analysed the tasks performed (Dearden & Becker, 2004), the impacts of caring on the lives of carers (Aldridge, 2008; Underdown, 2002), and the supports received or needed (Roche & Tucker, 2003). However, this area of research is also increasingly controversial. It is claimed that there is a conflict between the children's rights approach adopted by many researchers on young carers on the one hand and the promotion and defence of the rights of disabled and/or ill parents on the other (Aldridge & Wates, 2005). Researchers on young carers have, it is argued, made unwarranted claims about the negative effects of caring on carers, exaggerated the numbers of young carers, and implied that disabled and/or ill parents are incapable of proper parenting (Newman, 2002; Olsen, 2000; Parker & Olsen, 1995). As a result, disabled and/or ill parents, and those who champion their rights within the social sciences, must adopt a political stance of "resistance" to the movement supporting the rights of young carers (Parker & Clarke, 2002, p. 351).

This paper is based on data collected in Ireland from interviews with 26 young carers and 30 agency staff, as part of an exploratory nation-wide study. The findings suggest that not all caring situations are the same and therefore not all carers are impacted in the same way and nor is it the case that the parenting capacities of ill and/or disabled parents are always impaired. The effort required to recruit young carers for this study was itself an important finding as it highlighted the hidden or covert nature of the caring role. It was also found that there is little awareness of young carers, that the impacts of caring can be negative when formal and informal supports are weak, and as a result that caring can be detrimental to the rights of young carers.

The findings support the conclusion that the term young carer should continue to be used and also that services designed specifically for young carers are needed, and should be developed in regimes such as Ireland where they are lacking. This does reflect a 'children's rights' approach to the extent that it assumes the experiences of children should be viewed at least in part through a child-oriented perspective. It does not follow that the rights of ill and/or disabled parents should be given less than equal consideration or that their service needs are secondary to those of young carers. While rights can come into conflict, and so there may well be conflicting claims between child carers and their parents (or siblings), the potential for such conflict does not by itself invalidate the rights of young carers.

Background

Providing care in the home is something "most if not all children are encouraged to do" (Aldridge & Becker, 1999, p. 312-313). However, research on young carers has identified a 'continuum of caring,' with young carers at or close to one end of the scale (Frank, 2002). A young carer need not be the 'primary' (predominant) carer as many young people's lives are significantly affected by the support they give to an adult carer in the home as a 'secondary' carer (Gray et al., 2008). Also, as Dearden and Becker's (2004) survey of 6,178 young carers in the UK found, young people take on a variety of caring tasks, including domestic help, general care (help with medication, mobility, or feeding), emotional support (such as monitoring moods), intimate care (help with toileting, bathing, or dressing), and child care (looking after siblings

who may or may not have a specific care need). The health problems of those with care needs also varied, and they included physical health, mental health, learning difficulties, and sensory impairment (Dearden & Becker, 2004).

The 'hidden' or 'covert' nature of caring by children has received significant attention. Some families see caring as a normal part of family life, and for that reason do not believe that the label young carer is appropriate (Aldridge, 2006; Gray et al., 2008; Underdown, 2002). In contrast, many families and professionals fear that the only service response available to a young carer is a child protection intervention and for that reason are slow to call attention to this role (Halpenny & Gilligan, 2004; Roche & Tucker, 2003; Social Care Institute for Excellence, 2005). In the UK, efforts made to increase supports to and the visibility of young carers include the development of Young Carers Projects. These are bodies that represent the interests of and provide services to young carers, and use youth-friendly approaches including web-based resources (Roche & Tucker, 2003).

Caring need not be a completely negative experience either, it has been argued, for it may lead to greater maturity, compassion, and a closer bond with the person cared for (Aldridge, 2006). Nonetheless, negative impacts have been observed in the areas of education (Dearden & Becker, 2004), social life (O'Connell, Finnerty, & Egan 2008; Warren, 2007), emotional wellbeing (Thomas, Stainton, Jackson, Cheung, Doubtfire, & Webb 2003), and physical health (Hill, 1999; Waters & Rigby, 2008). The provision of intimate care and the status of primary carer are sometimes categorised as "inappropriate" (Gaffney, 2007, p. 21) and it is feared that caring can lead to "parentification" or role reversal between parent and child (Earley & Cushway, 2002, p.164).

Many researchers in the area of parental disability have responded with suspicion, even despair, to the findings from young carer research. Their concern is informed in part by Jenny Morris's (1993) work on the conflict of interests that can emerge between disabled people and informal (adult) carers. The tension arises, Morris argues, due to the tendency to socially construct disabled people as "dependent," and also a shift in policy towards providing support for the carer rather than the person with the care need (1993, p. 33). This line of critique has now been extended to research on young carers. Young carer researchers, it is argued, have exaggerated the prevalence of young carers (Olsen, 2000) and the number of primary carers (Parker & Olsen, 1995). They have also made the "unchallenged assumption" that caring is "unquestionably associated with negative outcomes" for the child (Prilleltensky, 2004, p. 211); although, they do not properly acknowledge the difficulties of ascribing particular "effects" to caring (Parker & Olsen, 1995, p. 2). In addition, the label young carer is necessarily "arbitrary" as it assumes a "normal" conception of childhood, namely one where parents are neither ill nor disabled (Olsen, 2000, p. 386), yet there has been no baseline study of normal childhood responsibilities in the home (Olsen 1996).

A further charge is that young carer researchers assume ill and/or disabled parents lack the capacities required to be good parents (Newman, 2002; Olsen, 2000; Parker & Clarke, 2002). It is assumed there is a role reversal whereby the child is parenting the parent (Prilleltensky, 2004), whereas in reality, if a child takes on some of the "tasks" of parenting, it does not follow that the adult's "parenting role" is compromised (Olsen & Clarke, 2003, p. 16). The commitment among

young carer researchers to a 'children's rights' approach also threatens the rights and interests of disabled parents. Young carers have been created as a new "welfare category" and therefore designated as the appropriate recipients of services, whereas the real problem for these families are external and structural factors (e.g., poverty, insensitive attitudes, inadequate services) that impede parental access to resources (Olsen, 2000, p. 384). What is required, therefore, is a radical political act of resistance against young carer research, and its children's rights agenda, by researchers who "align" themselves with disabled parents (Parker & Clarke, 2002, p. 351).

In an article written in response to some of these criticisms, Aldridge and Becker (1996) defended both the methodology and the conclusions of young carer research. When young carers were a difficult-to-recruit group, initial studies in the UK used purposive sampling techniques, rather than random sampling, and semi-structured interviews and case studies to uncover the experiences of young carers. However, it was possible to recruit larger sample sizes for subsequent studies, thanks largely to the numbers of young carers engaging in Young Carers Projects. The conclusions of these large-scale and quantitative studies largely confirmed the findings of the earlier exploratory studies. Aldridge and Becker (1996) also reject the charge that, in identifying negative impacts of caring, they are also making the assumption that children in other families are in contrast "living full and opportune lives" (p. 62). No such assumption need be made, as can be seen when for example studying the negative impacts of child abuse (Aldridge & Becker, 1996). Nonetheless, the lives of young carers are different from other children because, firstly, often they do not begin caring from their own free choice, and secondly often they perform intimate care tasks (Aldridge & Becker, 1996; Warren, 2007).

Due to the open and ongoing conflict between the two approaches, a recent series of exchanges attempted to "move the debate on" (Aldridge & Wates, 2005, p. 81). However, Michelle Wates's (2005) contribution was to insist that the "time has come to reconsider the use of the term young carer and perhaps to move away from it altogether" (p. 84) and also that prioritising disabled parents' access to "services that will expedite and support the parenting role" will remove the need for children to provide care and better promote child welfare (p. 83 & 91). Wates's concern, like others in the disability rights movement, was that young carer research re-enforces "unspoken question marks over the parenting capacity of disabled adults" (Aldridge & Wates, 2005, p. 82). Meanwhile, in this series of exchanges Jo Aldridge (Aldridge & Wates, 2005) concluded that the continued use of the term young carer is important as to consign the term "to history would suggest children's individual and particular needs, and rights, are of no, or of little importance" (p. 90). Moreover, Aldridge argued, although better services to the person with the care need may reduce the need for young people to provide care, young people often have "subjective" reasons to continue caring, including feeling needed, helping to contextualise and understand the illness, and helping to "cement" the relationship (Aldridge & Waters, 2005, p. 89).

Both sides in this debate agree that better service provision is required both for disabled and/or ill parents as well as for their children, and also that external structural factors (including disadvantage) worsen the situation of both groups. Disagreement persists, however, over whether to continue using the term young carer as a label and also whether services should be designed specifically for young carers.

Methods

This paper is based on an exploratory national study of young carers in Ireland. As was the case in the UK two decades ago, when research in this area began there, in Ireland, young carers are a hard-to-reach population. The prevalence of young carers has not been calculated with accuracy as Irish Census data provides figures on carers above the age of 15 only. It found there to be a total of 3,166 (1.85%) carers between the ages of 15 and 17 out of a total population in this age category of 171,585 (Central Statistics Office (CSO), 2007). Professional knowledge of young carers among service providers is also limited, and this is hardly surprising as there is no legislation, policy, or services specifically for young carers in Ireland. Supports are available to adult informal carers, including income support as well as services designed to assist the carer in his/her caring role, but no such supports exist for young carers (Halpenny & Gilligan, 2004; O'Connell et al., 2008).

To recruit participants for this study, a nation-wide information campaign was embarked upon, which involved the distribution of posters and flyers to all post-primary schools across Ireland and to a wide range of youth organisations. It did not lead to any young carers volunteering as participants. Instead, all participants were recruited through the use of agency staff as gatekeepers. In qualitative research, it is not unusual to make use of a gatekeeper, that is, someone who helps researchers gain access to the study population. The research team drew up a list of organizations that were thought likely to have contact with, and could potentially introduce the study to, young carers. In the statutory sector, the research team focused on Health Service Executive (HSE) personnel, in particular staff in the areas of care, disability, social work, youth work, and public health nursing. In the non-statutory sector, the research team approached health and disability organizations and organizations with a more general remit covering children. Other studies of young carers that relied on written requests for referrals experienced recruitment difficulties (Thomas et al., 2003). Similarly, in this study written requests sent out to agency staff generated only six referrals initially. In response to this difficulty the research team decided to approach agency staff again, usually by phone, and take time in particular to explain the meaning of the term young carer. This approach was adopted because, although initially agency staff often reported that they had no personal knowledge of young carers, frequently this judgment was based on the assumption that the term applied only to primary carers and/or to those involved in age-inappropriate care and/or those caring for a parent. On the basis of this further contact, many agency staff were successfully engaged to act as gatekeepers, generating 20 further referrals. The following definition was used when contacting gatekeepers:

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction, or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate, or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences

¹ This additional data was provided by the CSO at the request of the Office of the Minister for Children and Youth Affairs, who in turn made it available to the research team.

and a level of physical or emotional caring that impairs the child's health, development, or welfare.

Problems experienced in recruitment reflect the fact that young carers are, to an important extent, 'invisible.' Findings from interviews with 30 agency staff as part of the study also uncovered gaps in knowledge about the prevalence of young carers, the provision of intimate care, the age at which caring began, and the primary status of some young carers. Most significantly, some agency staff were unaware of these facts concerning the young people they had referred to the study as young carers.

Following an expression of interest to participate in the study, the next stage in the recruitment process involved efforts to obtain parental consent and the consent of young carers. To increase the likelihood of agreement from all parties and to facilitate informed consent, adult and child- and youth-friendly information sheets were prepared.

Young carers took part in semi-structured interviews. The areas covered by the interviews included household structure, the care need, tasks performed, the child's health and feelings, and experiences in school and in social life. In a pilot study, two different interview schedules were developed appropriate for those aged 5-11 and 12-17. Interviews lasted between 30 minutes and an hour.

Results

Profile

Of the 26 young carers interviewed, there were 7 boys and 19 girls, and the average age was 13. Fifteen of the young carers were caring exclusively for a sibling(s) and seven were caring exclusively for a parent(s). Of the 28 people with a care need, there were instances of autism (n=10), intellectual and/or physical disability (n=9), physical illness (n=5), mental illness (n=3), and one person with sensory impairment. Young carers also differed in terms of the level of their responsibilities. Nine of the participants were primary carers, and 17 were secondary carers. In all cases, secondary carers cared for another sibling(s), while all primary carers cared for a parent(s) (while two cared for siblings in addition).

Supports

Of the supports that young carers reported receiving, the most common was home help received by the person with the care need. This was followed by peer support, income support (received by parents/guardians), medical treatment for the person with the care need, respite care, support from teachers, advice and information, and help at home with transport and renovations. Young carers also wanted to receive more of these supports, in particular home help, advice, and support from teachers. It should be noted that none of these supports were services designed specifically for young carers.

Tasks

While all 26 participants reported performing domestic tasks, young carers also provided general care (n=19), child care (n=17), intimate care (n=16), emotional support (n=7), and various other kinds of support (n=7). Both male and female carers provided intimate care. In some cases, intimate care was provided to a parent(s), and girls provided it to brothers.

Impacts

To explore the impacts of caring on young carers, the participants were asked about their experiences in the family and school, their activities outside of school, their health, and also their worries and anxieties. In most cases, the young carers made both positive and negative reports in each area.

While some young carers reported doing well in school, others said they were distracted when in school or absent from school whenever there were care-related concerns at home. Although many said they could socialize with friends, join clubs, and take part in sports, for others, caring placed significant restrictions on their social life. The corollary of this was a feeling of boredom when away from school:

I like school. I don't like being off school, you know. I get really bored in the holidays and most of my friends would be doing loads of stuff, going on holidays. I'd rather be in school

Nearly all reported feeling more mature than their peers. Greater maturity often meant greater awareness of issues pertaining to illness and disability, or in some cases simply having heavier responsibilities. The young carers also experienced some negative physical impacts, including in one instance back strain caused by lifting an adult.

Impacts on primary carers deserve special consideration due to the higher level of responsibility. For instance, a 16 year old girl, caring for her father with a mental illness and her three siblings with intellectual disabilities, said she was glad to help. Nonetheless, she said that, if there was a care-related crisis in the household, she would leave school straight away to address the problem herself: "school would be the last thing," she said.

Gender

In some families, boys took on considerable caring responsibilities. However, in other households care tasks were taken up by girls, even when brothers were available and able to help. One young carer stressed that her responsibilities as a carer were very different from those of her brothers: "the lads decide where they go [on social outings] first," and "I'd probably do it [the caring task] just to avoid the argument."

Inequality

A further factor influencing the impact of caring on carers was socio-economic disadvantage. A number of families were heavily dependent on whatever income support they were entitled to receive from the State. There were eight young carers living in households without any adult in paid work. These were all one-parent households, where the parent was in receipt of care from the young carer (in one of these households, children also were in receipt of care). In contrast, most other young carers were caring for siblings in households with at least one parent in paid employment.

Intimate Care: Two Scenarios

Intimate care was provided to siblings and parents and, once again, the impacts on the carer were both positive and negative, as illustrated by the following two scenarios. One teenage boy was caring for his three brothers with intellectual disabilities. Although he sometimes felt "stressed" at school, he believed that his school work did not suffer. He said that he had received advice and information from professionals treating his brothers, but also from his parents who were the primary carers in this household and also involved in a voluntary organisation that supports families living with intellectual disabilities. Although the burdens of caring may have led to negative outcomes for this teenager, in particular for his schooling, there is evidence that he had a positive self-image of his caring role:

I personally feel that if I can make their life a bit easier for them, then I'm happy. I just feel that I am their bigger brother so I should help, you know.

Others provided intimate care to a parent. In one case, a teenage girl was the primary carer for her mother with a physical illness. The young carer did not receive much support from her brothers at home, and there was a need for more services in the form of home help, respite care, medical treatment for her mother, and household modifications to lessen the caring burden. The negative impacts in this case included absences from school and being unable to spend time with friends. Although she did feel close to her mother because of her caring role, her on-going obligation to provide intimate care was a source of worry and anxiety. Indeed, she was eager to find an alternative to her continued provision of intimate care:

I'm trying to convince her to get the [colostomy] bag for going to the toilet instead of having to bring her all the time. It would be the worst part of it, like, having to lift her onto the toilet and not getting there on time and things

Conclusions

The findings from this exploratory study suggest that in Ireland young carers are a hard-to-reach or invisible group, and also that many caring situations can have negative impacts. Better supports for and greater awareness of young carers therefore are needed. However, given the tension elsewhere, between researchers in areas of disability and those studying young carers, such conflicts must be avoided in the Irish context if at all possible. Although there is good reason to retain the term young carer and also to call for supports specifically for young carers, this need not be seen as a hostile act challenging the rights of ill and/or disabled parents.

Its critics have argued that young carer research exaggerates the prevalence of young carers (Olsen, 2000). As an exploratory study, the purpose of this research project was not to estimate

prevalence. However, it can be said that current Irish Census figures are an underestimate given that they are only collected in regard to those over 15 years. Moreover, there is little awareness of this issue. The gaps in professional knowledge about young carers among agency staff in this study suggest that staff knowledge of, and training in, this area should be addressed. Finally, there seems to be little association with the term among young carers themselves in Ireland, as can be seen by the fact they did not self-refer to this study. In the UK, Dearden and Becker (2004) were able to recruit survey participants via Young Carers Projects, suggesting that the latter have had some success in getting young people to associate with the term young carer.

Research on young carers also exaggerates the number of primary carers, according to Parker and Olsen (1995); in this study, the majority of participants (n=17, 65%) were secondary carers, but nonetheless a significant minority were primary carers (n=9, 35%). In any event, this study has found that level of responsibility is not the only variable explaining impacts on the carer. In the second of the two scenarios of intimate care provision discussed above, the primary status of the young carer was one significant variable, but so too were the tasks performed, levels of awareness and recognition, and the formal and informal supports enjoyed. The second scenario was marked by insufficient support to the young carer, as well as insufficient support to the person with the care need.

In addition, it is claimed that researchers on young carers do not properly acknowledge the difficulties of ascribing particular "effects" to caring as a child (Parker & Olsen, 1995, p. 2). This study did not claim to have established a causal relationship between caring and impacts on the carer. Instead, the views of young carers themselves were sought about their experiences in a variety of areas, and the characteristics of the situations where young carers reported positive and/or negative experiences were then highlighted. The findings from those semi-structured interviews suggest that, although not all caring is "age-inappropriate," the negative impacts can be serious and can impact rights to education, leisure and recreation, information, and the highest attainable standard of health, as well as the best interests of the child principle (United Nations (UN), 1989).

A further criticism is that the term young carer is necessarily "arbitrary" as it assumes a "normal" conception of childhood, namely one where parents are neither ill nor disabled (Olsen, 2000, p. 386). However, any child well-being measure requires some understanding of a normal childhood (for example see Department of Health and Children, 2000). What is more, as other researchers have reported (see Lloyd, 2006), this study found that caring situations vary markedly. To respond appropriately, whether through formal or informal supports, it will be necessary to respond with sensitivity. Furthermore, it is not parental disability and/or illness itself that has been identified here as a cause for concern (a departure from the accepted norm), but rather the access to formal and informal supports for the young carer, the awareness and recognition of the caring role, the socio-economic disadvantage of the family, and the protection of the young person's rights. It has not been assumed that ill and/or disabled parents will provide less support or be less aware or do less to protect children's rights. Likewise, it is wrong to focus exclusively on the experience of young people caring for a parent. This study also looked at the experiences of young carers caring for siblings, and recorded negative and positive experiences there as well.

It is also argued that researchers on young carers assume ill and/or disabled parents lack the capacities required to be good parents (Olsen, 2000). No such assumption has been made in this study. Nonetheless, it has found that informal support for the young carer and awareness and recognition within the household of the young carer's role are crucial in determining the impacts of caring on the carer. It therefore follows that parents do have responsibilities in regard to support for and awareness of their children as young carers. Young carers themselves said they wanted respite breaks from their caring role. However, this does not necessarily imply a critique of the parental role of an ill and/or disabled parent, as the need for respite arose also when the person with the care need was a sibling rather than a parent. Finally, the socio-economic situation of a child in a one-parent family who is also the primary carer for that parent, may infringe the child's rights, in particular the right to a standard of living adequate for the child's physical, mental, spiritual, moral, and social development (UN, 1989). Once again, this does not imply a critique of the parenting capacity of disabled and/or ill parents, but concern for the rights of the child entail that it should be a significant policy and service issue.

The final claim made as part of the critique of young carer research is that its children's rights agenda should be "resisted," and it should be resisted by researchers themselves (Parker & Clarke, 2002, p. 351). However, there is no evidence in the literature on young carers reviewed in this study to suggest that there has been a concerted effort to stigmatise disabled and/or ill parents. Nor does the demand for better protection of children's rights imply a critique of the parenting of ill and/or disabled parents. Moreover, it can also be said that this study has been conducted without taking sides in a supposed conflict of interests between two social groups. There may well be cases uncovered in this study where parents were expecting their children to do too much and/or not providing sufficient support, but it is equally the case that young carers have reported good experiences and they are associated with better support, including support from parents. Finally, at the level of morality, we are required to give equal consideration to the like interests of all (Singer, 1993), whether they are children or adults, able-bodied or ill and/or disabled. It is this imperative that supports calls to recognise children's rights, but it would equally support calls to recognise the rights of ill and/or disabled parents. It does not follow that the interests of the parent should be subordinated to those of the child, for to do so would be to fail in our moral obligations to treat others as our equals.

If the term young carer is retained and if supports for young carers are to be put in place in Ireland, the policy implications will be wide-ranging. First, given the lack of awareness about young carers among carers, parents, and professionals, raising public awareness should be a policy priority. However, it is essential to do so without exaggerating the negative impacts of caring or stigmatising either those with the care need in the family or the parents. Also, as a matter of social justice, awareness rising should go hand-in-hand with the development of services designed specifically for young carers. Second, the continuum of caring situations and the diversity of supports required must also be recognised. Given the wide range of impacts observed in this study it is clear that one response will not "fit" or work for all young carers or their families. Third, as the UN Convention on the Rights of the Child states (1989), young people themselves must have a voice in matters that affect them (Article 12). Although it does not follow that the voice of parents, including ill and/or disabled parents, should be silenced, nonetheless, any developments taking place nationally, regionally, or locally, to deal with issues relating to children and young people as carers, should ensure the voice of young carers are

heard and taken into account. And fourth, an improved understanding of young people as carers is also essential. As an important first step in addressing the gap in knowledge of young carers, the Irish government has now committed to collect Census data on carers below the age of 15.

There are also a number of important ways in which the findings from this study can be applied to practice and service provision. First, services should respond to needs. Although better service provision for the person with the care need was a recurring theme in the findings, carers also had needs as young carers, including the need for informal support within the home, help with school from teachers, information about services that can assist them, emotional support and advice from mentors (including youth work), time to be with friends, and time to take part in sport and other activities. As Roche and Tucker (2003) found, despite policy and legislation developed to aid young carers, in the UK services rarely responded to the child or young person's needs as a carer and instead usually only intervened when there was a child protection concern. Second, mechanisms are needed to enable young carers to make contact with service providers. This could include targeted information campaigns in schools, increasing the profile of potential caring by young people among service providers, and raising awareness about the characteristics of young people who act as carers. Much can be learnt from the success of Young Carers Projects in the UK. In Ireland, on foot of the study's findings, the Carers Association received funding for a dedicated staff member to work in this area and also the development of a web-based support for young carers. Third, service providers in Ireland should attempt to proactively identify young carers where there is a known care need in a family. One way that this could be done is to extend the remit of organizations already providing services to the person with the care need. At the same time, however, youth-focused organizations could provide support in the form of mentoring as well as opportunities for sport, recreation, and other social activities. Such practice and service developments would require continued use of the term young carer and greater awareness of caring by young people so as to ensure that supports are appropriate to the caring situation and also respond to the real needs of the carer as well as the person with the care needs.

References

- Aldridge, J. (2006). The experiences of children living with and caring for parents with mental illness. *Child Abuse Review*, 15(2), 79-88.
- Aldridge, J. (2008). All work and no play? Understanding the needs of children with caring responsibilities. *Children & Society*, 22(4), 253-264.
- Aldridge, J., & Becker, S. (1996). Disability rights and the denial of young carers: The dangers of zero-sum arguments. *Critical Social Policy*, 16(3), 55-76.
- Aldridge, J., & Becker, S. (1999). Children as carers: The impact of parental illness and disability on children's caring roles. *Journal of Family Therapy*, 21(3), 303-320.
- Aldridge, J., & Wates, M. (2005). Young carers and their disabled parents: Moving the debate on. In T. Newman & M. Wates (Eds.), *Disabled parents and their children: Building a better future* (pp. 80-99). Ilford, UK: Barnardos.
- Central Statistics Office (CSO) (2007). *Census 2006: Disability, carers and voluntary activity*. Dublin, IE: The Stationary Office.
- Dearden, C., & Becker S., (2004). Young carers in the UK: The 2004 report. London, ENG: Carers UK.
- Department of Health and Children (2000). *The national children's strategy: Our children their lives*. Dublin, IE: The Stationery Office.
- Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry*, 7(2), 163-178.
- Frank, J. (2002). *Making it work: Good practice with young carers and their families*. London, ENG: The Children's Society and the Princess Royal Trust for Carers.
- Gaffney, M. (2007). A research study of young carers: The development of a recording tool for agencies to identify young carers. Wellington, NZ: Ministry of Health in association with Carers New Zealand.
- Gray, B., Robinson, C., & Seddon, D. (2008). Invisible children: Young carers of parents with mental health problems The perspectives of professionals. *Child and Adolescent Mental Health*, *13*(1), 169-172.
- Halpenny, A. M., & Gilligan, R. (2004). *Caring before their time? Research and policy perspectives on young carers*. Dublin, IE: Barnardos National Children's Resource Centre and the Children's Research Centre.
- Hill, S. (1999). The physical effects of caring on children. *The Journal of Young Carers Work*, 3(1), 6-7.
- Lloyd, L. (2006). Call us carers: Limitations and risks in campaigning for recognition and exclusivity. *Critical Social Policy*, 26(4), 945-960.
- Morris, J. (1993). *Independent lives? Community care and disabled people*. Houndmills, UK: Palgrave.
- Newman, T. (2002). Young carers and disabled parents: Time for a change of direction? *Disability and Society, 17*(6), 613-625.
- O'Connell, C., Finnerty, J., & Egan, O. (2008). *Hidden voices: An exploratory study of young carers in Cork*. Dublin, IE: Combat Poverty Agency (Working Paper Series 08/07).
- Olsen, R. (1996). Young carers: Challenging the facts and politics of research into children and caring. *Disability and Society*, 11(1), 41-54.

- 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), 384-394.
- Olsen, R., & Clarke, H. (2003). Parenting and disability: Disabled parents' experiences of raising children. Bristol, UK: Policy Press.
- Parker, G., & Olsen, R. (1995). A sideways glance at young carers. In *Young carers: Something* to think about. Papers presented at four SSI workshops May–July 1995 (pp. 63-74). London, ENG: Department of Health.
- Parker, G., & Clarke, H. (2002). Making the ends meet: Do carers and disabled people have a common agenda? *Policy and Politics*, *30*(3), 347–359.
- Prilleltensky, O. (2004). My child is not my carer: Mothers with physical disabilities and the well-being of children. *Disability and Society*, 19(3), 209-223.
- Roche, J., & Tucker, S. (2003). Extending the social exclusion debate: An exploration of the family lives of young carers and young people with ME. *Childhood*, *10*(4), 439-456.
- Social Care Institute for Excellence (2005). *The health and well-being of young carers*. London, ENG: Social Care Institute for Excellence. Retrieved from www.scie.org.uk/publications/briefings/files/briefing11.pdf
- Singer, P. (1993). Practical Ethics. Cambridge, UK: Cambridge University Press.
- Thomas, N., Stainton, T., Jackson, S., Cheung, E. Y., Doubtfire, S., & 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), 35-46.
- Underdown, A. (2002). 'I'm growing up too fast': Messages from young carers. *Children and Society*, *16*(1) 57-60.
- United Nations (UN). (1989) *Convention on the Rights of the Child*. Geneva, SZ: United Nations Office of the High Commissioner for Human Rights.
- Warren, J. (2007). Young carers: Conventional or exaggerated levels of involvement in domestic and caring tasks? *Children and Society*, 21(2), 136-146.
- Waters, S., & Rigby, A. (2008). *The Lulus Model: A peer support pilot program for young people*. Victoria, AS: Carers Association Victoria.