Voices of Hidden Young Carers in Cork
Joe Finnerty and Cathal O’Connell

Abstract
Informal provision of care by family members of elderly, ill, and disabled persons is one of the foundations of caring in Ireland. The primary assumption underpinning much informal care is that it is provided by adults, and this undoubtedly is the case for the vast bulk of care provided. There are, however, others who provide informal care and who are rarely mentioned, seldom credited for the work they do, and are only beginning to be acknowledged at policy level. Specifically, these are ‘hidden young carers’ whose experiences are the focus of this article.

The findings of the small-scale, exploratory piece of research presented in this article point to the long term impact of caring on these young people’s health and quality of life, education, employment, risk of poverty and social relationships. Hidden young carers are unable to live their lives as their peers do, and compounding this they have been largely invisible to policy makers and service providers.¹

The article begins with a review of the international literature on definitions and perspectives on young carers, followed by a brief overview of existing Irish research and policy. It then details the lived experiences of current and former young carers, based on interviews with a small Cork sample, to illustrate the impacts of caring on various aspects of their lives. The article concludes with some commentary on the issues arising from the research for policy and service provision.

Keywords
Informal care; experiences of young people; Irish social policy; young carers

Introduction
There are a number of key theoretical paradigms which inform research on young carers. These paradigms have evolved over time, and according to Halpenny and Gilligan, changes in societal conceptualisation and understanding of terms such as ‘disability’, ‘caring’ and ‘childhood’ contribute to a shift in emphasis from a focus primarily on outcomes and risks for children as carers to a broader focus which encompasses young carers as competent social agents (Halpenny and Gilligan, 2004:14).

Becker et al. (1998) outline the key perspectives as including the medical perspective, which originated in the early 1950s and is primarily concerned with the impact of ill-health and disability on families, including children. The young carers perspective is rooted in a children’s and carers’ rights model which views children and carers as
fulfilling distinct family and social roles, including being the main providers of care in the community. The social perspective on disability is primarily concerned with the rights and needs of disabled people and their experiences of ‘disabling barriers’ including discrimination and exclusion. Becker et al. (1998) identify what they term a ‘sub-literature’ of the social perspective on disability, which has challenged the mainstream work on young carers and has focused instead on the rights and needs of those who have physical or mental impairments (Keith and Morris, 1995; Parker and Olsen, 1995; Newman, 2002). Finally the family perspective has grown out of the debate between the rights of disabled people and the rights of children who care, emphasising prevention in a ‘whole family’ context as opposed to protection (Becker et al., 1998).

Due to the complexity and diversity surrounding the role of young carers, a satisfactory definition has proved difficult to arrive at. Several definitions of young carers can be identified within the literature on social work and from caring organisations. A range of factors can be cited which set young carers apart from both adult carers and other young children within families and households who do not take on a caring role. Aldridge and Becker (1997) suggest the following definition:

A child or young person (under 18) who is carrying out significant caring tasks and assuming a level of responsibility for another which would usually be undertaken by an adult.

**Research on Young Carers in Ireland**

There is little by way of a young carer research literature in Ireland, with existing research overwhelmingly focusing on adult caregivers (see for example O’Donovan et al., 1997; Garavan et al., 2001). While Halpenny and Gilligan (2004) have undertaken a wide-ranging literature review on young carers which surveyed the international literature and policy context, they did not undertake any primary research with hidden young carers.

Two short studies which made references to young carers were carried out in the mid-1990s. The first was by Multiple Sclerosis Ireland (1996) on MS sufferers and the second was a pilot study by Carers Association (Ireland) (1997) which aimed to obtain an overall picture of the contexts within which young people were providing care. The MS Ireland study was focused on care needs of sufferers of that condition and the source of the care they received while the Carers Association research focused on the nature of the tasks and extent of caring undertaken by young people rather than exploring the impacts on young carers and their attitudes and feelings in relation to their caring responsibilities.

**Policy and Provision in Ireland**

In the Irish context, recognition and responses to the existence and needs of young carers could be best described as uneven. No national policy strategy exists with an explicit focus on young carers, and no reference to young carers is made in either the National Children’s Strategy 2000–2010 or the Office for Social Inclusion (2007) publication *A Social Portrait of Children in Ireland*. Additionally, there is a noteworthy absence of mention of the ‘young carer’ issue in the Comhairle document *Supporting Carers* (2002), or in the Joint Oireachtas Report on the Position of Full-Time Carers (2003).
The same is true of other recent literature on caring in Ireland (Cullen et al., 2004; NESC, 2005; Browne, 2005).

However, evidence is now emerging of a belated awareness of the roles played by young carers and the subsequent needs of these young people. Some recognition of young carers is evident in a report entitled Implementing Equality for Carers by the Equality Authority (2005), which asserts that ‘the state has a clear responsibility to provide a full range of services for young carers’, beginning by identifying the young carers, followed by the provision of practical supports such as counselling, respite, access to education, social inclusion and meeting personal development needs.

Most recently, policy documents arising from the social partnership process overtly acknowledge the existence of young carers as a specific cohort within the caring population overall, especially where they may be undertaking ‘inappropriate care roles’. Arising from the participation of the Carers Association in the negotiation of the current national partnership agreement, Towards 2016, there is a commitment to undertake research on ‘the extent, degree and impact’ of caring on the lives of the children concerned. It goes on to commit to the development of supports to ‘alleviate specific problem areas identified for children’, based on the findings of the research (Government of Ireland, 2006: 46; see also Carers Association of Ireland, Carer Alliance Ireland and Caring for Carers Ireland, 2008). The sporadic nature of policy recognition in Ireland of young carers contrasts with that of other countries such as the UK and Australia, where significant progress has been made in identifying and responding to their situation.

The Prevalence of Young Carers in Ireland

It is difficult to assess the true extent of caring undertaken by young people in Ireland, though rough estimates can be made to gauge the extent of caring by young people from census sources. The Census of Ireland 2002 and 2006 (Volume 10 Carers and Disability) provides data on self-reported caring activities within the population as a whole. With respect to persons in younger age groups who provide care, however, Census 2002 data are only available for persons from the age of 15 years upwards. A total of 2,996 persons aged between 15 and 17 years were recorded as providing unpaid personal care. Of these 819 were aged 15 years, 1,037 were aged 16 and 1,140 were aged 17, which in total accounted for 2 per cent of the total caring population (Halpenny and Gilligan, 2004). It is not possible to make comparisons between 2002 and 2006, as the latter census did not publish figures for persons in younger age groups who provide care.

Research Design and Methodology

The remainder of this article presents some of the findings of an exploratory Combat Poverty Agency funded study into young carers’ experiences in the Cork region in the south of Ireland. Given the hidden nature of the role they fulfil, a major challenge facing the research was the identification of a sample of young carers and gaining their consent to participate in the study. In attempting to identify potential participants, contact was made with a wide range of organisations and individuals who work with families and young people in the wider Cork area and who could be in a position to identify and introduce young carers to the researchers. Data was gathered via
qualitative and semi-structured interviews, which were conducted in awareness of the sensitive nature of the material involved and the youth of some of the respondents.

In total nine interviews with young carers – comprising five young carers and four former young carers – were conducted from 2004 onwards in Cork city and county. Two of the young carers are siblings. The interview sample reflects a range of age groups, with a roughly even balance of male and female participants (Table 1). While no young carers under twelve years of age were interviewed, a number of the participants had been caring from as young as four or five years of age.

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Table 1: Interview participants by age and gender

In the following section the young carers are profiled in terms of who they cared for, the duration of the care, and the nature of the care provided. This is followed by an account of their views on their caring role, and the effects it has had on various aspects of their lives.

**Person Cared for and Reason for Caring**

Eight of the nine young carers and former young carers interviewed were caring for their mother. The ninth interviewee took over caring for a younger sister when her mother suffered a nervous breakdown. Four of the young carers and former young carers were caring for more than one person. In three of these cases, the carer also took responsibility for the care of a younger sibling, as their mother was unable to do so. The fourth carer was responsible for caring for three people: her mother, aunt and grandfather.

**Length of Time Caring**

A total of five young carers began caring under the age of ten, four of whom began caring when they were less than six years of age. Four young carers and former young carers began caring in their teenage years. All those interviewed had been caring for a long period of time, from a minimum of around four years up to over forty years of caring. All interviewees were – or had been – caring on a daily basis, although there was variation in the nature and intensity of the caring.
Nature and Extent of Caring Responsibilities

The nature and extent of caring responsibilities varied among the young carers and former young carers interviewed. One former young carer was caring for three people – her mother, aunt and grandfather – from when she was a toddler. Her mother and aunt both suffered from mental illness, while the grandfather was elderly and physically ill. She cared for all of them daily and was also often up at night with them. Her father was present but was working, so she had primary responsibility for caring for them. A younger brother was also present but he was not expected to do the caring work. The caring involved personal care (such as dressing and emptying commodes), housework and cooking, as well as the need to constantly watch her aunt who was inclined to wander the roads, and her mother who was paranoid and would keep hiding things in the house.

Another former young carer took care of her sister, who has Down’s Syndrome, from when she was nine years old and her sister was a baby. Her mother suffered a nervous breakdown and was unable to care for her. Her father was working, an older sister had left the country and her brothers played no role in caring. Her father died when she was sixteen, leaving her as primary carer. Caring responsibilities included personal care, cooking, shopping and housework. She also took care of her mother who was self-neglecting. At a later stage she arranged and monitored education and rehabilitative care for her sister.

Two young carers who are siblings provide a great deal of physical and personal care in addition to assisting with housework and cooking. This includes helping their mother in and out of bed, in and out of the car, on to and off the toilet and assisting with dressing. The daughter, on occasion, has had to assist in changing her mother’s catheter.

Another young carer takes care of her younger sister (six years old) and used to also care for a younger brother. This involved all the tasks associated with caring for a young child as well as trying to make sure her brother went to school. She also has to watch her mother, who suffers from manic depression, and ensure that she has not fallen asleep smoking or left all the doors unlocked.

The Impact of Caring on the Lives of Young Carers

The research revealed that in a number of key aspects of their lives the caring responsibilities carried by young carers were significant, and usually negative. The impacts of caring at a young age are multidimensional, affecting education, physical and mental health, risk of poverty, social life, career and life chances and choices. In the following section of the article, a selection of experiences are reported which give a voice to the young people themselves and highlight the effects across a range of their life experiences.

Feelings about Caring Responsibilities

Interview participants expressed a range of emotions in relation to their caring role: acceptance, resentment, anger, annoyance, stress, trauma and upset. Some felt that caring for their relative, while difficult, was just something one did because of family bonds.

*It’s not all that bad like. The odd time there you’d get fed up of it like. But what can I do, it’s my mam. You have to look after her. She does the same for me.*
Some felt that they did it because they were used to it or knew no different. ‘It was difficult but you knew nothing different at that time.’ Other young carers expressed a clear dislike and resentment of having to provide care. All the young carers and former young carers interviewed found the situation stressful and traumatic, to a greater or lesser extent. ‘You were constantly stressed to the limit….terribly stressful; I grew up in a terribly stressful situation.’

**Education**

Being a young carer had a significant impact on the education of the young carers and former young carers interviewed. For one of the former young carers, who was caring from when she was around six years of age, being a young carer resulted in her missing out almost completely on her education. Because of caring responsibilities she was kept home from school from an early age, which had significant implications for her education and life chances.

You’d have a couple of days at school, days off from school – you’d have to stay at home if there was no one to look after them. Now I loved school. I wanted to be educated. It affected me all through life. Now I can’t apply for a job or anything like that now ‘cos I’m not educated enough.

She was very angry that no-one intervened to ensure she received an education. Doctors, nurses, TDs and the school were all aware of her situation.

And yet I went through the net, stopping at home from school and caring at home. And nobody ever came to say this can’t go on, this child has got to go to school.

There was an clearly discrimination in this case. Her brother was educated but it was not considered as important that she be educated because she was a girl.

And being a daughter, it was kinda seen in those days that a daughter, sure why would you bother educating her, she’d only be getting married. In those days it was nothing thought of a daughter. A son had to be educated but not a daughter. So I was the one.

Her lack of education impacted on her throughout her life, affecting in particular her self-confidence and work opportunities.

It has affected me now like if I’m applying for a job or talk up at meetings or things like that, I’m afraid of saying the wrong thing. I know it’s all inside me what I want to say out but I’m afraid I’ll say the wrong words, my grammar would be very bad.

She had wanted to work with children with special needs but didn’t do well enough in her leaving certificate to enter the training course. Her practical experience in providing care for her sister with special needs was not taken into account.

Caring responsibilities also impacted significantly on the educational experience of an eighteen-year-old carer who was caring for her mother and younger siblings since she was twelve. She missed out on lots of school: she would miss a few days each week and would sometimes be out of school for a few months at a time.

I lost out, that was the main reason I never finished my leaving cert was ‘cos I was always at home minding my sister. … so I missed out so much at school that I never got to finish it. I missed out on lots of secondary school.
She has now returned to education and is attending Youthreach, which she really enjoys.

_I love to come here in the morning. I’m the first up because it gets me out of the house for a few hours…..Hopefully I’ll get college or something out of it._

A fifteen-year-old carer had been missing out on a lot of school, partly because of the situation at home.

_I wasn’t go to school at all. Because my mam was sick I thought I didn’t have to go to school. I didn’t bother going._

His mother became very upset because he was missing school and getting into trouble. Given their close relationship, this affected him and he decided to go to a Youthreach programme, where he is now studying for his Junior Certificate Examination. He finds Youthreach to be a much more supportive environment than his previous school and they also understand if he needs to come to school late because he is helping his mother.

The interviews revealed that being a young carer adversely affected the education of the young carers and former young carers interviewed. This ranged from completely missing out on education, to difficulties balancing homework and caring responsibilities. Most received little or no support from their schools and there was little intervention to ensure that their education was not affected. Missing out on education has had implications for their life and career choices. It is positive to note, however, that two young carers’ experience of education changed when they began to attend a Youthreach centre. Both are now enthusiastic about their education and have plans to continue with further education and training. This demonstrates how a more supportive and aware educational environment can mitigate the impact of caring on young carers’ education.

Work/Career Experiences

It was clear from discussions with former young carers that it impacted significantly on their work and career paths. For most of them this was directly linked to the fact that their caring responsibilities had adversely affected their educational opportunities, as outlined above. This limited the range of employment opportunities open to them and many ended up in factory jobs or doing what one woman described as ‘menial work’.

For some the impact on employment prospects has been felt right through their lives and continued to affect their confidence to apply for jobs.

_I’ve been offered different jobs since that are better paid but I feel I wouldn’t be educated enough for it. It hits me all the time. You’d be knocked down all the time. You’re being reminded all the time of what you missed out on._

Most of the former young carers have ended up working in the field of caring. One woman has spent her whole life providing care for family members and subsequently working as a carer in a convent. ‘So the caring role is still there; it will never leave me; it’s there.’ Another woman wanted to train to work with people with special needs but, because she had missed out on so much of her education, didn’t have the right educational qualifications and her practical work experience in this area wasn’t taken into account. She now works as a home help where her years of caring experience are valued and she provides training for other home helps and works with ‘high
maintenance’ patients. Another woman went from school into factory work which she hated. She was in her twenties before she returned to education and trained as a social worker and now works as a social worker in the psychiatric services.

One of the current young carers wants to work in the medical field and feels that her experience in caring for her mother would be of benefit to her. ‘Well I kind of want to do medicine when I’m older so I’ve kind of got a head start.’

Social Life/Relationships

Most interviewees said that being a young carer impacted on their social lives and relationships. Because of their caring responsibilities they had less time to spend with friends, to develop relationships and to engage in social activities. Young carers who missed out on school because of their caring responsibilities also missed out on the opportunity to develop friendships with classmates. They also missed out on social aspects of school life, such as school outings. One former young carer has been providing care since she was nine years old. Now in her thirties she has never had a relationship and she feels that this is directly a result of being a carer.

‘I’ve never had time to get into a relationship because you couldn’t go out, you didn’t have babysitters and things like that. There was never any kind of a relationship. You couldn’t. Being a carer is a very lonely experience.’

Some of the young carers resented the fact that they had little time to ‘hang out’ with their friends and that while their friends were out playing and having fun they had to stay home and help out.

‘I went out for the first time in about a month last Sunday and stayed overnight in a friend’s house. That was the first time in about a month that I done that, went out for longer than a few hours.’

Others felt unable to invite friends to come to their homes because they were embarrassed about the situation at home or because their family didn’t want anyone to know what was going on. ‘I usually go to my friends’ houses. I’m kind of embarrassed about the situation at home.’ For some young carers it was the constant interruptions which caused frustration. They would be in the middle of doing something, spending time with friends, being out, watching TV, and would be called away to help out and provide care. The lack of free time for their own activities also caused difficulties for young carers.

‘Like as a carer you were always clock watching, always, always clock watching. You never ever had free time. You might get two hours, you know what I mean.’

Mental and Physical Health

Being a young carer can have a detrimental impact on the health (mental and physical) of the young people involved. This can be most clearly seen in health problems that are directly related to or caused by the caring work. Examples of this include tiredness, stress, physical exhaustion and back problems.

‘I don’t like doing it. It hurts my back sometimes. And I pull my muscles a lot as well. My back, my arms and my legs.’
Other physical health problems can be linked to the stress associated with being a young carer. One woman developed allergies, with associated health problems, which she feels was because she was in such a stressful situation at home.

*My health was deteriorating; I had a lot of allergy problems, but that time they didn’t know it was allergy problems. I was getting sick a lot, then the doctors, and in and out of hospitals; they didn’t know what was wrong with me. Stress, my system had broken down.*

For many young carers the greatest impact is on their emotional and mental health. The majority of the young carers and former young carers interviewed experienced stress because of their situation. For some this led to depression and anxiety. Some former young carers have needed to go to a counsellor to deal with the impact of this stress on their emotional and mental health and some of the current young carers felt that they needed to see a counsellor to help them deal with their current situation.

*Looking back I would say most certainly my older brother and myself, I would say certainly our mental health suffered. And I would say that we became depressed for quite some time.*

**Poverty**

Many of the young carers and former young carers interviewed had to deal with financial hardship directly linked to their position as young carers. For some this was because they were living alone with a parent who was unable to work because of illness or disability and the family was subsequently dependent on social welfare payments. *‘We were completely pauperised through all this as well.’* In one situation the young carer was caring for an ill parent and, when the situation worsened, the second parent had to give up work to help care for the ill parent. This had subsequent implications for the family’s financial position. Another young carer had to leave school and to go to work to support her family because her father died when she was sixteen: *‘There were days when we barely had food. There were days when we had to burn shoes, we didn’t have coal.’*

In one particular case, the current young carer and her siblings are occasionally in a position where they have no food or money. Their mother suffers from manic depression and when she is ‘high’ she takes the family’s money and leaves nothing for the children.

*‘Cos when my mother gets like this she takes any money that we get and basically spends it on cigarettes and nothing else really. So there’d be no food or anything.*

When asked what kind of supports would help to make her situation better her answer was: *‘Financial really, because she takes money, and coal and stuff like that. It’s just food basically and heating that is sometimes needed.’*
Information, Professional Intervention and Supports

One of the biggest problems identified by the young carers and former young carers in the study was the lack of information and of professional interventions and supports for the young people. Many interviewees mentioned that they didn’t understand what was going on when their parent became ill and that nobody explained the situation to them. This was very confusing and frightening, particularly when they were so young. Former young carers expressed anger that, even though professionals such as doctors, teachers or social workers would have been aware of their situation, nobody had intervened to assist the young people.

*What hurts me most is the fact that all that went on and there was no one took any notice.*

Discussions with current young carers show that there is still inadequate professional intervention and supports for young carers. For example, one young carer who is caring for a young sibling because of her mother’s mental illness has stated that she receives no professional support, receives inadequate information and intervention from her mother’s doctor and has never been contacted by a social worker. However, one of the other current young carers spoke of the difference that an engaged and supportive social worker had made to his family. She engages with the son as well as the mother and provides practical supports for the family.

*She comes around a lot and helps out with stuff to do with the house, like the chairs and carpets. She’d be up the whole time. She and my mam talking and having a cup of tea. You wouldn’t think she was a social worker at all, you’d think she was one of my mam’s friends.*

Both current and former young carers stressed the need for more adequate Home Help and Respite Care and expressed anger at the recent cutbacks in these services. In addition to the lack of adequate professional supports, some former young carers were angry at the lack of support and help from family members and at the fact that they were left with all the caring responsibilities: ‘For years I was very angry that they weren’t doing their bit like.’

Contact with Other Young Carers

Isolation can be a major problem for young carers. Because of their caring responsibilities they often have less time to spend with their friends and peers. Young carers also felt that it could be difficult for friends to understand what it was like to be a young carer and some felt too embarrassed to discuss their home circumstances with their friends. Few of the young carers knew of, or had contact with, other young carers and they often felt that they were the only one in that situation. Two of the young carers had participated in an event for young carers which was organised by the local Multiple Sclerosis Society. They found it beneficial to learn that there were other young carers and that they shared similar experiences.

*I actually didn’t realise that there were others. I thought that there’d only be a few others but there was a good few.*
Most of the current young carers expressed interest in meeting with other young carers and in participating in a Young Carers’ Group if one were established. The prime motivation was to combat their sense of isolation and to be able to talk with other young carers who would understand their experiences.

Doing this you feel very alone. You feel that there’s nobody else around. So it would be nice to find out how other people deal with it and stuff. I think that [a young carers’ group] would be a very good idea alright.

Conclusions

It is clear that being a hidden young carer has significant implications for the lives and wellbeing of the young people involved. Being a young carer can lead to impoverishment, not only in terms of financial hardship and lack of basic resources such as food, but also in terms of affecting education and employment opportunities, social lives and interactions, and physical and mental health. Furthermore the lack of adequate information, supports, and professional interventions has exacerbated already difficult situations for young carers, and it is clear that adequate professional supports and interventions are essential in mediating the impact of caring on young people’s lives.

A number of important conclusions emerged from the research, with implications at the level of policy formulation, service planning and practice interventions.

A greater level of awareness of the existence and of the needs of young carers on the part of social professionals such as social workers, youth workers, community development workers, health professionals and home-school community liaison officers is essential to help in early identification and in devising appropriate responses. For other organisations working with families where young carers may exist, strategies for heightened awareness of their needs should be devised.

The interruptions/dilution of formal educational experiences caused by caring responsibilities places hidden young carers at a considerable disadvantage in terms of life chances, labour market participation or acquisition of formal qualifications. Nonetheless, the research outlined in this article has revealed that despite the adversities they endure, young carers build up significant skills and resources in taking on care responsibilities. In this regard consideration should be given to policy initiatives aimed at giving recognition to these experiences and skills through certified training initiatives, EU led vocational training initiatives and distance learning programmes, in line with recent proposals for recognition of adult carers (see for example Government of Ireland, 2006: 6).

Finally it is evident from the literature and policy review that official awareness levels of the existence, contribution, needs and experiences of hidden young carers in Ireland is uneven and needs to be strengthened. Future policy documents should directly acknowledge these young carers and highlight the necessity for policy and support measures to meet their needs. Having said that, policy responses to the negative impacts identified in the research must be carefully considered. Special initiatives, while welcome, must be sensitive to the dangers of isolation, stigmatisation and tokenism arising from targeted interventions. Since the burden on young carers is also bound up with the absence of, or lack of, access to services and supports for those
cared for, responding to the needs of young carers should ideally focus on the needs of all family and household members within a wider social policy context.

As the Irish welfare state faces into a period of uncertainty and fiscal rectitude, services such as caring which have traditionally been performed on an unpaid and informal basis, including those provided by young people, will come under greater strain. It is therefore imperative that policy recognition, appropriate interventions, and sensitive responses are put in place to prevent this vulnerable group of young people from experiencing even deeper levels of marginalisation both as young people now and as adults in the future.

Notes
2. For a comparative discussion, see Becker (2007).
3. Difficulties in identifying and researching young carers arises partly out of the highly private nature of the role and the fear of both the young carer and the person they are caring for that either will be taken away from the family setting, and of stigma often associated with some kinds of mental or physical disability (Multiple Sclerosis Ireland, 2003; Halpenny and Gilligan, 2004; House of Commons Select Committee on Children, Schools and Families, 2008). A further issue in relation to recognition is that many professionals who deal directly with children or with those being cared for, may not be sufficiently aware, informed or resourced in addressing the young carers issue (Gillam et al., 2005; Barnardo’s, 2006; House of Commons Select Committee on Children, Schools and Families, 2008).
4. Details of the organisations contacted, of the manner in which the interviews were arranged and conducted, and of the role of a consultative committee to advise on these aspects of the research, are contained in the CPA report.
5. A national strategy on carers was committed to in the last national partnership agreement Towards 2016 (see Government of Ireland, 2006: 54). However, this has now been postponed or shelved by the government on the grounds of lack of resources (Department of Social and Family Affairs (2009).
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