

# A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'

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### Abstract

The reality for many families where there is chronic illness, mental health problems, disability, alcohol or substance misuse, is that children under the age of 18 are involved in caring. Many of these children – known as ‘young carers’ – will be providing regular and significant care, either episodically or over many years, often ‘hidden’ to health, social care and other welfare professionals and services. These children have most often been invisible in social policy and professional practice. What are the reasons why some countries recognize young carers as a priority for social policy while others (most) do not? What are the key factors that influence a country’s awareness and responses to these children? This article provides an original classification and analysis of country-level responses to young carers, drawing on published research, grey literature, policy documents and the authors’ extensive engagement in policy and practice networks for young carers and their families in a wide range of countries. The analysis identifies two of the key factors that influence the extent and nature of these policy responses, focusing on the importance of a reliable in-country research base and the contribution of influential national NGOs and their networks.

Keywords: classification, cross-national comparison, young carers, in-country awareness, policy responses

### Introduction

While there is general awareness that many adults around the world provide unpaid care to elderly, chronically sick or disabled family members, far less is known about the contributions that *children* under the age of 18 make to family care. These children, ‘young carers’ as they are referred to in some countries, can be defined as young people under the age of 18 who provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or any other relative who is disabled, has some chronic illness,

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2  
3 mental health problem or other condition connected with a need for care, support or  
4  
5 supervision (Becker 2000, 378).  
6

7  
8 Research shows that young carers provide many forms of care, including personal and  
9  
10 intimate care, emotional support and supervision, household management and domestic  
11  
12 duties, child care, health and medical care, and self-care (Carers Australia 2001, 9; Gays  
13  
14 2000; National Alliance for Care giving 2005, 2; Morrow 2005, 58; Moore 2005, 5; Warren  
15  
16 2007). Estimates vary as to the number of children in caring roles in different countries but  
17  
18 figures suggest that between 2-8% of all children in advanced industrialized capitalist  
19  
20 societies will be carers, depending on which methodology is used to identify and to count  
21  
22 them (Becker and Becker 2008; Cass et al. 2011; Hill et al. 2009; Howard 2010; Hunt,  
23  
24 Levine, and Naiditch 2005; Warren 2007; Wayman, Raws, and Leadbitter 2016).  
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27  
28 Research from a number of countries also suggests that young carers are often drawn into  
29  
30 caring roles because there is no alternative (Becker, Aldridge, and Dearden 1998, 21-26).  
31

32  
33 Most families in which children provide care have low income, are often reliant on state  
34  
35 benefits, and cannot afford alternative forms of care. Nor do these families have private health  
36  
37 or care insurance. There is a social justice, health inequalities and child health and well-being  
38  
39 case to be made here. These children constitute a 'hidden army' of carers in all countries,  
40  
41 largely irrespective of the nature of their welfare regime or the nature of their 'mixed  
42  
43 economy of care' (Hill et al. 2009; Evans and Becker 2009). Consequently, young carers need  
44  
45 to be recognized, identified and supported as a distinct group of children with specific needs.  
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48  
49 What have some countries done, and why have most nations done nothing at all? The authors  
50  
51 have reviewed the published literature and research from all countries that have produced  
52  
53 articles, reports etc., by searching databases and bibliographies in published research,  
54  
55 including the Oxford Bibliography of Young Carers (Becker and Leu 2014, 1). Additionally,  
56  
57 the authors have collected and collated grey literature, policy documents and information  
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3 from their contacts and networks in countries where young carers' services have emerged or  
4 developed; and they have drawn on their site visits and knowledge of country-level responses  
5 gained from over twenty years of engagements with policy makers, governments and service  
6 providers internationally. The classification of the countries was developed based on the  
7 following five questions: 1. Does country X. recognise or do anything *specifically* about YCs?  
8 2. Does country X. *define* them as YCs (or anything else i.e., 'children as next of kin')? 3.  
9 What does country X. *do* in terms of policy and services? 4. Does country X. have any  
10 *legislation* that is *specific* for YCs or could be used to support YCs? 5. What factors have  
11 been particularly influential in moving policy and practice forward for YCs in country X.?  
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### 23 **Cross-national Comparisons and Classification**

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26 Figure 1 identifies the few countries that have so far developed any discernible level of  
27 awareness and policy response to young carers and where there is some published or grey  
28 literature. Some, such as the UK and Australia, have policies and systematic responses for the  
29 identification and assessment of young carers, while a few more are now 'catching up' and  
30 developing their awareness and thinking about how they should proceed (including, for  
31 example, Sweden, Norway, Canada, New Zealand, Switzerland, Austria, Germany, France,  
32 although to varying degrees). The available (and sometimes limited) research from these  
33 countries has provided a relatively uniform picture of the characteristics, experiences and  
34 needs of young carers, showing that these children have far more in common, irrespective of  
35 where they live, than that which divides them by geography (Evans and Becker 2009). In  
36 other words, a young carer in the UK looks similar to a young carer in Australia, Sweden,  
37 Norway and the USA – despite each country's welfare system being different. There will of  
38 course be country-specific nuances, variations and differences, but the needs of children who  
39 are carers appear to be relatively uniform in advanced capitalist societies.  
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3 In 2007, Becker provided the first preliminary review of awareness and responses to young  
4 carers across a number of countries, showing that only a handful had developed any research  
5 evidence base and specific policies (Becker 2007). Almost a decade later, the authors develop,  
6 extend and update this analysis and ask ‘how we can understand and categorize the different  
7 and emerging types and levels of policy response to young carers across (more) countries?’  
8

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12  
13 Figure 1 provides a new classification.

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15  
16 [Figure 1 here]

### 17 18 19 **Research Evidence, NGOs and Policy Transfer**

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22 Whilst some countries have identified and have responded purposefully to the needs of their  
23 young carers, a few others have been very slow to respond, and most countries in the world  
24 appear to have done little if nothing at all (Levels 6 and 7, Figure 1; Becker and Leu 2014, 1).  
25

26  
27  
28 What is clear, however, is that those countries with the largest and most robust and reliable  
29 research evidence base are the more ‘advanced’ in terms of their awareness and policy  
30 responses to young carers. In other words, they are the countries that would be classified as at  
31 Level 1, Level 2 and Level 3 in Figure 1. Moreover, countries with strong and influential  
32 NGOs also appear to be more ‘advanced’, as our analysis shows. In some countries, these two  
33 factors are linked – NGOs have been instrumental in commissioning, funding or publishing  
34 research and in utilising the findings and evidence to influence policy, law and practice.  
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#### 44 ***L2 Advanced: The UK***

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47 In the UK, it was the work of a University research group, the Young Carers Research Group,  
48 in particular Becker, Aldridge and Dearden, which initially focused on young carers and  
49 developed a body of research evidence for more than a decade, a «fundamental cornerstone of  
50 literature on the subject» (Oreb 2001, 10). Aldridge and Becker’s earliest research (1993) on a  
51 dozen young carers in Nottingham is generally acknowledged as being the «firing gun» for  
52 the emerging interest in young carers by academics, researchers and policymakers in the UK,  
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3 and for raising initial awareness amongst the public (Becker and Leu 2014). The UK can be  
4  
5 characterized as *advanced* in terms of awareness of young carers, research, law, social policy,  
6  
7 government guidance and service delivery. Young carers in the UK have specific legal rights  
8  
9 (as carers and as children) as well as access to a national network of dedicated services. They  
10  
11 are referred to in the policy and guidance documents of government, social care, health and  
12  
13 education agencies. England, for example, introduced legislation for young carers as early as  
14  
15 1995 (Becker 2011), with various other pieces of relevant legislation since then, with the most  
16  
17 recent being the 2014 Children and Families Act and the Care Act. The 2014 legislation  
18  
19 committed English local authorities to ensuring that carers are identified, offered an  
20  
21 assessment and, where appropriate, to ensure that the necessary support structures are in place  
22  
23 to protect and promote their mental health and well-being. English councils are now required  
24  
25 by law to identify and assess young carers under 18. Beside legal rights to an assessment of  
26  
27 their own needs and of their ability to provide and continue to provide care, as well as rights  
28  
29 to services, many young carers in England could be considered as «children in need» and they  
30  
31 and their families therefore have a right to specific support and interventions (Becker 2007,  
32  
33 36). In Scotland, the government plays an important role by working with key organisations  
34  
35 especially the Scottish Young Carers Services Alliance (SYCSA). These organisations run an  
36  
37 annual festival where direct exchange between young carers and government officials takes  
38  
39 place. In Ireland, young carers are recognised by the state in The National Youth Strategy  
40  
41 2015-2020 as a cohort of marginalised and disadvantaged young people within the Irish  
42  
43 population. Although there is an absence of legislation, there are policies and services that are  
44  
45 delivered to young carers by statutory and non-statutory organisations. In order to lobby, raise  
46  
47 awareness, research, develop policy, and establish support for young carers, Family Carers  
48  
49 Ireland (formerly The Carers Association) have an established Young Carer Programme and  
50  
51 employ a full-time Young Carer Development Manager who is funded by the Irish  
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3 Government. However, it is clear that this level of resource is not adequate to provide a  
4  
5 comprehensive service or support.  
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7  
8 The reality is that although governments across the UK have responsibilities, and even with a  
9  
10 well-developed legal structure and welfare system, young carers still fall through the gaps in  
11  
12 policy and legal safety nets, and through adult and children's services. In practice there is  
13  
14 some distance between the legal foundation and the actual implementation of the law. First,  
15  
16 the UK legal framework is complex and varies from one country to another (as we have  
17  
18 shown above), with an abundance of regulations and guidance for each country (England,  
19  
20 Scotland, Wales and Northern Ireland). Many professionals are not aware of the specific legal  
21  
22 requirements and responsibilities placed upon them to identify and support young carers (and  
23  
24 their families in some cases). Second, there is a gap between the ambition and purpose of the  
25  
26 law - to identify, recognize, assess and support young carers - and actual implementation on  
27  
28 the ground by those professional groups (including social workers, health and medical  
29  
30 professionals, teachers, and so on) who have responsibilities in this area. Third, the resources  
31  
32 available to professionals to implement the law are often insufficient to do the job properly,  
33  
34 especially in an economic climate of 'austerity'. Despite good legal intentions, most young  
35  
36 carers in the UK have not had their legal right to an assessment met (Dearden and Becker  
37  
38 2004) and most young carers receive no dedicated support at all.  
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43  
44 Despite this 'service gap', there is nonetheless a relatively advanced legal and policy  
45  
46 framework to identify and support young carers and their families. Non-governmental  
47  
48 Organisations (NGOs) have played a key role in the UK in moving the policy and practice  
49  
50 agendas forward and in determining the nature and level of awareness and response to young  
51  
52 carers locally and nationally (Becker 2007, 41). In the UK, the Children's Society and Carers  
53  
54 Trust, two national NGOs with local branches and services, have been especially important in  
55  
56 campaigning for young carers, raising awareness and developing services for them over a  
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3 period of almost twenty years. The Children's Society has published studies, guidelines and  
4  
5 models of best practice (Frank 1995; Frank, Tatum, and Tucker 1999) as have other NGOs  
6  
7 including Barnardos, Carers UK and others. More recently, the National Young Carers  
8  
9 Coalition (NYCC), a partnership of around a dozen NGOs, charities and organizations,  
10  
11 originally led by Carers Trust and now by the Children's Society, secured a legal victory for  
12  
13 young carers and their families in 2014, helping to deliver new legal rights to assessments and  
14  
15 support that are referred to above.  
16  
17

### 18 19 ***Level 3 Intermediate: Australia, Norway and Sweden***

20  
21 Australia inhabits an *intermediate* position and it is closest to the UK in terms of awareness  
22  
23 and policy responses. There is a growing Australian-specific research evidence base, partial  
24  
25 rights in some regions and a growing distribution of young carers projects and initiatives. The  
26  
27 earliest studies of young carers in Australia can be traced back to the early 1990s. It was the  
28  
29 NGO, the Alzheimer's Association of South Australia, which for the first time highlighted the  
30  
31 situation of children in families with dementia (Alzheimer's Association 1995, 7). This study  
32  
33 was first and foremost one of children *affected* by a parent's illness. The following two  
34  
35 Australian studies, from the nationwide NGO, Carers Association of Australia Inc (1996,  
36  
37 1997), focused specifically on young carers and provided the first substantive attempts to  
38  
39 research Australia's younger carers. The Australian and the UK research on young carers  
40  
41 identified similar policy issues and showed the importance of supporting the young people  
42  
43 and their families through a 'whole-family approach' (Banks et al. 2001; Cass et al. 2011;  
44  
45 HM Government 2008, 2010; Kroehn and Wheldrake 2006; Moore and McArthur 2007).  
46  
47  
48 Thanks to successful funding as well as undertaking national research on young carers (Oreb  
49  
50 2001, 11), Australia has increased its efforts and success with regard to the recognition and  
51  
52 identification of young carers. The country implemented the Carer Recognition Act in 2010  
53  
54 and since then, young carers are explicitly noted in the statement of core principles: *Children*  
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3 *and young people who are carers should have the same rights as all children and young*  
4  
5 *people and should be supported to reach their full potential* (Australian Government 2010, 9)  
6

7  
8 There is a growing awareness and identification of young carers, and specific attention (and  
9 rights) under the 'children as next of kin' legislation and initiatives in Norway and Sweden.

10  
11 Norway has a long tradition of focusing on children's behaviour and how parents function as a  
12 parent. Within the government's «children as next of kin-commitment» (2007-2010), the  
13 country has mainly focused on giving information to the child who is 'next of kin' to a parent  
14 with some health condition; helping these parents to look after their own children; giving the  
15 child a place to share/talk about what is on their mind; helping children and parents talk  
16 together; giving the child, parents or family the opportunity to meet others in the same  
17 situation; and giving the child or the family a break (activities, vacations) etc. The focus on  
18 children as 'next of kin' started with children of mentally ill and drug addicted parents under  
19 the age of 18. In 2009 the government decided to include children of somatically (physical) ill  
20 or injured parents. This commitment was prioritized because research revealed that  
21 interventions with children as next of kin was far from consistent across Norway. While  
22 children as next of kin could get significant help in one region, a patient elsewhere would not  
23 even be asked if she or he had children. In 2010 there was a change in health legislation to  
24 strengthen the rights of children as next of kin. The Norwegian Health Personnel Act (2010)  
25 placed a duty on health personnel to protect minor children as next of kin. The focus here is  
26 on providing the appropriate support that young children of parents with mental illnesses,  
27 drug addiction or severe physical illness or injury may need due to their parent's condition.  
28 Furthermore, health institutions covered by the Act must now have child support personnel  
29 with a responsibility for promoting and coordinating the support to be given by health  
30 personnel to these children. However, under the Norwegian Health Personnel Act, children  
31 who are siblings of a sick child and children who have lost a parent are excluded.  
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3 In Sweden, similar developments have taken place. The National Board on Health and  
4  
5 Welfare has a government assignment to improve the support for children as next of kin.  
6  
7 Similar to Norway, the Swedish legislation does not use the term 'young carer'. Since 2010,  
8  
9 health personnel have an obligation to respond to children's needs for information, advice and  
10  
11 support when parents or other adults in their household suffer from substance misuse,  
12  
13 psychiatric or severe illness, or die unexpectedly. This has not yet been fully delivered. The  
14  
15 implementation is an important part of the government's commitment to improve the support  
16  
17 for these children.  
18  
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#### 20 21 ***Level 4 Preliminary: Austria, Germany and New Zealand*** 22

23  
24 In Austria there is little awareness and recognition of young carers, a small research base and  
25  
26 very few dedicated services at local levels. The first and only young carers research study was  
27  
28 carried out by the Department of Nursing Science, University of Vienna on behalf of the  
29  
30 Austrian Federal Ministry of Labour, Social Affairs and Consumerism in 2012 (Nagl-Cupal et  
31  
32 al. 2012). There is growing public awareness of young carers through media attention, and  
33  
34 since 2009 young carers can – based on the Austrian Federal Care Allowance Legislation (§  
35  
36 21a) – receive government grants for compensation benefits. This provision (§ 21a) initially  
37  
38 addressed only adult carers but the Federal Ministry of Labour, Social Affairs and Consumer  
39  
40 Protection recently extended its remit to include young carers (BMASK, n.d.).  
41  
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43

44  
45 In contrast to a growing body of research on the situation of adult family caregivers, in  
46  
47 Germany little is known about the specific situations and needs of young carers. They are not  
48  
49 recognized as such, neither in the health or social sector, nor in education. Positive tendencies  
50  
51 indicate some growing interdisciplinary research collaborations of educational scientists,  
52  
53 doctors, psychologists, child and adolescent psychotherapists, public health professionals –  
54  
55 with a focus on the areas of absenteeism, drop-out and resilience (Kaiser and Schulze 2015).  
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3 New Zealand is similar to Austria and Germany, with only very limited research and service  
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5 provision at a local level (Carers New Zealand, n.d.).  
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8 ***Level 5 Emerging: including Italy, Netherlands, Switzerland and the United States***  
9

10 In spite of Italy being one of the European countries with a high proportion of informal carers  
11  
12 (Riedel and Kraus 2011) there is still little awareness and attention from policy makers and  
13  
14 practitioners to the needs of young carers. There is no distinction between younger and older  
15  
16 carers and hence a lack of attention to the specific group and needs of Italian young carers.  
17  
18 Some organizations as well as research projects address specific subgroups of young carers  
19  
20 (e.g. Boccaletti 2014; Farinella 2015). Nevertheless the current research base is  
21  
22 underdeveloped. Prevalence data on a national level, as well as any in-depth investigation of  
23  
24 the experiences, needs and outcomes of caring on children, are missing.  
25  
26

27  
28 The Netherlands, where young carers are called 'jonge mantelzorgers', has mainly focused on  
29  
30 the children of parents with mental problems of addiction (these children are called  
31  
32 'KOPP/KVO' – Kinderen van Ouders met Psychisch Problemen/Kinderen van Verslaafde  
33  
34 Ouders). Care professionals describe young informal carers as a group who warrant extra  
35  
36 attention (De Klerk et al. 2014). In 2016, a Dutch agenda on future informal care and support  
37  
38 was established, including some statements with regard to young carers. There are some  
39  
40 organizations offering special courses and support for young carers; schools, however, appear  
41  
42 to pay virtually no attention to this group (De Klerk et al. 2014, 5). Under the Law on  
43  
44 Domestic Violence and Child Abuse the use of the 'Kindcheck' (childcheck) is obligatory for  
45  
46 professionals in healthcare in contact with adults with serious mental or addiction problems to  
47  
48 assess the safety of children involved, and this should of course extend to young carers in  
49  
50 these situations.  
51  
52

53  
54 In Switzerland, it is the Young Carers Research Group led by first author, which initially  
55  
56 focused on young carers and is developing a body of research evidence. Since December  
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3 2014, young carers have found national attention in Swiss media and politics. The Swiss  
4  
5 Federal Council (2014a) described in its Action Plan different fields of action, which are  
6  
7 intended to improve the situation for all carers. As part of implementing the Action Plan  
8  
9 special attention is to be paid to the specific needs of young carers (Swiss Federal Council  
10  
11 2014b). NGOs such as Pro Infirmis and Cancer Care are sensitive to the issue, raising  
12  
13 awareness and investing in programs and information concerning young carers.  
14  
15

16  
17 Researchers and policy makers in the US have been very slow in engaging with the research  
18  
19 and policy agendas for young caregivers despite some early studies and an estimate of the  
20  
21 numbers nationally. Gates and Lackey in the US (1998) examined the impact of care giving  
22  
23 on young people looking after adults with cancer and chronic physical illness (Lackey and  
24  
25 Gates 2001), while Beach (1994, 1997) focused on the impact of family care giving on  
26  
27 children where a parent has Alzheimer's Type Dementia. Other small-scale studies (Bauman  
28  
29 and Draimin 2003; Shiffren and Kachorek 2003; Winton 2003; Siskowski 2004; Shifren  
30  
31 2009) add to the US research base on children's care giving experiences and outcomes. NGOs  
32  
33 such as the National MS Society and Cancer Care invested in programs and information  
34  
35 concerning young carers. In 2003, the United Hospital Fund (based in New York) brought  
36  
37 together these and other researchers, policy makers, former child caregivers and interested  
38  
39 parties, including researchers and policy makers from the UK, for the first US seminar  
40  
41 specifically on young caregivers. The discussion included preliminary plans for the research  
42  
43 on the extent of young caregiving in the US, which was published in 2005 at a second  
44  
45 seminar in Washington DC, again attended by policy makers and researchers from across the  
46  
47 US, UK and Australia. The research, published by the nationwide NGO, National Alliance for  
48  
49 Care giving (2005) provides the first estimate of the prevalence of young caregivers in the US  
50  
51 (1.3 - 1.4 million children). Those attending the 2005 conference hoped that this study would  
52  
53 provide the 'tipping point' from which services would be developed. It did not. To date, there  
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3 has been little attention paid to the particular needs of young carers in policy or service  
4  
5 responses. Like adult caregivers, young caregivers in the US have no specific legal rights.  
6  
7 Today there is still only one dedicated initiative that we are aware of in the US, the American  
8  
9 Association of Care giving Youth's (AACY) program, the Care giving Youth Project (CYP),  
10  
11 which works in partnership with the School District of Palm Beach (Barber and Siskowski  
12  
13 2008). In 2014, the Caregiving Youth Institute (CYI) was established by AACY, and since  
14  
15 2015 the Caregiving Youth Research Collaborative (CYRC) is a platform used by researchers  
16  
17 and professionals with the objective of developing projects as well as bringing together  
18  
19 research and practice for youth caregivers and their families. The mentioned report and  
20  
21 organizations use the term 'Youth Caregiver', to focus mainly on those carers under the age  
22  
23 of 18. However, in the US in general the term 'Young Caregiver' is used to cover caregivers  
24  
25 aged 18-40 years old. In the US, NGOs have played some role in funding research and in  
26  
27 increasing general awareness of young caregivers, but they have not had a national policy  
28  
29 breakthrough and their impact is limited, unlike NGOs in the UK and Australia. This lack of  
30  
31 'power' to influence, shape and deliver legal rights and service developments for young carers  
32  
33 in the US, combined with a small research base, leads to our categorization of the US as  
34  
35 'emerging', despite a larger research base than in some other countries which have  
36  
37 'overtaken' the US in terms of policy and practice.  
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42 So why is the most advanced capitalist society in the world at L5 in our classification? There  
43  
44 are a number of possible reasons. One explanation could be related to the nature of the US  
45  
46 'welfare system'. This offers some of the benefits of systems in other developed countries,  
47  
48 such as health insurance, pension, housing allowance and childcare. The difference to many  
49  
50 other countries (with welfare *states*, such as the UK) is that this protection remains partial and  
51  
52 individualised, and the distribution of 'welfare' (a term with negative associations in the US)  
53  
54 and support can create significant inequalities and stigma. In essence, the US welfare system,  
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3 unlike that in the UK, relies very heavily on private insurance-based benefits and services,  
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5 secured through personal or employer contributions, and often provided by 'for profit'  
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7 companies rather than by government as a Collective Good. Government provided welfare  
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9 especially can often be stigmatising and lower quality. Thus, young carers in the US have few  
10  
11 options to seek or receive good quality public services and support. Additionally, the nation's  
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13 poverty rate rose past 15% (46 million) in 2010 (U.S. Census Bureau), which is the highest  
14  
15 level since 1993. Research evidence suggests that there is a relationship between financial  
16  
17 resources, *and*/or the absence of adequate professional support services, *and* children's  
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19 greater participation in care giving (Becker 2007; Becker, Aldridge, and Dearden 1998;  
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21 Dearden and Becker 2000; Laird 2005; Price 2006; Robson et al. 2006). A further reason for  
22  
23 the slow progress in recognising young carers as a distinct social group in the US is the  
24  
25 country's (negative) attitude to children's rights and participation. The US is one of the very  
26  
27 few countries in the world that does not endorse the UN Convention on the Rights of the  
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29 Child.  
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### 33 34 ***Level 6 Awakening: including Greece, Finland, the United Arab Emirates and France***

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36 In Greece there is a general lack of specific policies that support family carers. The  
37  
38 organisations and the programmes which support carers are limited and they usually focus on  
39  
40 the carers of elderly people. Research about caring children and adolescents in Greece is  
41  
42 almost non-existent. Given austerity and the imposed financial settlement on Greece  
43  
44 regarding loans and debts, it is perhaps not surprising that the interventions of the State in  
45  
46 some key social policy areas are practically absent. In the current economic climate the few  
47  
48 existing NGO activities are not adequate to cover the needs of young (and adult) carers.  
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52 France, the United Arab Emirates and Finland are also only now just 'awakening' in terms of  
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54 awareness of young carers. There are still no specific policies for young carers in these  
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56 countries. In Finland the starting point for research seems to be 2016, with funding for the  
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3 Central Association of Carers (2016-2018) with the aim of mapping out the situation of young  
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5 carers (Eurocarers, n.d.).  
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## 7 8 **Conclusions**

9  
10 ~~It appears that the existence of a robust country-specific research evidence base provides an~~  
11 ~~important foundation for policy developments and service responses. The more developed and~~  
12 ~~country-specific the research is, the more advanced is the policy and legal framework. This~~  
13 ~~suggests, with regard to young carers at least, that policy makers prefer to have a home-grown~~  
14 ~~research evidence base to inform their local and national decisions rather than drawing or~~  
15 ~~relying on research from other countries, even when research findings are or are likely to be~~  
16 ~~similar. However, having a reliable research evidence base, whilst a necessary precondition~~  
17 ~~for policy development, is not sufficient by itself to bring about change, as the case of the~~  
18 ~~United States shows clearly. Other factors are important in the development of national policy~~  
19 ~~and policy transfer across countries. Non-Governmental Organizations, as we have seen, have~~  
20 ~~played a key role in countries where there is a stronger awareness of young carers. These~~  
21 ~~NGOs, especially in the UK and Australia, have also played a strategic role in steering and~~  
22 ~~shaping public discourse and policy developments. Some have influenced the legal~~  
23 ~~framework in their country. The key people associated with these organizations and the~~  
24 ~~organizations themselves, have met at international conferences and events and have shared~~  
25 ~~ideas and research, facilitating policy development and practice transfer.~~  
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29 We have shown that there is a range of different responses to the issue of young carers across  
30 different countries. This varies from support for the young people in policy and legislation  
31 through to a total lack of recognition and no support. The question is, therefore, what drives  
32 policy and legal change? What are the causative factors? In the UK and Australia, where  
33 support for young carers is the most developed, non-governmental organizations (NGOs)  
34 have played a key role in raising awareness and campaigning for change. They have also  
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3 played a strategic role in steering and shaping public discourse and policy developments  
4 through engaging with policy makers and politicians. In order for them to be able to carry out  
5 this role, they have drawn upon research findings that are specific to their countries.

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9 We suggest that the presence of a champion organisation or individuals which can draw upon  
10 a reliable and country-specific evidence base are the drivers of policy and legal change. It is  
11 worth noting that the academics who have produced the research findings have also  
12 championed the cause of young carers. They have not simply published their work and relied  
13 on others to interpret and make use of them.

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23 The existence of a robust country-specific research evidence base provides an important  
24 foundation for policy developments and service responses. Policy makers may prefer to have  
25 a home-grown research evidence base to inform their local and national decisions rather than  
26 drawing or relying on research from other countries, even when research findings are or are  
27 likely to be similar. The more developed and country-specific the research is, the more  
28 advanced the policy and legal frameworks appear to be. Having the research evidence is not  
29 sufficient by itself to bring about change, as the case of the United States clearly shows.

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41 Whilst country-specific research is important, the exchange of ideas and experiences between  
42 countries enables such research to be conducted. Academics and key individuals from the  
43 NGOs have created an ‘international community of research and practice’. They have met at  
44 conferences and events, and through these and other networks have shared ideas and research,  
45 facilitating policy development and practice transfer. Knowledge and ideas generated in one  
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country, and models of best practice, have been transferred across some geographical  
boundaries and welfare systems. For example, a ‘whole family approach’ (Frank and Slatcher  
2009) is becoming the dominant paradigm in some of the countries now developing specific

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3 services for young carers and their families - the model originating in the UK. The Australian  
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5 approach to including young carers up to the age of 24 in their definition and service delivery  
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7 has informed the development in the UK of new research, policy and services for young adult  
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9 carers aged 18-24 (Becker and Becker 2008). Additionally, validated psychometric  
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11 instruments developed in the UK (Joseph et al. 2009; Joseph, Becker, and Becker 2012) to  
12  
13 measure and assess the nature and extent of caring amongst children, and the impacts, are  
14  
15 now being used in a dozen countries, including Norway, Sweden, Switzerland, USA and  
16  
17 Australia. These tools enable policy makers and practitioners working with young carers to  
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19 identify and assess young carers and, over time, will enable cross-national research and  
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21 comparisons. As the transfer of knowledge and policy increases between countries and over  
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23 time, so the classification presented here, will also need updating, as will the analysis of the  
24  
25 factors that have influenced these developments.  
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### 31 **Authors Confirmation**

32 The authors confirm that the text is original and has not been published or submitted  
33  
34 elsewhere.

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37  
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39  
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For Peer Review Only

## Figures

Levels 1-7	Characteristics	Country Example
1 <b>Incorporated / Sustainable</b>	<ul style="list-style-type: none"> <li>▪ Extensive awareness at all levels of government and society of the experiences and needs of young carers</li> <li>▪ Sustained and sustainable policies and interventions aimed at meeting young carers' needs and promoting their health, well-being and development</li> <li>▪ Responses and law built on a foundation of reliable research evidence and clear legal rights</li> </ul>	None
2 <b>Advanced</b>	<ul style="list-style-type: none"> <li>▪ Widespread awareness and recognition of young carers amongst public, policy makers and professionals</li> <li>▪ Extensive and reliable research base, and growing</li> <li>▪ Specific legal rights (national)</li> <li>▪ Extensive codes and guidance for welfare professionals and national and local strategies</li> <li>▪ Multiple dedicated services and interventions nationwide</li> </ul>	United Kingdom
3 <b>Intermediate</b>	<ul style="list-style-type: none"> <li>▪ Some awareness and recognition of young carers among public, policy makers and professionals</li> <li>▪ Medium-sized research base, and growing</li> <li>▪ Partial rights in some regions</li> <li>▪ Small but developing body of professional guidance</li> <li>▪ Some dedicated services and interventions, mostly local but a few nationwide</li> </ul>	Australia Norway Sweden
4 <b>Preliminary</b>	<ul style="list-style-type: none"> <li>▪ Little public or specialist awareness and recognition of young carers</li> <li>▪ Limited research base, but growing</li> <li>▪ No specific legal rights but other laws may be applicable or relevant</li> <li>▪ Few, if any, dedicated services or interventions at national or local levels</li> </ul>	Austria Germany New Zealand

<p>5 <b>Emerging</b></p>	<ul style="list-style-type: none"> <li>▪ Growing public or specialist awareness and recognition of young carers</li> <li>▪ Small but growing research base</li> <li>▪ No specific legal rights but other laws may be applicable or relevant</li> <li>▪ No specific services or interventions for young carers, but other services might be applicable</li> </ul>	<p>Belgium Ireland Italy Sub-Saharan Africa Switzerland The Netherlands United States</p>
<p>6 <b>Awakening</b></p>	<ul style="list-style-type: none"> <li>▪ Embryonic awareness of young carers as a distinct social group within the «vulnerable children» population</li> </ul>	<p>Greece Finland United Arab Emirates France</p>
<p>7 <b>No response</b></p>	<ul style="list-style-type: none"> <li>▪ No apparent awareness or policy response to young carers as a distinct social group</li> </ul>	<p>All other countries</p>

Figure 1 Classification of in-country awareness and policy responses to 'young carers'