



**Observatory for
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Young Carers

Support measures in Austria, the United Kingdom and Ireland

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Summary:

Young carers are defined as minor children and adolescents who regularly care for chronically ill family members. Two to four percent of all minors in western countries are considered so-called Young Carers. This expertise provides an overview of the situation of Young Carers and describes existing support measures in Austria, the United Kingdom and Ireland.

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1 Introduction

In Germany, about five percent of 12- to 17-year-olds regularly assume care tasks in their families. This means that there are some 230,000 children and adolescents who are significantly involved in caring for relatives. In comparison: international studies indicate that about two to four percent of all minors in Western countries are Young Carers. The welfare-state systems in the countries have no influence on these statistics. Young Carers are defined as minor children and adolescents who support, care for chronically ill family members on a regular basis. Their tasks can vary from caring for younger siblings, doing household work, preparing food and feeding, or helping with personal hygiene, and they may also include medical activities.

In June 2016, the German Centre for Quality in Care (*Zentrum für Qualität in der Pflege, ZQP*) conducted a survey among 12- to 17-year-olds in Germany in order to determine the needs of young caregivers. Young people were asked, for instance, about their experiences with need for care within their families, how they feel about their situation and what support they would like to have. More than half of the Young Carers admitted that they felt burdened by the care. Asked about possible support, 24 percent of the respondents said they would like to have a helpline (ZQP 2016).

For support measures to be developed and offered, society must gain a growing awareness around the topic, and the taboos must be dissolved. Family-oriented approaches and help concepts should cover the following points: assistance for the person in need of care, organisation of help via one-stop contact points, information, counselling, and time off from care.

The present expertise begins with a brief overview of the situation of Young Carers in Austria, the United Kingdom and Ireland. A few support measures for Young Carers in the countries involved will then be described. New and interesting support measures found in the course of the research will also be presented.

2 The situation of Young Carers in Austria

A study entitled *Children and adolescents as informal carers – insight into their situation, and possibilities of support* (Kinder und Jugendliche als pflegende Angehörige – Einblick in die Situation Betroffener und Möglichkeiten der Unterstützung), which was commissioned in 2011 by the Austrian Federal Ministry of Labour, Social Affairs and Consumer Protection (BMASK), provided the first well-founded figures for Austria. This scientific study revealed that 3.5 percent of children and adolescents in Austria have some form of care tasks. This corresponds to 42,700 children and adolescents. These Young Carers range in age from five to 18 years, and their average age is 12.5 years. Seventy percent of them are girls. The study attracted significant public interest and was discussed throughout Austria (Nagl-Cupal et al. 2015a).

On the basis of the results of this study, the BMASK commissioned a research project to develop concepts and design family-oriented support measures for Young Carers. The commission is pursued in Part 2 of a study entitled *Concept development and planning of family-oriented support measures for children and adolescents as informal carers*. This part of the project deals with the general recommendation that family-oriented measures and dis-burdening offers are a central point for improving the situation of Young Carers. An essential requirement is to ensure that Young Carers can experience everyday life without illness and care and have access to leisure activities (Nagl-Cupal et al. 2015b).

In Austria, financial support to cover the cost of substitute care (Section 21a of the Federal Care Benefits Act) is also available to Young Carers.¹ However, no further legal arrangements exist to date.

The following sections will describe two measures that offer help and support to Young Carers in Austria.

2.1 “Superhands Austria”

Young Carers in Austria can get help and advice from the [superhands](#) online platform. The project was initiated in 2012 by the Austrian Johanniter organisation. It is the first measure in Austria that is designed specifically for the target group of Young Carers.

The basic goals of superhands are to provide information and offer help and support. The platform offers a variety of information on legal issues and on diseases, practical suggestions for everyday life and for emergencies, and tips for recreational activities. The platform was developed in cooperation with young people. It also operates an anonymous free helpline and an online advisory service. In addition, Young Carers can get help and support anonymously via e-mail. The telephone helpline is open on Mondays and Thursdays from 3 p.m. to 5 p.m.

Through public relations (PR) efforts, the project also hopes to draw the attention of other groups – in particular, relevant occupational groups such as teachers, social workers and family physicians. The goal of this PR outreach is to ensure that Young Carers are identified more often and more quickly so that they can be offered support.

According to the director of superhands, reaching this target group and making them accept external help presents a great challenge. Helpful starting points are the media preferred by young people, for instance Facebook and Twitter.

2.2 “147 Rat auf Draht”

[Rat auf Draht](#) (roughly translated as “advice by wire”) is a helpline for children, adolescents and their families. Children and adolescents can dial 147 to get help and support, or they can

¹ The Federal Office for Social Affairs and Disabilities is responsible for these benefits.

access the service in a chat forum or through an online counselling service. However, this project targets all children and adolescents and their families, not specifically Young Carers. It offers help and tips on a wide range of topics. Among these, the topic of Young Carers is listed under the menu point [Pflegst du jemanden](#) (“Are you caring for someone”). The text directly addresses Young Carers and shows that they are not alone in their situation. It also explains that caring for another person is a difficult task, and that children and adolescents in such situations have a right to support and to satisfy their own needs.

Rat auf Draht operates its helpline around the clock. The chat option is available Mondays, Wednesdays and Fridays from 3:30 p.m. to 5:30 p.m. The online counselling service answers inquiries within a few days.

In addition to these options, *Rat auf Draht* also uses Instagram, Facebook and WhatsApp as platforms.

3 The situation of Young Carers in the United Kingdom²

Young Carers first came to public attention in the United Kingdom in the 1980s. There is a broad awareness of the Young Carers issue in the general public as well as among professionals and decision-makers.

The 2011 census³ estimates that in England and Wales there are approximately 178,000 Young Carers ranging in age from five to seventeen. About 80 percent of these Young Carers do between one and twenty hours of unpaid care a week. For England, this represents a 19 percent increase in comparison to the results of Census 2011.⁴

In 2013, a legal framework was created in the UK that gives Young Carers and their families the right to an *assessment* in order to determine their individual needs and their legal entitlement to assistance. The aim of these legislative changes was to simplify access to assistance and provide a better link between support services for sick family members and the young people caring for them. The various arrangements are laid down in the “Children Act”, the “Care Act 2014”⁵ and the “Community Care Act”.

Below are two support services designed for Young Carers in the United Kingdom.

2 The United Kingdom (UK) consists of England, Wales, Scotland and Northern Ireland.

3 The United Kingdom carries out censuses every ten years.

4 A summary of the 2011 census data on unpaid care provided by 5-17 year olds in England and Wales can be found at: <http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html>.

5 The “Care Act 2014” is available at: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>.

3.1 “Carers Trust”

Carers Trust is one of the largest interest groups in the United Kingdom. Between 2015 and the spring of 2017, it offered, among other things, special support services for Young Carers. These services included three online communities: “Babble and Matter”, and the “Carers Space Online Community”. The target group of the Babble platform was children and adolescents up to 18 years. Matter, on the other hand, addressed adolescents and young adult informal carers up to the age of 25. Between 2015 and April 2017, Young Carers were able to chat on these online platforms, post questions online and receive responses from an online counselling team. They could also share their experiences in forums with other young people living in similar situations. If needed, they could be helped in finding local contacts and services. The platform staff observed on the one hand that answers and advice from other young people are often more important than professional support. On the other hand, it also became clear that young people can be easily reached via social media because, having grown with these options, they are well versed in their use.

The Carers Trust online support project was discontinued for financial reasons on 12 April 2017. Users are referred to the [Carers UK](#) website, which offers a forum for informal carers (not necessarily Young Carers) and a telephone helpline, as well as to other services.

3.2 “Childline, on the phone, anytime”

[Childline](#) offers counselling and support for all children on a variety of topics including bullying, depression, suicidal thoughts, stress at school, forced marriage and problems with parents. The topic of [Young Carers](#) is also explicitly named. For assistance, young people can call, write an e-mail or chat online. Young people can call 24 hours a day, even if there is no credit on their mobile phones. The online chat counselling service is also available 24 hours a day, seven days a week. Appointments to chat with a counsellor can be booked between 5 p.m. and 7 p.m. from Wednesday to Friday. Childline is a service operated under the umbrella of the NSPCC⁶, an organisation dedicated to children and the prevention of cruelty.

Other providers of services for young people in the UK who are not specialised in caring:

- The [Samaritans](#) offer a 24-hour helpline for young people and the option of contacting counsellors by e-mail. Their slogan is “Whatever you are going through, call us free any time”.
- [Kooth](#) offers online support with individual counselling for young people on all questions and problems.

6 National Society for the Prevention of Cruelty to Children, UK.

4 The situation of Young Carers in Ireland

In October 2010, a first national qualitative study was published on young carers in Ireland: *Study of Young Carers in the Irish Population*. This study was commissioned by the Ministry of Children and Youth Affairs and run by the National University of Ireland⁷. In order to obtain accurate data and find out more about Young Carers and their needs, the authors of the study recommended, among other suggestions, that censuses should include a question about whether there is a Young Carer in the household (Office of the Minister for Children and Youth Affairs 2010). Ireland conducts a census every five years. The issue of Young Carers was also considered in the current census (2016).⁸ However, the data from the 2016 census have not yet been fully evaluated. The data for profile 9 – “Health, Disability and Carers” – are due to be published on 2 November 2017 (Census 2016).

Data from the 2011 census show the following figures for children and adolescents with care tasks (cf. National Carers’ Strategy 2012: 7):

- 4,244 Young Carers between the ages of 15 and 19
- 4,228 Young Carers under the age of 15
- 1,838 Young Carers under the age of 10

Young carers in Ireland currently have no specific legal entitlements. However, the topic has been receiving increasing attention among the general public and decision-makers in recent years.

For example, a national strategy for carers was initiated in 2012. This *National Carers’ Strategy*⁹ sets goals and lists pertinent actions to address different priorities, including Young Carers. Sub-objective 2.2 lists four measures to support Young Carers and to protect them against the negative impact of care (National Carers’ Strategy 2012).

In addition to the Carers’ Strategy, Ireland has also put in place a national policy framework for children and young people for the years 2014 to 2020¹⁰. It states that the government has recognised that children and adolescents may experience difficulties in their social networks and in maintaining friendships because of the care responsibilities and tasks they assume within the family.

7 Child and Family Research Centre at the National University of Ireland, Galway.

8 Detailed information on Young Carers in the 2016 census: <http://census.ie/and-communities/young-carers/>.

9 <http://health.gov.ie/wp-content/uploads/2016/02/National-Carers-Strategy.pdf>.

10 https://www.dcy.gov.ie/documents/cypp_framework/BetterOutcomesBetterFutureReport.pdf.

4.1 “Young Carers”

[Young Carers](#), which has existed since 2012, offers a telephone helpline, an online platform and membership in a community. Users can call or communicate a request via a contact form¹¹. To join the community, new members must provide a lot of personal information. They are also informed that the provider of “Young Carers” must speak with the parent or legal guardian of under-18 users in order for them to complete their registration. Once they are members, children and adolescents have access to a wide range of services, including a quarterly newsletter, information on events, training courses, competitions, and Young Carer groups in their area. The phone number is displayed prominently on the website together with the inviting slogan “Want to talk?” Information about when and how often the phone is reachable is not available.

“Young Carers” offers young informal carers help in finding suitable support options. The website also lists numerous other contacts and references to helpful information and support. Moreover, “Young Carers” advertise on Facebook, Twitter and Instagram.

Another service is “Childline”:

- Like in the UK, [Childline](#) offers a 24-hour, seven-day-a-week helpline for all children and adolescents. In addition to telephone counselling, users can chat with counsellors online or communicate by text messages. These two services are available every day from 10 a.m. to 4 p.m. The service does not mention Young Carers explicitly.

¹¹ The contact form is not particularly low-threshold, as many questions are asked (including address, phone number, date of birth, etc.).

5 General recommendations for effective support

The following conclusions on how to provide effective support for Young Carers – especially telephone helplines – can be drawn from the measures described, from telephone conversations with experts and from professional literature on the subject.

5.1 Target group

Young Carers are often described as a single target group. However, experts think it may be useful to address them in two separate groups. They recommend treating children (up to 12 years) as one group and adolescents (from 13 onwards) as the other. Another option is to approach young adults (18 and over) who had care tasks as children or adolescents. These young people would be in a better position to reflect and talk about their role as caregivers.

Most of the measures described in this expertise do not divide their target group. Offering only one service is more cost-effective, so that approaching target groups separately can therefore also be a question of what resources are available.

5.2 Availability

Some of the support measures described provide helplines that are available 24 hours a day, seven days a week. This is the ideal arrangement, as the need to talk and seek support does not depend on a particular time of day. Besides, school attendance means that late afternoons, early evenings and weekends are the most recommended times.

5.3 Public relations

Many experts believe that PR work is especially important. The goal of public relations is not only to reach the Young Carers themselves but also to create an awareness of the issue in society at large as well as among those who are directly concerned.

Large-scale campaigns, appeals and leaflets are outreach efforts that get the attention of families and professionals who are in contact with Young Carers (including teachers and social workers). The following measures and PR tools are used: advertising in public transport and on the radio, campaigns in schools, teaching materials and units for schools and in care training. Platforms like Instagram and Facebook are also used.

Experts say that it is important to ensure that the pertinent sites are found easily with popular search engines. According to the initiators, time must be invested continuously to increase the reach and create new, high-quality content.

Online support should be well networked with local offerings: for example, local counselling services and online services can promote each other. The goal here is to increase awareness of the situation of Young Carers so that they can be identified and offered support.

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