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Limiting and enabling the caring role: Young Carers and Young Adult Carers in Upper Austria

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Introduction

Young carers and young adult carers are children, adolescents and young adults who look after or care for a person living in their environment with a long-term illness, a disability or age-related complaints. Based on current research results¹, this policy brief addresses the question of how young carers and young adults in Upper Austria can be supported and unburdened. A special focus is on the areas of career orientation, training, education and career entry. On the basis of partial surveys in Austria and England, depending on the question asked in the survey, the share of young (adult) carers is between 9% and 18.6% in this age group (16-29 years). According to this, it can be assumed that in Upper Austria alone between 21,662 and 44,791 persons² are affected. The measures proposed in the following are not only relevant for Upper Austria, but should also be implemented throughout Austria.

Many young (adult) carers are not aware of their role as carers and/or are not perceived as carers by outsiders. In reality, this role often includes a wide range of tasks (e.g. caring, emotional support, help in the household) and it can sometimes take a lot of time. While the activities are similar to those of other carers, young (adult) carers often find themselves in a special (dependency) situation, especially because of their age: they are less able to get help, have few possibilities to set limits for their caring role and take on a lot of responsibility in their close environment, which is not typical for their age.

The caring role of young (adult) carers is usually accompanied by temporal, physical and emotional burdens and can also affect essential areas of life such as education, career, personal development, leisure time, friendships, mental and physical health

¹ The results presented here were produced in the project 'Young Carers and Young Adult Carers in Upper Austria. Status Quo, Fields of Action and Approaches', which was carried out between February and July 2023 at the European Centre for Welfare Policy and Social Research with the support of the Chamber of Labour Upper Austria (Kadi et al., 2023). We are grateful to Leonard Geyer and Felix Wohlgemuth for comments and thank Amalia Solymosi for proof-reading, layout and translation.

² These figures are based on surveys on informal care in the framework of the European Social Survey and the UK Household Longitudinal Study as well as an age group-specific conversion to the population in Upper Austria (for more specific information on the data used as well as the procedure for the conversion to Upper Austria see Kadi et al., 2023).

as well as financial resources. Although young (adult) caring can go hand in hand with restrictions of basic needs, there is currently little awareness of the topic in Austria. In international analyses, the situation in Austria was assessed as being in the early stages, and thus, in need of further development (Leu et al., 2022). In particular, specific support measures are lacking for the age group 16-29 and the area of career orientation, training, education and career entry. In other countries, however, there are already several relevant initiatives in this context that can serve as orientation for the development of support services in (Upper) Austria³.

Support services for young (adult) carers – status quo and further development

Identification, sensitisation and awareness raising

Few people are aware of the phenomenon of young (adult) caring, and even those affected themselves or people in their close environment are often unaware that they are taking on caregiving tasks not typical for their age. However, a fundamental prerequisite for supporting caring children, adolescents and young adults is that those affected perceive themselves as such or are identified as such. Only if the situation of young (adult) carers is recognised and perceived accordingly, is it possible to make use of support services or to refer them to such services. A fundamental condition for better support of young (adult) carers is, therefore, the implementation of measures for general awareness raising, sensitisation of relevant professional groups and systematic identification.

General information campaigns can improve awareness and knowledge about young (adult) carers among the population. Existing examples in Austria are the national campaigns around the *Young Carers Austria App* (https://www.young-carers-austria.at/) of the Federal Ministry of Social Affairs, Health, Care and Consumer Protection and the national action day "Caring Children and Adolescents" of the *IG Pflegende Angehörige* (an interest group for informal caregivers). However, the existing initiatives have not yet achieved any significant reach. An international example of raising awareness and supporting young (adult) carers is the Carer Passport from the UK (Carers UK, 2023). This is a document issued by organisations such as educational institutions, companies or municipalities, with which young (adult) carers can "identify" themselves within these organisations. The passport automatical-

³ The policy measures presented in the following – both existing measures in (Upper) Austria and international examples of support services – were collected within the framework of the above-mentioned project on the basis of an internet search and the existing scientific literature. The recommendations for the development of measures are based on a comparison between existing offers and current support needs. The needs of young (adult) carers were assessed through 16 qualitative interviews with young (adult) carers and experts.

ly gives them access to certain benefits (e.g. vouchers) and other forms of support, such as more flexibility in education or at work. Through this institutionalised form of support, young (adult) carers do not have to tell their situation to superiors or every teacher and are not dependent on the goodwill of individuals.

General awareness raising and sensitisation of relevant professional groups are needed to better reach and support young (adult) carers Raising awareness of the issue of young (adult) caring among professional groups that deal with children, adolescents and young adults is another important aspect in order to identify those affected and to be able to offer appropriate support. There are already individual training offers in Austria, but there is a need for a nationwide sensitisation of professions in the areas of education, health and care. This could be implemented, for example, by integrating the topic of young (adult) carers into the respective training and curricula. Successful sensitisation of the aforementioned professional groups can contribute to the recognition of young (adult) carers – even if those affected do not perceive themselves as such.

The sensitisation of professional groups that potentially come into contact with young (adult) carers is, thus, a necessary prerequisite for support on site, for referral, and finally, also for their systematic identification. The latter is currently left to chance both in Upper Austria and at the federal level. However, international examples show that a number of actors can contribute to their identification (Leu et al., 2022). In England, it was already anchored in the law in 2014 that municipalities must take an active role in identifying young carers. Another example is the establishment of a designated person for children of ill parents in Norwegian health facilities (Skogøy et al., 2018). These persons have the task of identifying underage children with ill relatives and organising support. (Upper) Austria could follow suit and promote the simultaneous development of identification measures and the implementation of initiatives to provide concrete support for young (adult) carers in various areas (e.g. health, school, career, finances).

Vocational orientation, training, education and career entry

Schools and educational institutions play a central role in the (self-)identification of young (adult) carers. Children, adolescents and young adults themselves can be reached through awareness-raising measures, which also contribute to self-identification, mainly via educational institutions. An example of an existing measure at schools is the *Young Carers Infobox* with learning materials of the Austrian Youth Red Cross, through which knowledge about caring for relatives is conveyed.

Furthermore, as already mentioned, teachers can play a central role in identifying young (adult) carers. For a direct support of young (adult) carers on site, the expansion of school social work and school psychology and the implementation of these in all educational institutions can be helpful.

Specific offers in connection with education, training and work can reduce multiple burdens of young (adult) carers However, educational institutions and teachers are also faced with the challenge of how to deal with the young (adult) caring phenomenon when the caring role has a negative impact on the performance of those concerned and possibly leads to dropping out of school or training. To support young (adult) carers in this context, recommendations have been made in the UK to make learning conditions in educational institutions more flexible, regarding, for instance, attendance or deadlines for handing in homework (Carers Trust & NIACE, 2015). However, on the one hand, it is important to keep in mind the age group and the type of school or training. On the other hand, flexibility should only ever be provided as one of several types of support. During studies, the extension of existing regulations for students with children (e.g. extension of the standard period of study and corresponding claims to financial support) should be applied to young (adult) carers. Another example of financial support in the context of education is the Young Carer Bursary (Young Carers Network, 2023), a bursary for young (adult) carers aged 12 to 25 in Australia (https://youngcarersnetwork.com.au/bursary/ young-carer-bursary/).

Within the framework of the empirical study on needs and preferences, young (adult) carers as well as experts also suggested training- and work-related coaching measures. Examples of this are individual coaching for affected apprentices and the extension of individual coaching within the framework of compulsory education until 18 (BMBWF, 2023). Finally, training institutions could address the specific needs of young (adult) carers in the context of counselling on future educational and career paths. In the context of career guidance, training, education and career entry, it should be ensured that young (adult) carers have, as far as possible, similar opportunities for personal and professional development as all other adolescents and young adults. This means that the caring role – as far as possible – is not adopted as a starting point to make decisions on education and career. Rather, the latter should serve as a basis and starting point for adjusting the caregiving role accordingly.

Further individual support measures

Further general measures on an individual level include psychological support, counselling incl. peer counselling, relief measures and sponsorships. This enables young (adult) carers to talk to people who are not directly involved in their lives or to other people affected, to reflect on their own caring role and, if necessary, to reduce it. In addition, support services can provide knowledge and skills for caregiving and inform about access to financial support and other services.

Currently, there are only a few measures available for young (adult) carers in (Upper) Austria that have been specially developed for this group. However, there are some

Expand psychosocial services and promote peer exchange between young (adult) carers disease-specific services for children, adolescents and young adults with ill family members (e.g. counselling, self-help groups, recreational services). While these are important, it is worth mentioning here that due to the focus on certain diseases, age-specific restrictions, regional differences in the offer and project-based funding, only certain groups of young (adult) carers can be reached with these.

In addition, young (adult) carers also have access to general support measures of child and youth welfare and social work (e.g. telephone hotlines). Young (adult) carers can benefit from such services, but in order to ensure better individual support, target group-specific services are needed. In addition to establishing specific support measures, this includes the strengthening and focusing of youth social work as well as the expansion of affordable psychotherapy places for all young people who bear a considerable amount of care responsibility.

General considerations: Limiting and enabling the caring role

Measures should, on the one hand, support the reduction of the caring role, but on the other hand, enable it Support measures for young (adult) carers are always in a field of tension between limiting and enabling the caring role, which in many cases can also be desired and can have positive implications. It is, therefore, important that children, adolescents and young adults are offered opportunities to adapt the caring role to their own needs in a way that reduces adverse consequences for different areas of their lives. However, the caring role cannot usually be arbitrarily restricted, especially since young people also have a right to the close (family) relationships within which they fulfil the caring role. Emotional stress associated with life-threatening illnesses or addictions of close relatives, for example, are difficult to avoid. However, counselling, coaching and therapeutic offers can also be relieving in such complex situations. A major finding of the study we conducted on young (adult) carers was that those affected often feel abandoned in their caring role. Therefore, such individual support measures are of great importance.

Conclusions for policymakers

In summary, the (further) development and implementation of support for young (adult) carers should focus on the following aspects:

 Expansion of professional services for care and support: Caring children, adolescents and young adults are often overwhelmed because they do not know about professional services, these are not accessible for other reasons, or not available.



- Improving the data throughout Austria: More research on young (adult) carers in Austria would create a basis for better understanding the phenomenon and its impact on different areas of life and on young people's biographies.
- Political and administrative institutionalisation: Responsibilities for general awareness raising, identification and support of young (adult) carers should be integrated into existing and newly created structures.
- Offers of counselling and guidance: Support offers should be available throughout the country, consistently and for different age groups. In the field of education and training, school social work and youth coaching as well as own offers in vocational training could deal with the topic of young caring in a situation-specific way.
- Involving young (adult) carers and other key stakeholders: Support measures should be developed with the involvement of young (adult) carers themselves and across different policy fields such as youth, care, education and labour market.
- Valuing young (adult) carers: Unpaid care work contributes to maintaining social and economic cohesion. However, it often imposes burdens on individuals that require solidarity-based support. Young (adult) carers are in a similar situation to other carers – but they are less able to get help or set their own boundaries. At the same time, taking on the role of carer can have long-term consequences for training, education and employment, which is why young (adult) carers need special appreciation and support.



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