

## Eurocarers' Policy Paper on Young Carers

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# Eurocarers' Policy Paper on Young Carers\*

by Eurocarers – European Association Working for Carers

**Abstract:** *Demographic ageing in Europe is leading to an increasing need for care and a serious challenge for the sustainability of our social and healthcare systems. Informal carers across the EU currently provide over 80 per cent of all care. If not adequately supported, caring can have many difficult consequences for carers. Carers should not be socially and economically penalised as a result of their caregiving activities. Measures designed to support them should therefore aim to recognise them and their vital role in society, provide them with the essential information and counselling they need, give them access to allowances that offset the costs they face and truly values their contribution, develop flexible working arrangements and care leave schemes to allow them to maintain an active life, and improve the provision of equitable and accessible formal care services to ensure carers can rely on professional alternatives to informal care. This policy paper outlines the unique challenges faced by young carers and underscores the significance of addressing them. It briefly discusses different forms of support measures and makes recommendations for better support for Young Carers.*

**Keywords:** *young carers; adolescent young carer; policy paper; informal care; family care*

## Introduction

Europe's demographic ageing gives rise to a growing prevalence of age-related diseases, a growing demand for care, and a serious sustainability challenge for our social and health-care systems. Against this backdrop, community care [1] has become a prominent EU priority in the last few years and the shift towards home-based care is seen as a practical measure to contain the costs of services while also seconding widespread preferences among the elderly for being cared for in their own home.

Informal carers across the EU currently provide over 80% of all care, with women providing approximately two thirds of care, mainly as daughters (in law) and wives/partners. Even in countries with a well-developed supply of formal long-term care, using narrow definitions of informal carers, their number is estimated to be at least twice as big as the formal care workforce. Advances in medicine also mean that carers find themselves having to deliver more and more sophisticated levels of care, with very little training and minimal support. Caring can have – if not adequately supported – many challenging consequences for the (physical and mental) health and well-being of carers, their capacity to balance paid work with care responsibilities, their financial situation, their social integration as well as their access to employment and education.

We strongly believe that people should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose who they wish to be their carers. Carers should not be socially and economically penalised as a result of their caregiving activities. Measures designed to support them should therefore aim to recognise them and their vital role in society; provide them with the essential information and counselling they

need; give them access to allowances that offset the costs they face and truly values their contribution; develop flexible working arrangements and care leave schemes to allow them to maintain an active life; and improve the provision of equitable, accessible and good quality formal care services to ensure carers can rely on professional alternatives to informal care.

## Background

### *Definition of young carers and young adult carers*

Young carers are “children and young persons under 18 who provide or intend to 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 other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision”.

Young adult carers are people aged 18-24 who provide or intend to provide care, assistance, or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child, or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support, or supervision [2].

When young carers are mentioned, young adult carers are generally also meant, unless the context indicates otherwise or the publication is with limited data relating only to young carers.

Young carers and young-adult carers may undertake a wide range of caring responsibilities including practical tasks (such as cooking, housework, and shopping); physical and personal care (such as helping someone out of bed or helping someone dress); emotional support and supervision; managing the family budget and collecting prescriptions; helping to give medicine; or helping someone communicate. Being a young (adult) carer can have a big impact on different aspects that are important to growing up. It can affect a young person's health, social life, and self-confidence – over 45% report that they have experienced a mental health problem. Many struggle to manage their education, working life and caring role, which can cause pressure and stress [3].

Very often families view caring as an extension of family or personal relations rather than as a distinct type of ‘care giving’. Research has shown that in a situation where a young person may be caring for someone who has mental ill-health or who misuses drugs or alcohol, they are less likely to be identified as having caring responsibility within the family. This contributes to the self-awareness issue, meaning that children and young people themselves might not be aware of being carers.

Although there is currently very limited data regarding the number of young (adult) carers across Europe, some national statistics and pilot projects have helped to unveil a substantial – and yet largely unknown – population group. The 2011 Census in the UK, which included an unpaid care question, allowed to collect

statistics about ‘young carers’, i.e. children and young people aged 5 to 17 who provide unpaid care for family members, friends, neighbours or others because of long-term physical or mental ill-health, disability, or problems relating to old age. In 2011, there were 177,918 young unpaid carers in England and Wales. Of these, 54% were girls and 46% were boys.

An increase in the number of unpaid carers aged 5 to 17 was observed in all regions between 2001 and 2011. In England and Wales combined, the number of young unpaid carers increased by almost 19% during this period.

In Ireland, the 2016 Census [4] showed that 3,800 children under 15 years of age engaged in providing care to others, accounting for 1.9% of all carers. Half of these children (1,901) providing unpaid care were aged 10 and under.

According to the 2016 Census in Ireland:

The number of hours care provided per week by children under 15 is 42,227.

The number of hours care provided per year by children under 15 is 2.2 million. [4]

In Italy, young people (15-24 years) with caring responsibilities are thought to number 169,000 (2.8% of same age group) [5] while in the Netherlands nearly one in ten adolescents (13-17 years) live in a household with a chronically sick family member and 65% of them provide help [6]. In Sweden, the only survey study available indicates that 7% of all children aged 15 years carry out ‘substantial amounts’ of caring [7].

Although there are no precise figures about how many young carers there are across Europe today, the above-mentioned data suggests that about 7-8% of children in Europe will have caregiving responsibilities. These are children who are largely invisible to public authorities, social policy and interventions from health and social care services.

### **The impact of caring**

There is no doubt that both young carers and young adult carers are at risk of mental ill-health as a result of their caring situation, and especially among high-intensity young carers [8]. Statistics show that young people with a sick family member tend to have more mental health problems and more adverse outcomes in behavioural, psychosocial, and academic adjustment than their counterparts without a chronically ill family member. Those effects mainly manifest themselves in lower life satisfaction and internalised problem behaviour such as feeling depressed, being withdrawn, and anxiety. They also report a greater need for and use of help and support. The caring tasks often impact on the personal spheres of young people’s lives, such as their education, social participation, and personal development [9]. Furthermore, young adult carers deserve attention, as they are in a delicate transition phase (18-25 years) where they may have to reconcile new life challenges with caring tasks, such as entering the labour market, attending university courses and/or starting their own family [10]. The nature of the care tasks provided also seems to make a difference: adolescents who provide parents with emotional support or personal care reported more mental health problems than those who perform other tasks. Performing domestic tasks is found to be a predictor for overall mental health problems. The intensity of the help given is related to the need for help by the adolescent. It is concluded that growing up with a chronically ill family member and spending a lot of time performing (domestic) tasks are

risk factors for adolescents developing mental health problems and adolescents’ need for help [11].

Being an adolescent young carer is recognised as a risk factor for mental health and well-being, with around 50% experiencing care-related stress and 40% experiencing mental health problems [12].

The most common worries expressed by young carers concern the health of the person being cared for, their own health, who will look after them (if their parent is hospitalised for example), school work, money, bullying, and having no friends. Their most common problems relate to sleeping, suicidal thoughts, self-harm, and eating disorders.

Research has also highlighted a high level of concern regarding young carers and education. The major educational difficulties identified concern punctuality, attendance and problems with homework/coursework. Additional problems cited were difficulties joining in extra-curricular activities, low attainment, anxiety, and fatigue [13].

It is nevertheless important to note that not all young carers will experience all of these difficulties, depending on the availability of support and adaptational strategies; indeed some will have no educational problems at all. Educational disadvantage can be viewed as a continuum ranging from ‘severe’ at one end, through ‘moderate’ and ‘occasional/less severe’, to ‘no obvious impact’ at the other end.

Research has also shown that – provided adequate support is available – the young carer’s personal capacity may be enhanced as a result of caring, so positive aspects may co-exist with the negative effects of caring [14]. For instance, young carers may gain satisfaction from caring [15] and experience a range of enhanced emotional aspects such as self-mastery, self-esteem, maturity, and empathy, together with a greater repertoire of coping strategies [16]. Living with and making allowance for a sick family member on a daily basis can help young people learn to be more understanding and tolerant of (the feelings of) others. Looking at the positive as well as the negative aspects is important for an understanding of what it means for adolescents to have a chronically ill relative at home and to develop interventions to improve the support for them.

### **Resilience**

The ability of the young carer to adapt himself/herself to the challenging situation of caring is defined as resilience and is a crucial factor influencing the coping strategies he/she develops and applies, with subsequent effects on personal well-being. However, it should be remembered that resilience has clear limits and may be not sufficient to guarantee good mental well-being if the situation and risk factors become prolonged in time and intensity [17]. A range of factors have been identified as relevant for promoting resilience across a child’s lifespan [18], and these include, for instance, the presence of strong social support networks, a strong supportive parent (or other relative/significant other), a committed mentor outside the family, a positive school and extra-curricular experiences, mastery and belief in own capacity, self-recognition and re-framing of one’s own situation. The promotion of resilience might pass through different types of interventions [19], focusing on (1) reducing or preventing risks, (2) improving asset resources for adaptive functioning (e.g. access to healthcare, tutoring), (3) enabling adaptational strategies for positive development.

### **Why the need to address the challenges faced by Young Carers?**

*Our vision: children have the right to...*

Eurocarers strongly believes that everyone – and especially young people – should be protected from any kind of discrimination resulting from their caregiving activities and should benefit from equal opportunities to realise their full potential through social inclusion, education, and employment. In that spirit, the England Care Act 2014 Statutory Guidance defines caregiving activities that are likely to have an impact on the child’s health, well-being or education, or which is unsuitable for that particular child as ‘inappropriate’ or ‘excessive’. We therefore call on policy makers to introduce specific positive actions to ensure that young carers and young adult carers’ rights to have access to education [20] and employment, to the highest attainable standard of physical and mental health, to (social) participation, to an adequate standard of living and to a family life be respected.

This demand is also in line with the UN Convention on the Rights of the Child. It states, inter alia, that every child has the right to rest and leisure (article 31), education (articles 28 and 29), an adequate standard of living (article 27) and the right to the highest attainable standard of health (article 24). The (daily) challenges and difficulties faced by young carers and young adult carers often stand in the way of exercising their rights. Therefore, they need additional and tailored support measures to ensure that the equality principle is respected [21].

The human rights argument forms the core of our vision. Yet, other forms of argumentation, such as the economic argument, also correctly highlight the need to address the challenges faced by young carers. The economic argument is perhaps overly prevalent in policy debates, but remains very convincing.

### **Investing in children and young people is a social investment**

It is well accepted that prevention is the best medicine. As a consequence of this, we should favour policies that aim to strengthen people’s current and future capacities by helping them to ‘prepare’ for life’s risks rather than simply ‘repairing’ the consequences. Such policies should be seen as social investment. This means taking into account the risks and needs of individuals throughout their entire life, and investing in children and young people, are perhaps some of the best social investments. There is indeed ample evidence that, due to its strong multiplier effect, social investment not only pays off for children individually but also for society as a whole.

It is in that spirit that in 2013 the European Commission adopted the Recommendation ‘Investing in Children: Breaking the Cycle of Disadvantage’ which was supported unanimously by all European member states. The recommendation states that “breaking the cycle of disadvantage across generations requires an integrated approach focused on children and their families. This means identifying and removing structural barriers and combining prevention and support”. The recommendation underlines the need for equal access to inclusive and non-segregated quality education as well as for strong family support. The impact of informal care on young people’s life prospects and well-being is a perfect example of the structural barriers mentioned in the recommendation. We can easily make use of this political instrument to advocate for the recognition and support of young carers through a combination of universal and targeted approaches.

### **Early school leaving is an obstacle to economic growth and employment**

Along the same lines, the European Commission has identified early school leaving as an obstacle to economic growth and employment. It hampers productivity and competitiveness, and fuels poverty and social exclusion. Young people who leave education and training early are bound to lack skills and qualifications, and face a higher risk of unemployment, social exclusion, and poverty. This has been recognised in Europe’s overarching strategy for smart, sustainable, and inclusive growth – the so-called Europe 2020 strategy, which has set the goal of bringing the share of early leavers from education and training among those aged 18-24 to below 10% [22]. Still, in 2015 there were more than 4 million early school leavers across Europe, only 40% of whom are employed. The 2013 Youth Guarantee Council Recommendation commits EU Member States to ensure that every young person under 25 receives a good quality offer of employment, training, traineeship or apprenticeship within four months of leaving education or becoming unemployed. Now, research has not only highlighted the educational difficulties that many young carers face, we also know that access to employment, training or apprenticeship will only be possible if alternative care options are provided to the caree. So, the fight against early school leaving is also a powerful message to be used for the benefit of young carers.

### **Poor mental health is a cost for societies**

Evidence shows that improved mental well-being during childhood and adolescence has a broad range of impacts across the life course including the prevention of mental disorders. This is important since mental disorders account for one of the largest and fastest growing categories of the burden of disease (OECD 2011), in part because up to 50% mental disorders experienced across a lifetime arise before adulthood [23]. Effective interventions exist to treat mental disorder during childhood and adolescence, prevent it from arising, and also to promote mental health with economic savings even in the short term. However, the majority who would benefit do not receive such interventions which has a broad set of impacts and associated economic costs [24].

It is in that spirit that the Joint Action for Mental Health and Well-being recommends that Member States:

- Promote schools as a setting where the promotion of mental health, prevention of mental and behavioural disorders and early identification of mental disorders can reach all children and young people.
- Strengthen information about the levels of well-being and different mental disorders as well as coverage and outcomes of effective school based public mental health intervention.
- Enhance training for all school staff on mental health and consider schools as part of a wider network with other stakeholders and institutions involved in the mental health of children and adolescents in local communities.

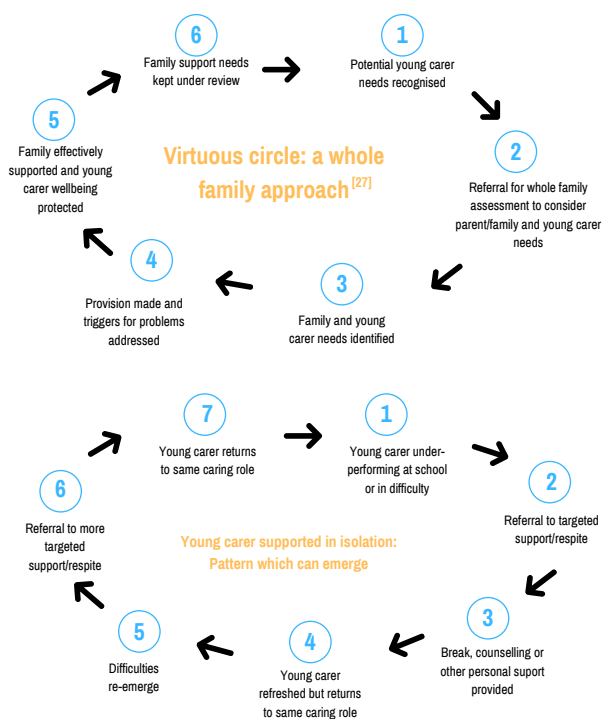
Given the impact that caring responsibilities can have on young carers’ mental health and well-being, it is evident that a preventive action aimed to avoid the negative consequences of caring on young people’s health is also an effective way to save society the costs of increased health care.

“A Swedish study revealed that the long-term extra-societal costs for children of parents with mental illness and alcohol or drug abuse is 3.5 billion Euros per year” [25].

### The measures of support

Overall, there are two main elements with regards to support for young (adult) carers. Firstly, it is crucial to boost the provision of more adequate and intensive formal care services to the cared-for person (enabling respite and better time management of the young carer). We acknowledge that the level of impairment of the cared-for person (usually a parent) and the lack of formal care services received or available are among the main root causes of young people assuming a caring role. However, it is important to note that, despite good faith and will of professionals, some families may resist formal care services for a variety of reasons, including the fear that family members may be separated or that these services may be insufficient to relieve the young carer of his/her caring responsibilities. Furthermore, they might be limited if legal and policy frameworks at country and regional levels do not support these services adequately and/or consistently.

A second option is the provision of direct support to the young carer through training, counselling, psychological and emotional support, following an initial needs assessment by formal services, based on a ‘whole family approach’ [26] which looks at the needs and views of all individuals within the family. The added value of this assessment lies in the possibility to identify health and social needs of care recipients, carers, and the family as a unit. In doing so, this approach contributes to a ‘virtuous circle among services’ which in turn contributes to positive mental health in young carers [27]. The main aim, therefore, is to ensure that services focus greater effort on early intervention and prevention and that they do so by providing properly integrated support around both the person cared for and the family as a whole. However, a limitation is that often young carers lack sufficient information about the services available, and lack awareness of where they can find support outside the family and close networks. Furthermore, they may be too overwhelmed by their caring activities to be able to seek external help or may fear to reveal themselves to ‘not be good enough’ at caring.



Preventative measures are very important to young carers as they can help them to overcome the barriers that are preventing them from accessing positive activities – for example, transport issues or emotional issues related to the anxiety felt by the young carer on leaving the cared for person. Practical (e.g. transport, phones for communication) and emotional support (e.g. building relationships with all family members to ease the anxiety felt by the young carer) can contribute to overcoming these obstacles. Interviews with practitioners and young carer families suggest that engaging young carers in positive activities can effectively address the social isolation they experience. Young carers themselves say that it gives them the opportunity to make new friends and talk to young people in a similar situation to themselves, which in turn helps reduce their levels of stress and anxiety [28].

### Recommendations

Ensuring that young carers are identified, their needs are addressed, and the needs of the whole family are assessed requires good joint working between adult and children’s services. Interventions focusing on young carers should follow the following approaches during the various phases of family support or strategic change in the services [29]:

### Delivering strategic change

#### *Improving awareness and the identification of young carers*

As has been detailed, a lack of identification of young carers means that young people are more likely to take on inappropriate caring roles. Many young carers do not recognise that they are a carer and may not be receiving appropriate support. Furthermore, practitioners across adult and children’s services do not always have a clear understanding and awareness of young carers and how their caring role impacts on their lives, particularly in families where the young carer is caring for a family member with alcohol/substance misuse or mental health issues. Therefore, a key focus of the work undertaken should be to raise awareness of young carers in order to improve identification and ensure that young people and families receive appropriate support. Schools play a vital role in both early identification and in the provision of support for young carers and their families. The desired outcome is that children and young people are able to engage fully with the educational and social opportunities available to them. A key focus should therefore be in developing work with schools. A range of strategies can be used to raise awareness of young carers in schools, identify potential hidden young carers, and provide appropriate support, including:

- Raising the pupils and staff’s awareness of young carers through assemblies, curriculum development, and class based work.
- Providing opportunities and activities where children and young people can identify themselves as young carers.
- Providing training for school staff on addressing and supporting the needs of young carers and their families.

Adult services also have a critical role to play in identifying young carers, particularly given the numbers of children and young people caring for a family member with mental health problems and/or issues of substance misuse. Thus, initiatives should focus on developing links with adult services in order to raise awareness and improve identification. This work should also focus on increasing agencies’ awareness of the support available and the benefits (for adults, children and young people, and services) of taking a family focused approach.

The experiences, needs, and preferences of young carers have been highlighted in various ways by different campaigns in countries such as the United Kingdom [30]. For example, those promoted by Rethink, The Children's Society and Carers Trust [31], as well as the initiatives of the Carers Strategy for Scotland (including individual services and national camps and fests for young carers). Researchers found, by working with young carers [32], that there are some positive examples of good practices which include:

- Young carer groups, young carer forums and young carer days, which help encourage young carers to socialise and help each other, building trusting relationships with peers and staff in a safe environment.
- Awareness campaigns, which often provide information packages, DVDs, websites for raising awareness of young carers, especially in the school context.
- Key workers or outreach workers, who are perceived as befriending and help facilitate skill development for caring tasks.

Individual and group support for young carers can also be based on information and communication technologies (ICTs), like the good practices of the Young Carer App developed by the Carers Federation in the UK [33]. Effectiveness of ICT- and web-based interventions for young carers is still a research issue [34].

#### *Improving integrated working across services, for example adult and children's services, and the health and voluntary sectors*

A key component of the whole family approach is to bring together services from different sectors to work more effectively together (for example adult services, children's services, and the health and voluntary sector). This can be implemented through joint planning and commissioning as well as training to improve communication between key partners. Joint planning can make services more flexible and responsive to the needs of all family members, whilst joint commissioning can be cost effective in reducing possible duplication across services.

Joint working requires effective communication and cross-agency support. Staff need to be able to refer young carer families to a range of different services; share information on family need; and review families' progress with the support on a regular basis. Nevertheless, cross-service communication can be hindered by a lack of staff awareness about family issues outside their own service remit and how to address them effectively; and the processes and systems that operate within other services and agencies. This can make staff feel uncomfortable in engaging with and supporting wider family members and may lead to a misinterpretation/misdiagnosis of need. A lack of awareness of the support available from other services means referrals may not always be appropriate and limited awareness of referral mechanisms can make appropriate referrals more difficult. Moreover, the different language and terminology used by different services and agencies can make it difficult for practitioners to accurately communicate and plan effective support for a family.

#### **Delivering family-focused support**

**Assessment:** In order to provide a holistic package of family focused support that meets the needs of all family members, it is important to have an understanding of the needs of the family as a whole. It is therefore important to develop a whole family approach in assessment, enabling both the individuals who need support and those who will support them to identify their own needs and desired outcomes. This is much more likely to result in individual care packages that can be sustained effectively. A

whole family approach will also minimise the risk of young carers feeling forced into undertaking inappropriate caring roles. **Planning and review:** Some existing initiatives (in the UK) are using Team Around the Family (TAF) approaches to bring practitioners who are supporting the family together to provide a coordinated and integrated response to meeting families' needs. This is reflected in the development of integrated care plans and joint delivery across services. The aim is to bring services together and increase joint working and information sharing in order to improve support for families.

**Delivery:** Key workers can act as case managers and provide (where appropriate) intensive, one-to-one support for the family, providing emotional and practical support, identifying additional support needs and co-ordinating support from other agencies. Practitioners are also encouraged to give young carers a voice by involving them in the overall design of local care provision and in planning individual care packages. Individual communication with young carers and enabling opportunities for young carers to know each other and to meet are also important.

#### **Primary prevention interventions for young carers**

From a social work perspective, preventive interventions for young carers can serve to [35]:

- Prevent growing numbers of children who need support as carers.
- Benefit disabled or ill parents and families as a whole.
- Relieve the financial burden on support services presently in place to help children who are already caring.

Findings from interventions targeting social and emotional skills of the young carers pointed out that some types of interventions have positive outcomes on young people's mental health, among others. In this respect, social and emotional skills are defined as a set of interrelated cognitive, affective, and behavioural competencies [36]: self-awareness, self-management, social awareness, relationship skills and responsible decision making. The following available evidence was identified [37]:

- *School programmes:* Their effectiveness relies on the focus on teaching skills, the use of competence enhancement and empowering approaches, the use of interactive teaching methods (including role play, games and group work), well-defined goals and use of a coordinated set of activities to achieve objectives, provision of explicit teacher guidelines through teacher training and programme manuals. These have proven useful to reduce behavioural problems, including aggressive and disruptive behaviours, bullying and victimisation as well as risk-taking behaviour (e.g. alcohol, cigarette and drug use).
- *Out-of-school programmes:* Their effectiveness relies on having specific and well-defined goals, a direct and explicit focus on desired outcomes, provision of structured activities, training of facilitators and use of a structured manual and implementation over a longer period of time. These have proven useful to enhance young carers' skills including self-esteem, confidence, emotional regulation, organisation and leadership, self-worth and relationship with peers and parents.

#### **Key messages [38]**

*To local, regional, national authorities:*

- Identify young carers as early as possible (via improved vigilance and screening tools of professionals).
- Assess young carers' needs and preferences together with the ones of other family members (whole family approach).

- Provide support that is flexible. Indeed, caring can be variable over time. Hence, the system has to be reactive, flexible and proactive. The initiatives carried out by the volunteer sector should be embedded in the system.
- Reduce barriers in accessing support and services and empower young carers to access the system.
- Adopt a lifelong approach, focusing on specific needs at specific times. This approach will ensure that the different needs of young carers and young adult carers are taken into account.
- Improve referrals and collaboration between professionals from different services (youth, education, care, health, family).
- Create a 'market' willing to support young carers.

#### *To the EU*

- Support further research on the profile and needs of young (adult) carers.
- Ensure existing good practices are disseminated and made visible across Europe.
- Make use of instruments at hand – i.e. European Semester, European Structural and Investments Funds, European Platform for Investing in Children, Youth Guarantee and Open Method of Coordination – to promote the development of integrated approaches for the identification, support and social integration of young (adult) carers across Europe.

#### *To schools*

- Insert the topic of young (adult) carers in the curricula.
- Establish a clear framework of support for young carers, which is embedded into the school's policies and communicated to parents.
- Appoint carer leads to assist young carers so that they can achieve their true potential.
- Put better systems in place to identify young carers and review the impact of caring on their educational performance and attendance, leading to appropriate personalised support.
- Record 'absence due to caring role' as a specific category so that data can be collected and statistics can be analysed.
- Implement a policy and strategy for dealing with bullying of young carers.
- Ensure that young carers receive a regular review of their own needs, by proactively making certain that appropriate action is taken by appropriate services.
- Support young adult carers in the transition to employment.
- Adapt school methodologies so that they can meet young carers' needs.
- Create new opportunities for peer recognition and awareness of young carers among school pupils.
- Make young carers more comfortable at school, satisfied with education, and avoid drop outs.
- Increase the educational and social environment for young carers at school and combat their social exclusion, loneliness, social stigma, unmet educational and support needs (for instance, ensure young carers do not miss out on out of school activities).

#### *To career advice services*

- Ensure that advice given adequately addresses and takes account of caring responsibilities.
- Provide clear information about the financial support that exists for young adult carers going to college and university.

- Put in place procedures so that young adult carers know who to tell, how to access services and support and are aware of the nature of the support they can receive.

#### *To general practitioners, health and social care*

- Establish systems to identify and regularly assess the health-care and social needs of children and young people in families where family members are experiencing ill health or disability (alongside the needs of their family members).

#### *To young and young adult carer support services*

- Help young people access service and information and facilitate contacts with local authorities and service providers.
- Enable young carers to access relevant training to help them in their caring roles.
- Work in co-operation with adult service providers to ensure that disabled or ill parents receive adequate support, thus reducing the need for children and young people to provide care.
- Offer non-formal education, personal development opportunities (to build young carers' confidence) and be a place of welcome where young carers are valued and supported.
- Make young carers aware of what opportunities the young services offer and of practical measures that can support their participation in the youth group (for example, by covering transports costs or facilitating travel arrangements etc.).

#### *To the media*

- Raise awareness on young carers and act against the stigma.

#### *To civil society*

- Engage media to raise awareness and contrast the stigma.
- Raise awareness in public and in professional workforce.

#### *To young carers*

- Be proud of your caring responsibilities, do not be ashamed!
- Don't hesitate to speak up and communicate your needs!
- You are not alone!

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\* This article was first published 2017 on the website of Eurocarers. <https://eurocarers.org/publications/eurocarers-policy-paper-on-young-carers/>. Individual formal adjustments were adapted to the IGJR specifications and the references were updated and supplemented. The table of contents of the policy paper has been removed. An abstract was added. The original system of endnotes has been retained and supplemented. Eurocarers receives support from the European Union through the European Social Fund + (ESF+) Programme. More information on Eurocarers under: [www.eurocarers.org](http://www.eurocarers.org).

1. The blend of health and social services provided to an individual or family in his/her place of residence for the purpose of promoting, maintaining or restoring health or minimising the effects of illness and disability. These services are usually designed to help older people remain independent and in their own homes. They can include senior centres, transportation, delivered meals or congregate meals sites, visiting nurses or home health aides, adult day care and homemaker services. See: WHO Centre for Health Development (2004): A Glos-

- sary of Terms for Community Health Care and Services for older people. In: Ageing and health technical report, 5. Geneva: World Health Organization.
2. Becker, Fiona / Becker, Saul (2008): *Young Adult Carers in the UK.: Experiences, needs and services for carers aged 16-24.* London: Princess Royal Trust for Carers.
  3. CarersTrust(2017):Aboutyoungadultcarers.<https://carers.org/about-caring/about-young-adult-carers>. Viewed 12 Feb 2024.
  4. Central Statistics Office (2016): *Census of Population 2016 – Profile 9 Health, Disability and Carers.* <http://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/>. Viewed 29 Jan 2024.
  5. Rosa, Mirko Di/ Barbabella, Francesco / Poli, Arianna / Balducci, Francesco (2015): *L'altra bussola: le strategie di sostegno familiare e privato.* In: NNA (ed.): *L'assistenza agli anziani non autosufficienti in Italia. 5° Rapporto*, 33-52.
  6. Roos, Simone A. de / Boer, Alice H. de / Bot, Sander M. (2017): *Mental well-being and need for support of adolescents with a chronically ill family member.* In: *Journal of child and family studies*, 26 (2), 405-415.
  7. Nordenfors, Monica / Melander, Charlotte / Daneback, Kristian (2014): *Unga omsorgsgivare i Sverige [Young Carers in Sweden].* In: *Nka Barn som anhöriga*, no. 5/2014. Kalmar: Nka, Linnaeus University.
  8. Kallander, Ellen K. / Weimand Bente M. / Becker, Saul et al. (2017): *Children with ill parents: extent and nature of caring activities.* In: *Scandinavian Journal of Caring Sciences*, 32 (2), 793-804 .
  9. Armstrong, Clare (2002). *Behind closed doors living with a parent's mental illness.* In: *Young Minds Magazine*, 61, 28-30; Charles, Grant / Marshall, Sheila / Remtulla, Yasmin (2012): *An Analysis of Responsibility, Attachment Security, and Relationship Efficacy among Young Carers.* In: *Relational Child and Youth Care Practice*, 25 (2), 49-57; Early, Louise / Cushway, Delia / Cassidy, Tony (2006): *Perceived Stress in Young Carers: Development of a Measure.* In *Journal of Child and Family Studies*, 15 (2), 165-176; Butler, Allister H. / Astbury, Gaynor (2005): *The caring child: An evaluative case study of the Cornwall Young Carers project.* In *Children & Society* 19 (4), 292-303, doi: 10.1002/chi.851.
  10. Becker, Saul (2000): *Young carers.* In: Davies, Martin (ed.): *The Blackwell Encyclopaedia of Social Work.* Oxford: Blackwells, 378; Becker, Fiona / Becker, Saul (2008): *Young Adult Carers in the UK.: Experiences, needs and services for carers aged 16-24.* London: Princess Royal Trust for Carers.
  11. Roos, Simone de / Boer, Alice de / Bot, Sander M. (2016): *Well-being and need for support of adolescents with a chronically ill family member.* In: *Journal of Child and Family Studies*, 26 (2), 405-415, doi: 10.1007/s10826-016-0574-7.
  12. Carers Trust (2016): *Invisible and in Distress: Prioritising the Mental Health of England's Young Carers.* London: Carers Trust. <https://carers.org/downloads/resources-pdfs/invisible-andindistressreport.pdf>. Viewed 14 Feb 2024.
  13. Marsden, R. (1995): *Young Carers and Education.* London: Borough of Enfield Education Department.
  14. Cassidy, Tony / Giles, Melanie / McLaughlin, Marian et al. (2014): *Benefit finding and resilience in child caregivers.* In: *British Journal of Health Psychology* 19 (3), 606-618, doi: 10.1111/bjhp.12059.
  15. Banks. Pauline /Cogan, Nicola / Riddell, Sheila (2002): *Does the Covert Nature of Caring Prohibit the Development of Effective Services for Young Carers.* In: *British Journal of Guidance & Counselling*, 30 (3), doi: 10.1080/030698802100002281.
  16. Aldridge, Jo / Becker, Saul (1993): *Punishing Children for Caring: The Hidden Cost of Young Carers.* In: *Children & Society*, 7 (4), 376-387; Charles, Grant / Stainton, Tim / Marshall, Sheila K. (2012): *Young Carers in Canada: The Hidden Costs and Benefits of Young Caregiving.* Ottawa: Vanier Institute of the Family.
  17. Chicchetti, Dante / Rogosch, Fred A. (1997): *The role of self-organization in the promotion of resilience in maltreated children.* In: *Development and Psychopathology* 9 (4), 797-815, doi: 10.1017/s0954579497001442.
  18. Newman, Tony (2004): *What Works in Building Resilience?* London: Jessica Kingsley Publishers; Schaeffer, Cindy M. / Tashman, Nancy A. / Weist, Mark D. et al. (2001) *Why did they graduate? A pilot study considering resilience among inner-city youth,* *International Journal of Mental Health Promotion*, 3 (2), 8-14.
  19. Yates, Tuppert M. / Masten, Ann S. (2004): *Fostering the Future: Resilience Theory and the Practice of Positive Psychology.* In: Linley, P Alex / Joseph, Stephen (ed.): *Positive Psychology in Practice.* New Jersey: John Wiley & Sons, Inc., 521-540.
  20. *International Covenant on Economic, Social and Cultural Rights (1976): Article 13.* <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>. Viewed 13 Feb 2024; *UN Convention on the Rights of the Child (1990): Article 23.* <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>. Viewed 13 Feb 2024.
  21. 'Me-We' – abbreviation for Psychosocial Support for Promoting Mental health and wellbeing among adolescent young carers in Europe (2024): *Enabling young carers to pursue their goals in life and reach their full potential – Converting research findings into policy actions.* Country Focus: Switzerland. [https://me-we.eu/wp-content/uploads/2019/06/Policy-Brief\\_Switzerland.pdf](https://me-we.eu/wp-content/uploads/2019/06/Policy-Brief_Switzerland.pdf). Viewed 13 Feb 2024; *Unicef (2024): Convention on the Rights of the Child.* <https://www.unicef.org/child-rights-convention/convention-text>. Viewed 20 Feb 2024.



22. The recognition that obtaining a quality education is the foundation to improving people's lives and sustainable development is shared also at international level. The Millennium Development Goal n. 4 aims to achieve inclusive and equitable quality education for all. See: The Sustainable Development Goals Report (2017): Goal 4: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all. <https://unstats.un.org/sdgs/report/2017/goal-04/>. Viewed 13 Feb 2024.
23. Frank, Jenny / McLarnon, Julie (2008): *Young Carers, Parents and their Families: Key Principles of Practice*. London: The Children's Society.
24. Joint Action. Mental Health and Wellbeing (2024). *Mental Health and Schools*. <https://mentalhealthandwellbeing.eu/mental-health-and-schools/>. Viewed 14 Feb 2024.
25. Hjern, Anders / Berg, Lisa / Hovstadius, Bo et al. (2017): Children as next of kin in Sweden. In: *Nka Barn som anhöriga*, no. 2/2017. Kalmar: Nka, Linnaeus University.
26. Belfer, Myron L. (2008): Child and adolescent mental disorders: The magnitude of the problem across the globe. *Journal of Child Psychology and Psychiatry*, 49(3), 226–236, doi: 10.1111/j.1469-7610.2007.01855.x.
27. Department for Children Schools and Families. (2009). *Improving support for young carers. Guidance Note 9. Think Family Toolkit: Improving Support for Families at Risk*. <https://webarchive.nationalarchives.gov.uk/ukgwa/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/Think-Family09.pdf>. Viewed 14 Feb 2024.
28. Ronicle, James / Kendall, Sally (2010): *Improving support for young carers – family focused approaches*. Manchester: Department for Education.
29. Ronicle, James / Kendall, Sally (2011): *Improving support for young carers – family focused approaches. Research report DFE-RR084*. York Consulting LLP. Manchester: Department for Education.
30. Robinson, Catherine / Seddon, Diane / Gray, Ben et al. (2011): *Supporting carers for people with mental health problems: needs assessment to service provision. Final report to the Big Lottery Fund*. <https://cfmhas.org.uk/wp-content/uploads/2020/03/CFC-final-report-Feb-2011-SUBMISSION.pdf>. Viewed 14 Feb 2024.
31. Aldridge, Jo (2006): The experiences of children living with and caring for parents with mental illness. In: *Child Abuse Review. Supporting professionals in safeguarding children*, 15 (2), 79-88, doi: 10.1002/car.904.
32. Robinson, Catherine / Seddon, Diane / Gray, Ben et al. (2011): *Supporting carers for people with mental health problems: needs assessment to service provision. Final report to the Big Lottery Fund*. <https://cfmhas.org.uk/wp-content/uploads/2020/03/CFC-final-report-Feb-2011-SUBMISSION.pdf>. Viewed 14 Feb 2024.
33. The Carers Federation (2017): <http://icare.aycnottingham.co.uk/login>. Viewed 31 Jan 2024.
34. Aldridge, Jo / Wates, Michele (2005): Young carers and their disabled parents: Moving the debate on. In: Newman, Tony / Wates, Michele (ed.): *Disabled parents and their children: Building a better future* (pp. 80-99). Ilford: Barnardos; Ali, Lilas / Krevers, Barbro / Sjöström, Nils / Skärsäter, Ingela (2014): Effectiveness of web-based versus folder support interventions for young informal carers of persons with mental illness: A randomized controlled trial. In: *Patient Education and Counseling*, 94 (3), 362–371. doi: 10.1016/j.pec.2013.10.020.
35. Aldridge, Jo / Becker, Saul (1997): *Prevention and Intervention: Young Carers and Their Families*. Leicestershire: Loughborough University.
36. Collaborative for Academic, Social, and Emotional Learning. (2005): *Safe and sound: An educational leader's guide to evidence-based social and emotional learning programs – Illinois edition*. Chicago: CASEL.
37. Clarke, Aleisha M. / Morreale, Silvia / Field, Chattrine-Anne et al. (2015): What works in enhancing social and emotional skills development during childhood and adolescence? A review of the evidence on the effectiveness of school-based and out-of-school programmes in the UK. Galway: Health Promotion Research, National University of Ireland Galway.
38. Most of the key messages in this section are from: Becker, Saul / Sempik, Joe (2013): 'Young adult carers at school: experiences and perceptions of caring and education'. In: *Carers Trust 2013*. London: Carers Trust.