

# ToYAC

Together for Young Adult Carers



Lifelong  
Learning Programme

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Date of Publication: May 2014

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This project has been funded with support from the European Commission. This publication reflects only the views of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained herein.

## Background

The ToYAC project is a European-wide project with the aim of supporting Young Adult Carers.

This handbook has been produced as a result of the work done by partners in the ToYAC project. See <http://www.youngadultcarers.eu/>.

### The partners are:

wir pflegen, Germany  
Movisie, Netherlands  
Anziani e non solo Soc. coop., Italy  
ASP Cesena Valle Savio, Italy  
Care Alliance, Ireland

Carers Trust/Scottish Young Carers Services Alliance, Scotland



Interessenvertretung begleitender Angehöriger und Freunde in Deutschland e.V.



## Purpose

This booklet is intended for anyone working with, or who has an interest in, Young Adult Carers (YACs). It has been put together by the organisations listed above, each of whom provides support to carers or is involved in developing supports for Young Adult Carers in its own country. We hope the information will be useful to you in considering how you might support this group in your own work context.

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## Why we need to support Young Adult Carers

A carer can be a person of any age who, without pay, looks after or helps to look after someone else who could not manage day to day without his or her help. The person cared for is usually a family member, but not always. Young carers are traditionally those under the age of 18, while adult carers are aged over 18.

### A time of transitions

Young Adult Carers may be described as aged between 16 and 24 years. Due to cultural/national variations, this definition would be extended in some countries up to 30 years of age. Young Adult Carers can benefit from being identified wherever they are engaging – in schools, youth services or further educational institutions. Following on from this, appropriate support needs should be identified. Particular supports should be provided around transitions. The impact of caring on the transitions that affect people at this time of life can be significant. It is to be expected that some young people will experience difficulties during these transitions from childhood through adolescence and into adulthood. Transitions occur when young people move from second- to third-level education, when they access training and employment opportunities, or when they leave home. The difficulties may be compounded when these life changes are complicated by their caring responsibilities.

### The numbers involved

Professionals involved in the caring context, in particular health and social care professionals, need to have increased awareness of the needs of Young Adult Carers. It is important that dedicated support services are made available to carers in this age group. Research in the UK by Saul and Fiona Becker (2008)<sup>1</sup> documents the issues comprehensively, and they found that 5.3% of 18–24 year olds in the UK provide informal care (see <http://tinyurl.com/7xupp9>).

We also have information indicating the prevalence of caring for this group from the following countries:

- Figures from Ireland's 2011 Census reported 4,244 carers aged 15–19 years and 5,761 carers aged 20–24 years.

- In the Netherlands, it is reported that about 450,000 children and young adults (5–23 years) live with a family member who has a long-term physical or psychological illness (12%), although no specific data is available on Young Adult Carers.<sup>2</sup>

- In the Emilia Romagna region of Italy, statistics indicate that 5.8% of girls and 1.6% of boys aged 15–24 years provide care to an adult family member.<sup>3</sup>

- While statistics for young carers and Young Adult Carers in Germany are not available, it is estimated that there are about 225,000 young and Young Adult Carers; this is not an exact figure, but is based on statistical extrapolation from the 2001 British census figures. Another number mentioned sometimes is 2.1% of the population aged 5–18 years.

### The economic argument

There is a sound economic argument for supporting this group of young adults. The case is well made by the Valuing Carers report produced by Carers UK in recent years. This documents a £10.3bn (€12.53bn) saving to the National Health Service budget in the UK. The savings are estimated on the basis that the caring provided by this group reduces the demands on the State to provide equivalent 'paid for' care.

When carers give up paid work to provide care, their contribution is not measured in economic output figures. As a result of their responsibilities, many Young Adult Carers under-achieve academically and lack quality work experience, with the long-term result that they often find themselves in low-paid, insecure jobs, or unemployed. Interventions with YACs could mitigate these impacts and provide opportunities out of poverty and isolation and towards further contribution to the economy.

### Differing levels of awareness

ToYAC project partners found that the level of general awareness about Young Adult Carers and the support services available differs dramatically in the five participating countries. Some have established support services that are well resourced, while others report poor awareness and recognition of the issues among their health and social care professionals. See <http://tinyurl.com/nehp445> for more.

## Young Adult Carers' stories and experiences

Nothing demonstrates the needs of Young Adult Carers better than the stories they tell to support agencies. These stories inform us what action on our part would make a difference, and are the key to developing good practice.

\*From Italy,  
Anna's story

"My name is Anna, I'm 24 years old and I've got a beautiful sister aged 28 whose name is Sabrina. Sabrina has Down's syndrome. I know that when Sabrina was born it was a shock at the beginning for my parents. When my mother was pregnant everything seemed normal. Doctors didn't realise anything; they said the baby was healthy, so when Sabrina came into the world, my parents' first reactions were shock and fear.

"But, as soon as they got her home, they started to love my sister and that love has never ended.

"I was born nine years later. When I was a child I felt ashamed going out with my sister. People turned to stare at her; I felt observed and uneasy. Other children teased me, shouting that my sister was handicapped.

"So, at the beginning it was difficult. My parents helped me; they tried to explain and make me understand that my sister was different from me and that I shouldn't feel neglected or ignored, because they loved both of us. They said simply 'Sabrina's needs are different from yours and sometimes it takes more time to respond to them'. Looking back, I realise that I started to love her gradually and then wanted to protect her. I remember that one of my big satisfactions was the first time when I had the courage to take on a class mate who insulted her.

"Now I'm older, almost adult I'd say. I'm attending university (a psychology course) in my town. One of the big issues with my parents [is about] me and my sister's future. They make me angry because they say that Sabrina should not influence my choices about the future and job research. They tell me that I don't need to worry about my sister because they are looking out for her and planning for her future. They don't understand that my sister is a piece of me, half of my heart, and I'm not going for any reason to leave her alone. Even when I find a boyfriend, he should be very clear in his mind that my sister is there; he should accept her and love her, because, if not, he will risk losing me too."

\*From Germany,  
Laura's story

"My mum suffered a stroke at the age of 47. At this time I was 17 years old. Because our parents are divorced, my brother (who is four years older than I am) and I had been at home alone for some months, while my mum was in hospital and then in a rehabilitation clinic. After she came home, I became the main carer. The stroke left paralysis and she also sustained cognitive restrictions. I supported her at home because she had to use a wheelchair. I helped her to get around, took her to the shops and to appointments like doctors' visits, and supported the household.

"The health insurance company decided on Level One care, which meant that she received approximately €200 per month, but she wasn't aware of the possibility of receiving external support. The assessor did not look into the fact that I was a child taking on the whole caring responsibility. They accepted our wish to get benefits in cash instead of in kind, which is much cheaper for the insurance.

"Just after my mum returned from rehab, my brother moved into a students' hostel. It was a great support to me that I had the opportunity to visit him often, and his new home became a duty free island for me. He also motivated me to resume school again. I started to go for my A-levels at the age of 18, while I was taking care of my mother, and finished at the age of 22.

"My mother became more independent. The role-switching situation between us was a great strain for her. She felt guilty, and was overwhelmed with the paralysis of her arm. I think I was overwhelmed with the whole emotional situation too and just tried to work it out, so that my mother had the chance to get along as well as possible. Within some years she learnt to manage her disorder, but her guilty conscience still bothers her. Today she lives in a barrier-free apartment, and I live in a shared apartment not far away. I have started an apprenticeship as an occupational therapist.

"The relationship between my mother and I returned to a healthy mother-daughter relationship again. I took less responsibility and we both learned to move back from each other's life.

"Looking back, there was nowhere to go to ask for information or mental support, so we had to get along all by ourselves. It would have been a great support if there was social counselling in school, so I could go there for support or just to talk about my situation, to relieve some of the pressure."

\*From  
Scotland

"I care for my young brother who is 11 years old and suffers from epilepsy. I have been my brother's carer for six years, and I am now 20 years old. When I became my brother's fulltime carer I didn't know that I was a carer; I just thought it was something that happened and I had to deal with it. Going through school was tough, not having a social life, and family issues at home didn't help either. When I was 14, I joined the young carers group but I didn't stay with the group and isolated myself from friends and became depressed. I didn't realise that it was ok, or normal, for me to have the amount of stress I had from a young age. When I turned 16 my mum left the family home and things became tougher. My depression got more severe and I began to self-harm. I didn't tell anyone about this because I felt like it was personal to me and it was an outlet from all the stress I had; I only recently told my doctor about my depression from a young age. At 18, things got harder, in terms of my further education in college, family life and my physical and mental wellbeing. It got so bad that I had nightmares and lacked sleep; I also starved myself because I felt hopeless. I decided to go back to the young adult carers group and spoke to my support worker who helped me through hell and back. He helped me to open up and talk about my feelings and [said that] it was ok and things are going to get better. Through his support, my worker gained my trust – I became more independent and more able to take care of myself. I joined a gym, and when I turned 20 I became a representative for Scottish Young Adult Carers through the Carers Trust UK team, who aim to massively improve the life of Young Adult Carers. I also decided to stay in further education and push myself through into the HNC Social Care [qualification]; [my goal is] to be able to work in my dream job with young people with mental health issues, using my past experience and knowledge.

"From the beginning until now, I wouldn't change a thing because, although it has been a hard road, it has made me a much stronger, more confident and self-reliant individual. My life as a Young Adult Carer has dramatically improved with support. If it wasn't for my brother and my support worker, I might well not have been able to continue much further."

\*From  
the Netherlands

There are many examples of Young Adult Carers who are forced to drop out of school or have a lot of catching up to do with their schoolwork. It's especially hard for them to combine their chores as carers and their schoolwork. Sometimes they can't finish their homework or study for an exam. Most of the time the school doesn't know or understand their home situations.

One girl that we spoke to lost her mother suddenly. She was the oldest child of the family and was automatically considered to be now responsible for all her younger brothers and sisters.

Her father had to work double shifts to make sure there was enough money, and the girl had to take care of all the chores in the house. She had to combine this with her schoolwork, which was impossible for her.

Another professional reported seeing that Young Adult Carers often excel in their achievements at school. Because of their care responsibilities, they are very precise in, for example, their homework.

## What do people already know and what is already in place?

Each of the six participating organisations undertook fieldwork in the form of a questionnaire which was circulated to a wide range of stakeholders.

While this fieldwork is not considered primary research per se, we believe that it begins to capture some of the key issues that face Young Adult Carers across Europe. A summary of the findings can be found at <http://tinyurl.com/nehp445>.

## Examples of current practice across the nations

### Ireland – Third level education

Young Adult Carers participating or wishing to participate in third-level education can face particular challenges. (See video link: <http://tinyurl.com/qfv4rf6> and report: <http://tinyurl.com/qyohd74>.)

One staff member at Ireland's largest third-level institute has taken the initiative of organising specific supports for student carers. The 'Networking Group for Students with Caring Responsibilities' is managed by a facilitator who has been both a child and student carer. To find out more, go to <http://tinyurl.com/osfoqx7>.

The same third-level institution in Dublin has undertaken to promote wider access to its courses, and has made specific progress in identifying young carers. To find out more, go to <http://tinyurl.com/oa2eyx9>.

### Netherlands – Migrants and talking groups

Many migrant young adults in the Netherlands are expected to take care of their parents. A joint collaboration between five organisations with experience in supporting young carers and/or with migrant communities have come together to produce a website to support these young carers. The website provides information, allows for interaction, and provides a question and answer forum for Young Adult Carers. It also has an online pharmacist and doctor. To find out more, go to <http://tinyurl.com/ppyse3s>.

Mental health care organisations in every region of the Netherlands provide talking groups for young carers and Young Adult Carers who care for a parent with a psychiatric disability or an addiction. To find out more, go to <http://tinyurl.com/navj97p>.

### Germany

There are no special initiatives for Young Adult Carers. Some agencies offer support for children and young carers, mainly for siblings and children with parents who have mental problems.<sup>4</sup> To find out more, go to <http://tinyurl.com/pm52lf8>.

### Italy – Sibling support groups

Across the country are Sibling Support Groups targeting brothers and sisters of people with disabilities. For example, the 'Fiori sulla luna' (Flowers on the moon) project provides:

- emotional and social support to siblings to allow them to become a resource for their families and for society;
- promotion of awareness about the role siblings play as carers within their families and about their future caring responsibilities;
- opportunities for joint working, promoting cooperation between the public and private sectors, and promoting services within the health, social and educational fields;
- a group of experts trained to work with carers;
- information and education to promote resilience, empowerment and self-efficacy, and to raise awareness in siblings about their role in society and within their families.

Referrals to the organisation are made by the family doctor. The project seeks to raise awareness, improve family wellbeing and enhance clients' educational outcomes. To find out more, go to: <http://www.siblings.it/> and <http://www.fiorisullaluna.com/>.

### Scotland – Strategy and peer support groups

Scotland's national strategy for young carers is called 'Getting It Right for Young Carers'; see <http://tinyurl.com/pa5q6jy>.

The strategy includes actions designed to support Young Adult Carers, including collaboration with colleges, universities and employers. Some parts of the strategy are currently being implemented. An example is Glasgow University's policy to support student carers, which can be seen here: <http://tinyurl.com/pof25f6>.

There are various government initiatives to support young carers, such as a young carer's authorisation card to assist with identification and information provision, and a targeted Employer Recruitment Incentive, to assist Young Adult Carers into employment.

Throughout Scotland, groups have been developed to provide peer support and training to Young Adult Carers; see <http://tinyurl.com/nam9gpj> for an example.

## Recommendations from the project work

Following reflection on the current support services available in each country, and on the feedback from the fieldwork undertaken, each partner organisation made specific suggestions to those seeking to work with and support Young Adult Carers:

- Raise awareness of the role of Young Adult Carers and the issues and problems that affect them, starting from a shared definition and going on to focus on risk and protection factors.

- Invest time in building relationships with a variety of educationalists and health and social care practitioners in your network. They are already likely to be working with YACs – they may just not have identified this.

- Present your ideas and your passion for supporting YACs to colleagues as a solution to problems. They may say 'We don't know how to identify carers' – give them the toolkits/checklists/publications to do it. Go to <http://bit.ly/1fR3GDV>.

- Remember that the progression from being a teenager to being an adult is a journey – some young adults will appear mature but may need to be supported in the same way a teenager would. Existing toolkits for teenagers might still be suitable for young adults.

- Use the strength of peers – connect Young Adult Carers up with other Young Adult Carers.

- Consider using Facebook or other social media avenues to engage with Young Adult Carers.

- For staff in education, try to understand the situation from the Young Adult Carer's perspective. Support the carer in planning homework and other activities. Young people find it extremely hard to plan their work.

- Ask the young person how he or she is. Most of the time, people ask how the person being cared for is doing – be interested in the person providing the care.

- Encourage health professionals to be aware of Young Adult Carers.

- Screening children soon after the parent has been diagnosed with a serious illness or mental health condition may be an important step for the prevention of persistent developmental problems. This may be achieved if professionals in contact with the target group (e.g., general practitioners, hospital staff, teachers, school doctors and counsellors) are alert to potential problem behaviour. Asking a few questions about the young person's adjustment during a consultation can be an important step in initiating help. The fact that parental ill health significantly affects offspring gives impetus to the idea that health care professionals should adopt a family-centered approach instead of focusing exclusively on parents.<sup>5</sup>

- Involve children during the rehabilitation of the ill parent by informing them about the disease, and help to meet their needs, as appropriate to their ages. Paying attention to children's adjustment to parental disease can enhance their quality of life and developmental prospects.<sup>6</sup>

- Promote awareness of possible Young Adult Carers at school and in Youth Work settings. Professionals and teachers dealing with children should consider the possibility of parental illness and accordingly be alert to signs of fear, depressed mood, somatic complaints, isolation and academic underachievement.

- *"We recommend professionals to communicate with parents and children about the diagnosis and the short and long term impact of parental illness on the family. Parents should be encouraged to make sure that their children have enough illness-related information and know how to deal with the medical condition. Considering that clinical levels of stress pose a threat to a substantial part of the target group, clinicians and researchers should collaborate to create evidence-based interventions aiming to reduce stress in this specific group. An intervention that may specifically help the target group is stress management, which particularly makes use of strengths and important resources such as coping skills."*<sup>7</sup>

- Read up on the issues here: <http://tinyurl.com/oqf9sj3>. Use Google Translate to read reports in foreign languages: <http://translate.google.com/>.

• Encourage further education institutions to use the resources produced by Scotland's College Development Network: <http://tinyurl.com/lwr63w9> and to adopt a policy for student carers, such as that of Glasgow University: <http://tinyurl.com/qh478hj>.

• Establish tailored support services for carers of this age and stage.

• Map and identify Young Adult Carers at local, regional and national level. This important activity could be carried out through:  
(a) the use of existing tools such as MACA-YC questionnaires <http://tinyurl.com/qzwqj9q> – an idea might be to administer these questionnaires within schools, universities, etc.), or (b) by integrating items specifically relevant to YACs in the regular forms and checklists in use by social services.

• Be understanding and empathetic when working with YACs, especially in counselling. Many YACs are very protective of their families, and family integrity may be their top priority. Be sure to respect that and understand that YACs may feel guilty about expressing negative thoughts or feelings. It is almost always a good idea to work with the family as a group. Parents may be very supportive and encouraging of an age appropriate development of the YAC.

## References

<sup>1</sup> Becker, F., Becker, S. (2008) Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24. The Princess Royal Trust for Carers and Young Carers International, Research and Evaluation, the University of Nottingham

<sup>2</sup> 'Kinderen en jongeren met een langdurig ziek gezinslid in Nederland, Aantallen en enkele kenmerken' ('Children and youngsters with an ill relative, numbers and some characteristics'). Writers: Alice de Boer, Debbie Oudijk, Lucia Tielen. tsg Volume 90 / 2012 numbre 3 forum – page 167 / [www.tsg.bsl.nl](http://www.tsg.bsl.nl)

<sup>3</sup> Istat 2011 (2011 Italian Census)

<sup>4</sup> Metzger, S. (2007) Kinder und Jugendliche als pflegende Angehörige. Erleben und Gestalten familialer Pflege. Bern: Hans Huber Verlag

<sup>5</sup> Sieh, D.S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M., Vander Leih, D. A.V. (2010) Problem Behavior in Children of Chronically Ill Parents: A Meta-Analysis. Clin Child Fam Psych Rev, 13(4): 384–97. Published online: 17 July 2010

<sup>6</sup> Sieh et al., 'Problem Behavior in Children of Chronically Ill Parents'

<sup>7</sup> Sieh, D.S., Visser-Meily, J.M., Oort, F.J., Meijer, A.M. (2012 ) Risk factors for problem behavior in adolescents of parents with a chronic medical condition. European Child and Adolescent Psychiatry, 21(8): 459–71

## Partner details

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You can download these booklets in English, Italian, Dutch and German from [www.youngadultcarers.eu](http://www.youngadultcarers.eu).



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