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A GUIDE TO SUPPORTING YOUNG CARERS

GUIDANCE REPORT
BASED ON THE OUTCOMES
OF EPYC PILOTING IN FIVE
EUROPEAN COUNTRIES

A guide to supporting young carers

Guidance report based on the outcomes of EPYC piloting in five European Countries

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THE EMPOWERING PROFESSIONALS TO SUPPORT YOUNG CARERS (EPYC) PROJECT

What is EPYC?

The EPYC project, funded by the European Commission under the Erasmus+ KA2 programme, was launched in August 2016 and implemented by a strategic partnership of 6 European organisations, namely Diakonisches Werk Berlin Stadtmitte e.V. (DE), Care Alliance Ireland (IE), Anziani e non solo (IT), Carers Trust Scotland (UK), Austrian Red Cross (AT) and IPS Versari Macrelli (IT).

The project aimed to enhance the skills and knowledge of youth professionals working with young carers in these five countries. Through the provision of information resources and a comprehensive toolkit (checklist, questionnaire, guidelines of good practice etc), professionals would be enabled to recognise the situation and difficulties of young carers and develop suitable support plans. In that way the project would reduce and aim to overcome possible obstacles that this particular target group often face, like disadvantages in their educational path and in social participation.

The process:

To start, the partnership created a data-base of resources to assist professionals who want to raise awareness about young carers and help with the identification of young carers. These included posters, films, reports and leaflets which could be downloaded for immediate use. The database section is publicly available from the project website www.ep-yc.org.

Each partner then went on to develop a model of support for young carers which would enhance what (if anything) was already there. It was the intention to pilot or trial these models and then look to embed them in the practice of professionals working with children and young people.

Lessons learnt from the piloting have been incorporated into this report.

JUMP RIGHT IN!

EPYC IN PRACTICE

The starting point for each of the nations was very different in terms of the knowledge and awareness of young carers. Scotland is an exception among the EPYC group, where unpaid carer issues are long recognised with a strong emphasis on supporting young carers and a commitment through the Carers (Scotland) Act 2016 to provide support to carers of all ages. However there are still some gaps in awareness across society. Ireland and Germany have some knowledge of young carers, however large gaps in understanding and awareness still remain. Austria and Italy lag further behind with low awareness of young carers in society.

- *the majority of professionals involved had never heard the word “young carers”, however – once the definition was explained – some of them could relate to cases that they have met during their professional experience. (Italy)*
- *most professionals had never focused on the specific needs of children, while primarily focusing on the needs of the care recipients. (Italy)*
- *From (academic) expert side the issue of practical support for young carers is new but quite prominent on the agenda and it is seen as quite an important challenge and interesting theme. (Austria)*
- *The level of awareness on what it means concretely to be a young carer (engagement, responsibilities, challenges, consequences, problems and needs) is still developable in Austria and the interest in how to identify and be helpful is high. (Austria)*

ACTIVITIES UNDERTAKEN AND GROUP SERVICES CREATED BY THE PARTNERS

Because of the different national contexts and background experiences, each EPYC partner was left free to decide how to implement practical actions at national level, with the goal to respond as much as possible to local needs and to integrate – and not to overlap – with existing experiences at local level.

AUSTRIA

The Austrian Red Cross launched a “Young Carers Club” for young people between about 10 and 17 years – the first one of this kind in Austria. It was implemented at the regional Red Cross branch in Vienna. The club meetings took place every two weeks. The idea was to offer a space of “supported normality”, trust and

companionship for youngsters in similar situations. In the course of time it turned out, that a separate group for “Young Carers” was less appropriate to the needs of this target group than to be included in general youth groups. Therefore the Young Carers Club was merged with another Red Cross youth group, giving all group members the opportunity to share issues and activities of a wide range – including care themes and questions of caring for others and responsibility in families.

GERMANY

In Berlin, Wir Plegen established a group activity for young carers between 12 and 17 years old. They called it a “creative group”, the sessions focus on creative art forms that the young people can try out. The sessions take place once a month. They started with improv theatre, a spontaneous form of theatre that everyone can engage in without experience. There was always one social worker present along with the improv theatre coach.

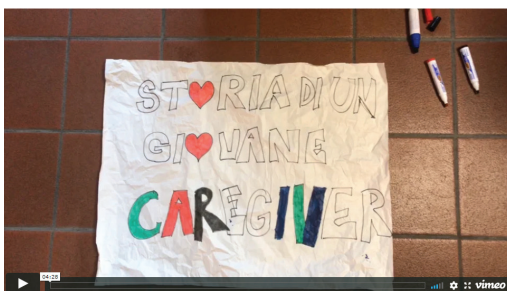
Even though the group was for young carers, having fun and having a break were the main goal of the sessions. In the medium term, the group shall be a space where talking about issues the young carers want to address will also be possible. The young people shall be empowered to structure the group to meet their needs.

IRELAND

The Irish team focussed on building a network of supporters around young carers in an effort to bring together those working with young people who may have family caring responsibilities. They also worked with volunteer led youth organisations, in particular the Irish Girl Guides, to raise awareness and understanding of the needs of girls and young women who may be providing unpaid family care. Case Alliance Ireland also undertook a snapshot report of young and young adult carers to better understand their perception of the supports that are available for YC in Ireland and how they have accessed those supports. The report, entitled “Engaging with Young Carers: A Virtuous Circle”, can be found at http://www.carealliance.ie/publications_youngcarers.

ITALY

The piloting in Italy was conducted by two different partners working in two different parts of Emilia Romagna Region: ANS (in the western part) and the Versari Macrelli Institute (in the Eastern).



ANS implemented two groups: one based on creative expression based in Carpi and involving teenage carers in general and the other targeting only siblings of children and young people with disabilities. The 1st group met monthly and explored feelings and emotions related with care through the use of photography and video production. At the end of the project, photos were shown to the public in an exhibition that took place in the framework of the Carer Day 2018. The video was disseminated digitally.

(To watch the video, click on the picture above or go to <http://www.ep-yc.org/being-a-young-carer-photos-and-video-exhibition-in-carpi-italy/>).

The 2nd group met 3 times to take part to an active workshop focused on understanding and expressing emotions related to siblingship in the context of disability.

In Versari Macrelli a Carer’s Day was organized within the school to make students and teachers more aware about the opportunities offered by the project to YCs. On that occasion an informative letter was provided to teachers and a flyer was distributed to invite supposed carer students to contact the project staff. Moreover, a poster was prepared to publicize the carer role and make them aware of what they were doing. It was hung in each classroom after a short oral presentation of the project. Finally, the teachers involved in EPYC prepared a specific school project for young carers, called PDP (“personalised learning plan template”). It’s a specific form, filled in after an interview with each young carer, which describes the student’s situation, his/her needs and we try to suggest some positive actions aimed at lighten his/her

school work, considering the family requirements and the student's real available time management.

SCOTLAND

In Scotland the focus was on participation and empowerment. Carers Trust developed the EPYC Youth Advisory Group, made up of young and young adult carers based across Scotland aged 14 to 25 years old, that met frequently to help lead and peer evaluate the EPYC project work. They also took part in a residential weekend event and many volunteered at the Scottish Young Carers Festival events. Carers Trust is working with these young people on youth accreditation awards so that they can be awarded for their voluntary roles.

COMMON CHALLENGES IN TRYING TO ESTABLISH PEER SUPPORT FOR YOUNG CARERS IN EACH COUNTRY

■ **Finding young carers.** All partners except Scotland had difficulties finding young carers. Main reasons behind that were:

- many young carers who got the information about the group decided not to participate: some because of other commitments (school, care responsibilities) but the majority because they didn't feel the need to take part in a young carer group.
- Many young people with additional caring responsibilities either do not realise they are a young carer or their family does not want to acknowledge this, possibly due to fear of intervention from state or other services.
- Lack of engagement of support services and agencies: without direct communication with young carers, it was impossible to engage them in accessing supports directly.

■ **Setting meeting dates.** It was not easy to fix meeting schedule because young carers are very busy.

■ **Creating a group.** We had difficulties in creating a group composed of people with different characteristics (age, personality traits, points of view). Young carers showed difficulties in socialising.

■ **Stigma and being different.** Young people do not generally wish to draw attention to their caring responsibilities and do not want their peers to know about their family lives.

■ **Building trust.** It is important for young people to trust the group they are entering in their precious free time, where they might otherwise be caring for their family member. The need to balance time to "forget" with being able to provide specific support about caring is important.

By contrast, peer support groups are already well established in Scotland, and there is a dedicated service in every local authority area.

WHAT WORKED WELL:

■ **Persistence:** every person is different and those who are more sensitive or introverted might need more time than others to find the confidence they need to share and participate actively

"Even the girl with a shy, introverted and reflective attitude slowly managed to share thoughts and feelings about her family and private life with the other girls."

Persistence also means being committed and keep trying in building up the group activity (i.e. keeping YC informed also when they didn't show up for a couple of meetings, sending flyers and information regularly to network partners asking them for help in the dissemination progress...)

■ **Re-establishing norms:** it is not only about sharing and providing emotional support, but also about helping young carers to get control over their lives and plan their future.

"A young carer that a year earlier abandoned school, enrolled again in school. We helped her finding a new school with courses in which she was interested in, we established contacts with a school representative and now she is successfully attending school."

■ **Good leadership:** it is important to choose carefully who will act as leader / facilitator of the group. Professionals skills are important, but it is even better when the person has gone through a caring experience, as it is easier to empathize with the YCs.

"We found a very able and authentic person as club leader. She has a background of "young caring" herself and knows very well what needs, problems and what strengths and hopes arise out of such situations. Empathetic access to the target group was guaranteed."

■ **Accessibility:** ensuring "accessibility" of a group can have different meanings. For example:

- a. Making the group about a fun, creative activity first to make it interesting to young carers;
- b. Being available to young carers via social media, email and whatsapp
- c. Offering the possibility to bring a friend to the first couple of meetings
- d. Offering space to chat after the workshop, to get in touch with the social workers and the young carers
- e. It is important to assure anonymity and privacy for the first approach

■ **Co-operation and having contacts with key people:** "no man is an island" and that is even more true in the case of young carers. Being a still under-developed topic in many countries and being difficult for young carers to recognise themselves as such, networking and creation of connections with relevant stakeholders at local level is crucial.

"The cooperation with stakeholders was great. Offering information and guidance to organisations that do not have their own resources to develop materials to support understanding the needs of young carers."

FACTORS THAT CONTRIBUTED MOST TO SUCCESS:

■ **Creating a positive mood:** The creation of a relaxed, warm, welcoming and informal climate, a friendly meeting.

"We used a delicate approach towards young carers: as a result, most of young carers did not feel afraid of talking about their situation"

■ **Respect** The respect of needs and characteristics of participants

"We started to talk about caregiving only when girls felt comfortable about this, they were never asked to answer direct questions that could let them feel uncomfortable, they didn't feel forced to tell and share private episodes, they did it only if and when they felt it."

■ **Participation and involvement:** Letting participants have their say on which activities the group should focus on.

"We started by using photography as expressive tool because it was a hobby shared by participants".

Make sure that facilitators got actively involved in the group:

“Our facilitators were doing the same activities and sharing personal experiences with the rest of the group. This contributed to the creation of a relationship of trust.”

- **Flexible schedule:** young carers are normally very busy juggling school, friends and care commitments, so participating to activities of a support group should not be perceived as an additional burden and it is important to schedule dates and time according to their needs and availabilities.
- **Stakeholder support:** being able to rely on support of important organisations and funds allows the sustainability of interventions.

“We were delighted that the Scottish Funding Council recognised the impact of the project in Universities and decided to give us continuation funding.”

PARTNERS' TOP TIPS / RECOMMENDATIONS

MOOD & APPROACH:

- Do not force openness (this should happen spontaneously).
- Never create a judging or competitive climate.
- Enhance personal strengths.
- Celebrate the results they achieve and validate them.
- Give new young carers to the group the possibility to step back in the group and observe first, without putting pressure on them to participate.

BUILD ON EXISTING GROUPS / NETWORKS

- Try to start the “Club”, or anything similar, with already existing small groups (friends, siblings). It is too big a barrier to join a completely unknown group (with a special, delicate theme) and the group can present itself much better when already “running”.
- Look for opportunities to raise awareness and provide support through youth groups where young people gather. You may have a group for young carers and non-carers and cover the caring topic in discussions about caring issues within families and individual expectations and dreams. This approach promotes awareness of diversity without putting the young carers under pressure of identifying themselves to the group. In that way, young carers do not have to go to a different place for their support.
- Raise awareness in schools – be where the young people are.

PARTICIPATION & MOTIVATION

- Involve young people in the planning and development stages of any initiatives when you can
- For many of the young people motivation to join these groups are mainly for making new friends. Keep this in mind when planning the group activities
- Be committed and don't expect too much in terms of numbers first. Building a steady group takes time. Be satisfied with those who join the group. Even if sometimes, you only have two participants.
- Offer transport to young carers to attend group meeting if that is possible.

NETWORKING AND GROUNDWORK

- Get local and national policy and decision makers on board with your ideas. Bring them face to face with young carers to hear their stories – that is very powerful.
- Do the groundwork! Meet important stakeholders that work with young carers or families with a person in need for care. Chances are that many of these families also have young people with caring responsibilities.
- Work with existing groups/networks where possible to encourage collaboration.
- Offer resources and tools to make it easy for organisations to support young people.

PARTNERS EXPERIENCES OF WHAT DIDN'T WORK

During the piloting partners experiences a number of challenges and difficulties

- **Small numbers of participants:** young carers are a “new” topic in many countries and this can impact in the success of recruitment process. Being a small group has a number of downsides, for example it makes the communication exchanges and comparison less articulated and stimulating and it also makes peer bonding difficult.

“The girls didn't create a real group; the only meeting point was the chance of sharing and talking about themselves and their families in a protected context, but not having conversation between them.”

- **Unclear messages and external communication:** again, being a not a mainstreamed topic, caring in young age is difficult to communicate sometimes. That's why the message must be clear and concise to gain attention, among young people and stakeholders.

- **Difficulties in engaging the right organisations:** Reaching stakeholders without direct contact to the target group is not sufficient. It is crucial to convince key persons who work directly and continuously with the target group to cooperate. On the other hand, we found it difficult to engage with youth agencies who did not have a specific remit around young carers as they were daunted by taking on additional commitments without internal resources to support that activity.

- **Barriers in accessing the target group:** although we know that there are many young carers who are out of the radar of support services or NGOs, we didn't manage to find a satisfactory strategy to reach them

“All young carers so far came to the group via stakeholders who are currently providing supports. We haven't found a way to reach young carers directly that are not already connected to the support system.”

On the other hand, even when young carers do are already in touch with other professionals or organisations, it doesn't necessarily make them easier to reach as there are other barriers, for example related with confidentiality.

“Organisations that do support young carers were reluctant to share information or allow contact with young people in their programmes.”

Also, it should be considered that sometimes YCs – although they recognise themselves as such – might prefer not to participate to support groups or programmes

"We noticed that some young carers did not accept the project on themselves, even if they recognised their role. Maybe this happened because of a sense of embarrassment when talking about their situation. Unfortunately some did not want to show their difficulties and preferred to go on as usual, without any help. This should stimulate us in finding better strategies to involve young carers."

FEEDBACK FROM YOUNG CARERS

We wanted to hear the voices of our participants. These are some of the feedback we collected:

- *I liked the opportunity to meet other people and learn new things, listen to other girls' point of views and feeling to be a part of a group*
- *I enjoyed the peaceful context and the creativity of the proposed activities*
- *The only thing I didn't like is that the group was small: we would have liked to be more in order to have the chance to know other people.*
- *I feel that the EPYC project which has provided funding for the Going Higher for Student Carers in Scotland award and initiative is an extremely important tool for colleges and universities to access. This award would mean that other student carers won't have the added worries and stress that I had throughout my college experience. It will mean that all student carers regardless of their situation should have the same opportunity to be successful in their studies! The Going Higher for Student Carers award will allow colleges and universities to have a better understanding of carers and the barriers they may face whilst studying and make real change to improve the lives of current and future student carers in Scotland.*
- *It is nice to have fun together, we enjoy the activity*
- *It is nice to be in a smaller group, more relaxing for us*

FEEDBACK FROM PROFESSIONALS

Youth workers and other professionals directly working with young people were the main target group of the EPYC project. Transversally, throughout the project, the partnership worked to help them increasing their knowledge and awareness about young carers and providing them with tangible and intangible tools to be more capable to recognise and sign-post young carers when they meet them.

These are some of the feedbacks we collected from those we involved at different stages of the project:

- *After awareness rising and training activities, professionals were quite positive that there is a need to support young carers and some of them understood that they could usefully play a role in the identification of these youths. As a consequence, some of them have started sign-posting the YCs they meet to us and distributing our informative material.*
- *Professionals who are in touch with the girls who are currently participating to our support group gave mixed feedback. Some of them explicitly acknowledged the importance of what we are doing for them (for example, in the case of the girl who returned to school, we got a call from the mum's psychiatrists saying how happy the family was about this outcome). In other cases, we were kind of criticised for the fact that we do not necessarily push participants to share their feelings, if they don't feel like doing that. According to a psychotherapist, the participation to the group would be kind of useless if they don't do that.*

- *“Don’t give up, even when the start is sluggish. It’s so important what you do!”*
- *“(New) things need time to develop and to become self-sustaining.”*
- *“Support for young carers is very important for their later life!”*
- *The EPYC project and Going Higher for Student Carers Recognition Award has significantly raised the profile of student carers in Scotland’s universities. The resource has enabled institutions to engage with Carers Trust Scotland who have helped them develop their student (and staff) carer policies. In the past few years young carers have been identified as a priority group and we (Scottish Funding Council) have seen colleges and universities vastly improve their systems to support young carers.*
- *Participant seems to be encouraged and more self-confident after taking part in the meeting*
- *Feedback from our multiplier event was good with one statutory organisation acknowledging the lack of reference to young carers in particular policies. This is to be remedied.*

HOW THE PARTNERS FEEL THEIR WORK HAS MADE A DIFFERENCE FOR YOUNG CARERS

Finally, in this paragraph we think it is important to reflect the point of view of organizations directly involved in the EPYC project. How do we feel about the work done? Which impact did it have in our perception?

- *We don’t know exactly what difference we have made for young carers, maybe we helped them to get out of an environment that can be oppressive due to the burden of the caring activities and the suffering for their mums’ diseases. We also offered them a supportive context willing to listen, a physical space where they could be themselves, felt free to complain about the situation, talked about their problems and fears without being and feeling judged.*
- *Young carers can now be confident that when they move from school to university that they will find the university is aware of carers issues and that the university will have a policy to support student carers.*
- *We are offering a “time out” of the family situation*
- *We show our respect and given them positive feedback on their behaviour, their engagement etc.*
- *We give them the experience that being “carefree” and having fun for a while is okay and possible! Hopefully this encourages them to make time for personal needs in their lives regularly.*
- *We managed to increase awareness of young carers among voluntary led youth organisations. We also developed an awareness leaflet which is a useful and engaged start.*
- *Maybe we have opened a window for young carers, making them feel more confident and relaxed about their difficult situation. Their big family problems will still be there, but at least there will be less trouble about school. When everything is perceived as a problem, having the chance to lighten and simplify life is a very good thing...*

SO, TO SUMMARISE...

WHAT HAVE WE LEARNED?

One of the benefits of the EPYC project was the ability to share knowledge and experiences across the five countries. The partners encountered a number of similar challenges in their work:

■ *“Children aren’t carers”*

A lack of openness from young people and their families and about sometimes difficult circumstances, which can result in young carers not being formally identified. Because this experience then becomes hidden, policy makers may disregard these young people’s experiences.

■ *“We know about them but...”*

Where young carers are identified and acknowledged, they may be side-lined for more obvious and more seemingly pressing social needs. The lack of understanding about young carers and their needs is an issue which needs to be addressed in order to ensure their needs are met.

■ *Lack of co-operation between services*

In many instances, information on young carers is held in silos and not shared across agencies and support services. This gatekeeping means young carers cannot always access the services they need and may in some cases cause young people in need to slip through the cracks.

The experience of the EPYC partners across Europe has been that **engaging with young carers directly is a challenge**. Carers Trust Scotland, where adult carer and young carer initiatives are well established found it less difficult to reach young carers.

“This partner recommends working with young people in the social activities that they already attend and to offer carer support both socially and in school.”

This was echoed by our Austrian partner, the Red Cross, which sought to implement a young carer programme within an existing youth group. Our Italian partner, Anziani e non Solo, and German partner, Pflege in Not, also encountered difficulties in identifying and connecting with young carers, despite extensive out-

reach activities.

Identifying young people with caring responsibilities is the first step and giving them an opportunity to engage is the second.

Lack of awareness of young carers and their support needs¹ is a hugely important area that must be addressed.

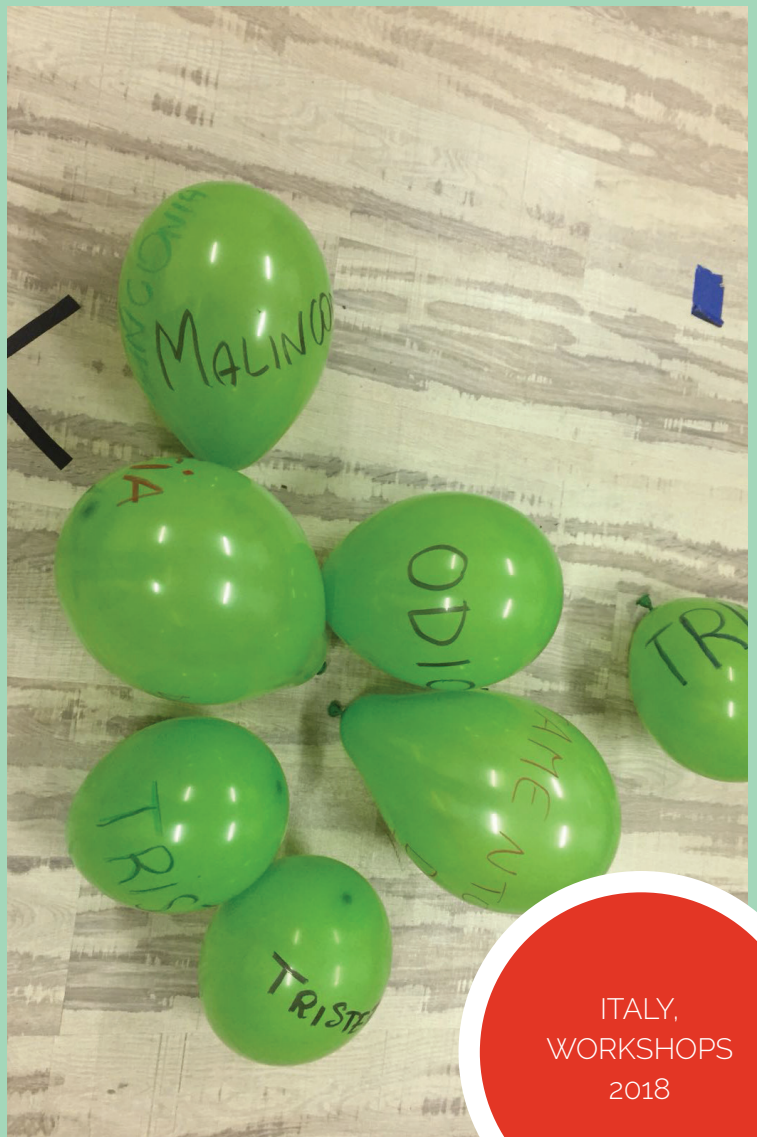
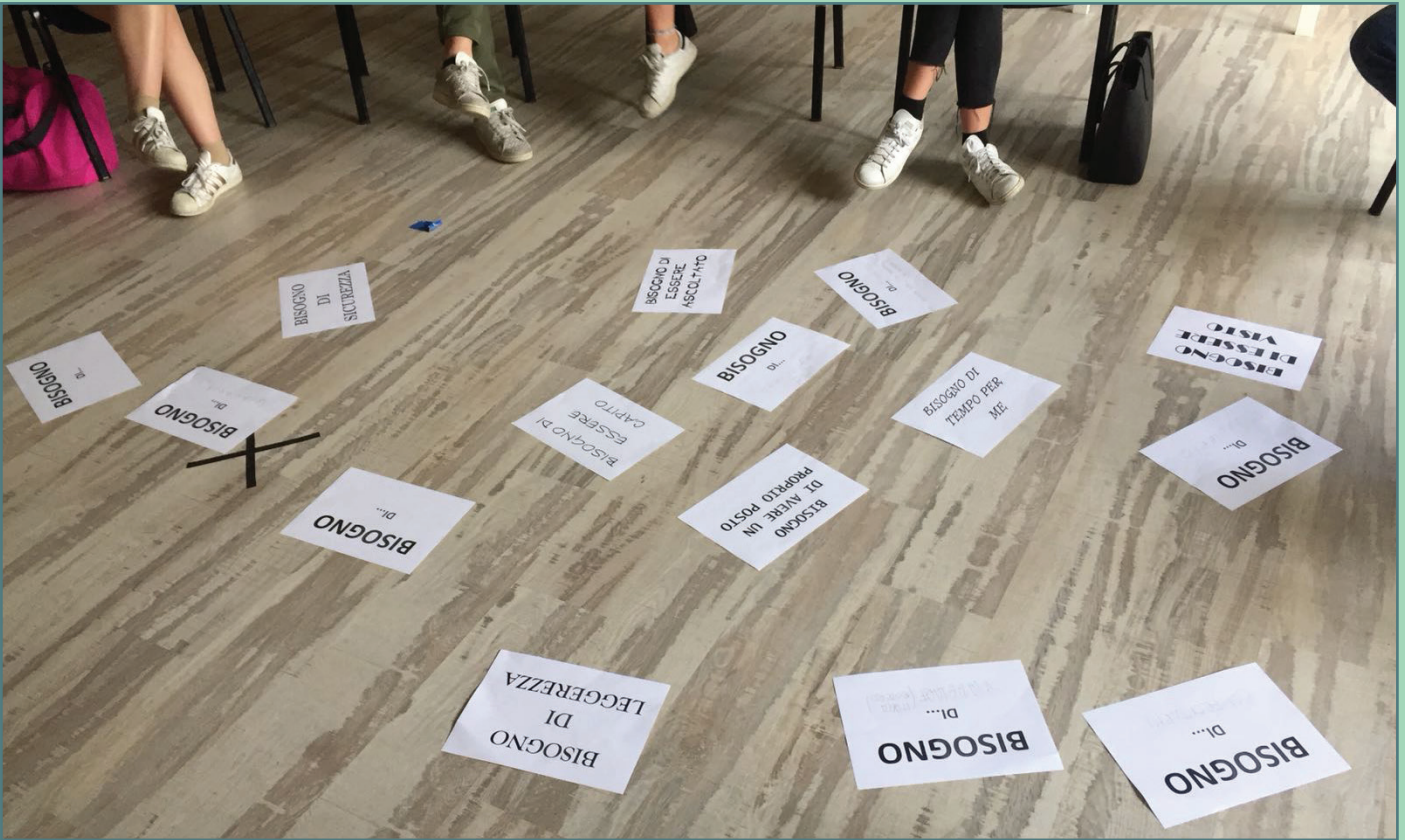
Professionals working with young people are generally motivated and committed to helping them to live happy lives and fulfil their potential. They are often practical and resourceful. They may be willing to support important campaign work by advocating on the issues of importance to the groups that they work with, particularly if the project is led by the young people in the service. The relationships they build with young people are based on trust which is likely to help them guide young carers to reliable support and resources. Education institutions are often seen as safe spaces for young carers – a place they are expected and committed to be at for a significant portion of each day during the academic year. Knowledgeable and supportive teaching and ancillary staff provide an opportunity for young people to trust an independent authority figure who can advise and support them in seeking resources that will allow them to access services that will benefit them.

Education and support staff should consider the possible family dynamics if they think a young person may be a carer and should be alert to possible signs of caring (which may include, but not limited to, unusual tiredness or aches and pains; academic underachievement; mood swings; isolation or being left out).

WANT TO KNOW MORE OR TO CONTACT US?

Visit: <http://www.ep-yc.org/partners/>

¹Baseline surveys of professionals and youth leaders by EPYC partners indicated low and very low levels of awareness and understanding of young carers.





SCOTLAND,
WORKSHOPS
2018

