ME WE
young carers

THE ME-WE MODEL

A co-created and scientifically tested support programme for adolescent young carers

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ME WE young carers

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Carers Trust	United Kingdom	CARERS TRUST
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The Netherlands Institute for Social Research	The Netherlands	The Netherlands Institute for Social Research
The national Centre of Expertise for Long-term Care in the Netherlands (Vilans)	The Netherlands	Vilans
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More information: **www.me-we.eu**

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Who should read this brief and why?

This brief targets professionals working with youth (school professionals, youth workers, staff of voluntary/carers organisations), or having a high chance of 'meeting' young people with caring roles in their work (health, care professionals and social workers), as well as policymakers across Europe and beyond.

It presents an **ambitious and ground-breaking new support programme** – the ME-WE Model- developed for a particular group of young people: **adolescent young carers** (AYCs) i.e., young people (aged 15-17) who provide care to a family member or a friend who has a chronic illness, disability, frailty, addiction or any other condition related to a need for care.

The ME-WE Model aims to **strengthen the resilience** (the process of negotiating, managing and adapting to significant sources of stress or trauma) and improve the mental health of adolescent young carers.

It has been developed in the framework of the Horizon 2020 ME-WE project - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe (January 2018-June 2021).

The ME-WE Model holds many firsts: it is the first scientific intervention in the form of a clinical trial involving adolescent young carers. It has been **co-designed with the target audience** and it has been **tested and evaluated in six European nations** (UK, The Netherlands, Sweden, Slovenia, Italy, Switzerland), with a varied level of approaches and awareness of young carers.

This brief presents the **methodology and the main results** of the ME-WE Model, providing clear indications about the benefits of this co-created and scientifically tested support programme for young carers.

The ME-WE Model is **easy to replicate**. The ambition is for it to be implemented beyond the lifetime of the ME-WE project and beyond its core partnership. In this way, many more AYCs will have the opportunity of getting psychosocial support from a dedicated programme and will be enabled to thrive.

Background

Young carers are children and young people who provide care, assistance and/or support to a family member or a friend who has a chronic illness, disability, frailty, addiction or any other condition related to a need for care. They assume a level of responsibility that would usually be associated with an adult.

Although there are no precise figures about how many young carers there are across Europe today, some national statistics and pilot projects suggest that about 7-8 percent of children in Europe have caregiving responsibilities.

Despite the relevance of the phenomenon, oftentimes policymakers, service providers and the general public are unaware of the existence of young carers and the challenges they face. In addition, young carers themselves often don't self-identify (because they think they are simply doing what is natural to do, because they grew up in the role, etc....).

The lack of awareness of the challenges faced by young carers entails a lack of support, with a negative impact at both an individual level and at societal level. Indeed, taking on a caring role constitutes a relevant risk factor for the occurrence of both immediate and long-term problems on AYCs' mental health, well-being and development, as well as for their transitions to adulthood, social inclusion, education and employability.

AYCs are those in the age group 15-17 years. They are in a transitional phase, from childhood to adulthood. They deserve a special attention, as navigating growing up and all the challenges that life throws at them, while caring for someone, can be overwhelming.

"Sometimes I think I miss out on some of the things other people my age do, like going out with my friends and stuff like that"

(AYC participating in the ME-WE intervention)

The ME-WE Project: aim and objectives

The Horizon 2020 ME-WE project - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe - aimed to **strengthen the resilience** of AYCs in order to **impact positively on their mental health** and well-being and mitigate the negative influences of psychosocial and environmental factors.

The project consortium - led by Prof. Elizabeth Hanson and team at Linnaeus University, Sweden- consisted of prominent research institutes and NGOs from 6 European States (UK, The Netherlands, Sweden, Slovenia, Italy, Switzerland), at different stages of awareness and development of policy and services for AYCs (from advanced to none) - plus Eurocarers, the European Association working for carers.

The project lasted 42 months (January 2018- June 2021).

The project had three specific objectives: (1) to systematise knowledge on AYCs; (2) to co-design, test and deliver psychosocial interventions in six countries; (3) to evaluate what works and provide knowledge translation actions at national, European and international levels.

The systematization of knowledge - on profiles and needs of young carers, legislation and policies and successful strategies to support them- took place during the first year of the project. A layperson translation of the research findings can be found in a set of Policy briefs – 6 country specific (Italy, Netherlands, Slovenia, Sweden, Switzerland and UK) and 1 European[1].

This document focuses on the innovative framework of primary prevention interventions that have been co-designed with young carers, tested and evaluated in 6 project countries. The document will present the methodology, as well as the results, in order to show what worked – what could be improved and how. This will serve as basis to provide evidence-based actions at national, European and international levels.

The ME-WE Model: a tool for young carers to process their emotions and talk about their feelings

The ME-WE Model consists of a psychosocial intervention and a mobile app for young carers. Both have been co-designed with young carers and professionals, as they were discussed in the framework of the Blended Learning Networks (BLNs) (a diverse group of people who share common interest(s)- in this case- young people in general and young carers in particular- and contribute with some form of expert knowledge to the community by creating a learning network that meets regularly) in the earlier stages of the ME-WE project.

THE ME-WE INTERVENTION

The ME-WE intervention is a resilience-based psychoeducational programme offering the opportunity for young carers to have a language to talk about their feelings and giving them tools to process their emotions and engage in positive behaviors.

The ME-WE psychoeducational intervention is an adapted form of the DNA-V model.

FOCUS ON THE DNA-V MODEL

The DNA-V Model is used in educational and clinical contexts to help adolescents to manage their emotions, to find solutions to daily problems, to connect with their own values, to reach a level of awareness and vitality and to develop positive relationships with friends and family. The model is focussed on the development of a strong sense of oneself and gives adolescents the confidence they require to make the transition towards adulthood.

D – 'Discoverer'.
This is where we try new things and see what works.
It's where we discover what we care about.
N – 'Noticing'.
This is a space we can move to when we feel stuck and want to
increase our awareness of where we are and the choices available to us.
A – 'Advisor':
that little voice that gives you advice based on the past.
V– 'Values':
these guide you as a compass in the direction you find important.

The Italian adolescent young carers called the ME-WE Model "VOCE". VOCE is a different combination of the letters DNA-V: "Valore (Value) Osservatore (Noticer) Consulente (Advisor) Esploratore (Discoverer). VOCE means "voice". The Model gave voice to a group of young people who often do not have a voice!

During the education/training course, young people were introduced to three roles (their discoverer, noticer and advisor) and were also invited to think about what is meaningful, of value, to them. They were provided with tools in order to be able to: handle difficult thoughts, get in contact with and notice their own feelings, grow and flourish, find meaningfulness and strength/energy, develop a flexible self-image and self-compassion, and build strong social networks.

By using the DNA-V roles they were encouraged to discover not only their role as an informal carer but also the existence of other roles.

The intervention included seven two-hour group meetings, one meeting per week over a seven-week period. Trained facilitators - psychologists or other social/health professionals such as nurses or youth workers - performed the intervention. The only exception was in the UK, where facilitators were professionals already working to support young carers—rather than professionals who merely work with adolescents generally or mainly with adult carers. This is due to the strong societal awareness of young carers in the UK country context, in contrast to the other partner countries with lower levels of young carer recognition.

THE ME-WE/YOUNG CARERS APP

The ME-WE Model also includes a mobile app, co-designed with YCs at earlier stages of the ME-WE project. The app offers psychoeducational, psychotherapeutic, and social support at distance, by means of educational resources, professional and peer support.

The mobile app has the advantage of gathering information related to AYCs in one place and makes it possible for AYCs to interact with their peers and professionals, by for instance sending messages in the chat to other ME-WE participants and facilitators, comment on news, and contribute with stories about being an AYC.

The ME-WE/young carers app includes the exercises that are used during the group meetings (information about each session, films, and mindfulness exercises).

The mobile app was included as a core element of the country interventions (the ME-WE sessions) in Sweden, Switzerland, and the Netherlands respectively.

It is a multilingual product (available in Italian, Dutch, Slovenian, Swedish, Swiss French, Swiss German, Swiss Italian and English).

The ME-WE /young carers app has been published in Google Play and App Store in the summer of 2021.[2]

Methodology

RECRUITMENT AND IMPLEMENTATION OF THE ME-WE INTERVENTION

Starting from May-June 2019, until September-November 2020, the ME-WE project partners were active in recruiting participants to the ME-WE intervention.

The main recruitment channel were schools: the project partners delivered presentations with all students and school professionals and distributed fliers and posters.

At a later stage, recruitment also took place through a wider range of additional stakeholders from the health and the social sectors, including NGOs.

The recruitment in the UK was different than in the other countries: it took place via young carers' services, that is, dedicated, supportive programmes for young carers relatively widespread in England.

When the COVID-19 outbreak started, recruitment was expanded with the development of a social media strategy (through Twitter, LinkedIn, Facebook and Instagram) in Sweden and Switzerland.

Overall, **488 young carers** – over the 6 countries - **were recruited** to participate in the ME-WE intervention.

After the recruitment, a screening interview was conducted by the research team members, to assess whether the young person met the inclusion and exclusion criteria to participate in the scientific study, respectively: being aged between 15 and 17 and being responsible for the care of family members or other people of significance in their life; not already receiving psychological/mindfulness-based therapy or medications.

After screening and taking out withdrawals, the number of AYCS dropped to 278.

The young people who satisfied the eligibility criteria and the exclusion criteria were placed at random in two groups: the first group took part in the intervention programme (intervention group), whilst the other group was placed on a waiting list and was offered participation in the group meeting once the intervention group had completed their follow-up meeting (control group).

Two different methods were planned for the delivery of the ME-WE intervention: a fully face-to-face approach (adopted by Italy, Slovenia, and United Kingdom), and a blended approach that combined face-to-face and online sessions delivered via the dedicated ME-WE mobile app (adopted by Sweden, Switzerland, and the Netherlands).

Once COVID-19 hit the project countries, to comply with the restrictions and precautionary measures introduced at national levels, the study was virtualized across all six countries, including a **fully online delivery** of the ME-WE intervention.

In most of the countries, some of the AYCs had completed their participation in accordance with the original plan before the lock-down, which meant that some AYCs had both face-to face ME-WE meetings as well as some online, while others had all their meetings online.

WHO ARE THE ADOLESCENT YOUNG CARERS WHO TOOK PART IN THE ME-WE INTERVENTION?

Participants in the study were aged 15-17 and caring for a family member or a significant other. In the first case, the most commonly mentioned conditions of the carer recipient are physical, mental (most frequently mentioned: depression, anorexia or anxiety) or cognitive conditions (most frequently mentioned: Autism, Dementia and Downs syndrome).

Interestingly, among care recipients who are AYCs' friends or other close persons, the most common health condition was mental illness (concerns the Netherlands, Slovenia, Sweden, and UK), where depression, anxiety and other mental conditions are mentioned. Italy reported a variety of health conditions except addiction, and Switzerland did not report AYCs taking care of a friend or other close person.

The average age of participants was around 16 years, with the oldest participants in the intervention group coming from the UK, while the youngest were from Sweden.

In all countries the majority of participants in either the intervention or control group were female with the exception of an intervention group in the UK, where approximately half of the participants were female and half were male.

The share of participants who belong to other nationalities varied from 6.3% in the Netherlands to 40.0% in UK for the intervention group and from 0% in Italy to 37.5% in Sweden for the control group.

The number of AYCs participating in the ME-WE intervention – 278 in total- differed between the countries:

56 in Italy,
97 in Slovenia,
64 in the UK,
30 in Sweden,
27 in the Netherlands
and 4 in Switzerland.

EVALUATING THE EFFECTIVENESS OF THE ME-WE INTERVENTION

In order to evaluate the effectiveness of the intervention, a mixed method evaluation was conducted, including a questionnaire to be filled by young carers who participated in the study (both in the intervention and in the control group) and interviews/online survey to be answered by stakeholders that had been either actively involved or actively supported the development of the intervention, the information, recruitment and/or implementation of the ME-WE intervention.

Questionnaire for AYCS

The questionnaire for AYCs was administered at three different moments in time: before the seven-week intervention (T0, baseline), immediately post-intervention for the ME-WE intervention group or after 7 weeks for the waitlist control group (T1), and again at three months' follow-up (T2).

The intervention and control group were compared in terms of the changes (between T0 and T1 and between T0 and T2) observed in a series of outcome variables.

The primary research question of the ME-WE study was: "Does the ME-WE intervention promote favorable changes in AYCs' mental health and well-being outcomes compared to a control group?"

The secondary research question was: "Does the ME-WE intervention leads to greater improvements in educational or vocational outcomes than a control group?".

The questionnaire included a number of validated instruments (to measure the effect of the intervention) as well as ad-hoc questions (on how they experienced the intervention and the impact of COVID-19).

Out of 278 recruited adolescent young carers, only 213 filled in all the three questionnaires. The numbers of respondent varied across countries (in Switzerland no data is available[3]). Some participants did not complete the questionnaires due to reasons such as technical problems, lack of interest or other issues. The limited sample size is a limitation of the scientific study, but it does not undermine the broader impact of the ME-WE Model. In order to compare the results among the different project countries in relation to validated instruments (quantitative data), the scores are aggregated for countries that applied face to face intervention delivery approach (Italy, Slovenia and United Kingdom) as well as for countries that applied blended intervention delivery approach (the Netherlands and Sweden) for both intervention and control group.

Hence, four groups have been considered in the cross-country analysis: intervention group with face to face delivery approach (n=75), control group with face to face delivery approach (n=90), intervention group with blended delivery approach (n=32), and control group with blended delivery approach (n=16).

Evaluation for stakeholders

In addition to the questionnaire for AYCs, a contextual evaluation was conducted, in order to gain a deeper understanding of success factors and challenges encountered during the recruitment and implementation of the ME-WE intervention in each country. A secondary aim was to explore to what extent the recruitment efforts have contributed to an increased awareness of AYCs' situation among key stakeholders in all six partner countries and to changes in the way they work.

In total, across the 6 countries, 81 stakeholders participated in focus group/individual interviews and 100 stakeholders answered the online survey. Respondents had different professional backgrounds, often working in the health care, social care or educational sectors (e.g., psychologists, directors, social workers), former young carers, researchers and local and national level policy-makers. Some of these stakeholders were facilitators of the ME-WE groups.

Results

Research question: Does the ME-WE intervention promote favorable changes in AYCs' mental health and well-being outcomes compared to a control group?

The results to this first research question, even though not always statistically significant, due to the limited sample size, are promising and go in the right direction.

There is clear indication of a positive impact of the ME-WE intervention on the resilience of AYCs: their resilience scores at the post-intervention increased compared to the baseline, but decreased again at the follow-up evaluation. This suggests that longer-lasting interventions, or follow-up support efforts are needed in order to achieve long-term positive effects. The need for longer-term efforts is also something that a number of the young carers themselves called for. Whether the ME-WE Model should be expanded with more group meetings or followed up by another form of support, and what this form of support should be, should be further investigated.

All groups – intervention and control, in face-to-face and blended delivery approaches- increased their mindfulness skills from baseline to the follow up and we can observe a statistically significant main time effect.

The face-to-face intervention group (Italy, Slovenia, UK) was the only one that reported greater psychological flexibility at the follow-up compared to the baseline, while all other groups increased their scores, corresponding to becoming more psychological inflexible. However, changes were not statistically significant.

Research question: Does the ME-WE intervention leads to greater improvements in educational or vocational outcomes than a control group?

The results in relation to this second research question are even more evident (and statistically significant).

At the follow-up, participants in the face-to-face intervention group more often reported being able to do their homework compared to the baseline and less often reported difficulties to perform well at school/training. A similar trend was also observed in the intervention group with the blended delivery approach. In addition, participants in the control blended group reported more frequently missing school/training/work or more frequently being late for school/training/work compared to participants in the intervention blended group. Further, participants in the face-to-face intervention group also reported to worry less about the person they care for while at school/training/work.

These findings are extremely encouraging, as they prove the positive impact of the ME-WE Model on (perceived) educational attainment. Considering that young carers are a group at high risk to be Not in Employment Education or Training (NEET), the benefit of the intervention for AYCs (and for society) is evident.

More details on the quantitative findings of the ME-WE evaluation are available in the country-specific briefs[4].

The following section offers a cross-country overview of the main qualitative results from the open-ended questions that were included in the questionnaire for AYCs. These results are highly supportive of the ME-WE Model: AYCs – using their own words- clearly stressed the help they received from the intervention and the positive impact it had on their lives.

THE EXPERIENCE OF ADOLESCENT YOUNG CARERS (AYCS) WHO PARTICIPATED IN THE ME-WE INTERVENTION

What kind of help and support did AYCs get from the intervention?

AYCs from all five countries expressed positive experiences and effects as a result of participating in the intervention. The most common comment by participants is that the intervention helped them to handle difficult thoughts and feelings and to know more about themselves.

In some of the countries, adolescent young carers mentioned that thanks to the intervention they had learnt to be kind to themselves and they could find meaning, energy and power through the group sessions.

The contact with peers was valuable to young carers. Some young carers from all the countries said that they felt in a safe and non-judgemental environment in the ME-WE groups which in turn helped them to relax, feel less alone and be more willing to tell their story in the presence of other AYCs in a similar situation.

"I've had a safe place to speak about commonality between people who care and have been in similar situations. I've learned more about myself and hope to continue embracing the emotional help that the intervention has given me."

(AYC participating in the ME-WE intervention)

The intervention's impact on AYCs' life and caring activities

AYCs in all five countries[5] stated that they had experienced positive changes in their lives due to their participation in the ME-WE intervention, mainly: handling stressful thoughts and feelings in a better way; being more forgiving and kinder to oneself and/or taking better care of oneself.

"I have felt better about myself, and for the first time in a long time, I have felt that I am important"

(AYC participating in the ME-WE intervention)

Some young carers reported that the intervention made them feel more confident in their caring role and some of them started working on getting the amounts of their caring tasks reduced or were looking for solutions to the caring tasks they found most difficult or trying.

"I have been able to do less of the caring jobs that I dislike and more of the ones that I actually enjoy after talking through my feelings around my role with others and family members."

(AYC participating in the ME-WE intervention)

What did AYCs not like about attending the intervention?

The AYCs were asked about negative aspects of the participation in the ME-WE intervention groups and in all five countries some aspects were raised, although many of the AYCs had no negative remarks about the intervention. The topics mentioned differed to a great extent between the countries, though one more common theme was that the subject matter of the intervention was at times triggering emotions and reflections for them and made them feel uncomfortable, because it brought difficult situations back to the surface.

"Sometimes they forced us to think about our feelings and we were sometimes upset or depressed."

(AYC participating in the ME-WE intervention)

Most of the participants from the UK – and few from NL and SE- thought the sessions were sometimes too long.

Online sessions were considered as a plus as training could continue during the pandemic, but they were also viewed as being less pleasant and fun, and several young people found it harder to open up about their feelings online. (IT, NL, SE, SI)

Few AYCs in more than one country mentioned other negative aspects, such as too many exercises to carry out and practise at home in between the group sessions (IT, SE, SI), some sessions lacking relaxation and fun (IT, SI, UK), or not so helpful assignments, as they lacked focus on the caring situation/real situations. (NL, SE, SI, UK).

How did AYCs experience the ME-WE app?

Three countries used the ME-WE app (NL, SE, CH) that was developed and tested during the intervention phase. Data is only available from the Netherlands and Sweden[6].

Most of the AYCs in SE and NL stated that the app had been helpful and supportive.

Many AYCs in both SE and NL would recommend the app to other AYCs and stated that the app provided functionalities that they could not find in another app/services.

AYCs in SE especially appreciated the stories, the information pages, group exercises, the puzzle pieces and the chat.

Negative reviews were all related to technical aspects based on the fact that the app was still undergoing development during the time of the intervention. This was due to the COVID-19 pandemic which led to a fully online approach and the need to further adapt the ME-WE app accordingly.

How has COVID-19 pandemic affected AYCs' lives and health?

AYCs were asked about how COVID-19 affected their lives. Many of the aspects raised concerned life in general during the pandemic rather than specifically relating to the ME-WE -groups.

One of the main differences between the AYCs in the participating countries at T1 (that is, second data collection point that took place directly after the end of the ME-WE groups) is that more respondents from Italy, Netherlands and Slovenia reported positive changes rather than negative changes, while the vast majority of the AYCs from Sweden and the UK reported negative changes resulting from the impact of COVID-19 on their lives. The most common reported positive change was

the experience of having more time for themselves, to spend on favourite activities or for self-reflection. Additionally, more time with the family was appreciated, making some of the AYCs more relaxed.

Furthermore, AYCs in some countries reported the online school being less demanding.

Among the negative responses, social isolation or not being able to meet up with friends was the most common. This, as well as an increased level of caring responsibility, the feeling of being left alone with the care recipient, and increased worry for the care recipient when not being allowed to see her/him, affected wellbeing and, for some AYCs, their mental health as well. Furthermore, loneliness and depression were reported.

"Surely it affected because a person with a fairly weak social network like me found himself practically more alone than usual for a long time."

(AYC participating in the ME-WE intervention)

"Because of COVID-19 I feel that people have forgotten about my caring role or that I do not need help anymore, when I need it more than ever."

(AYC participating in the ME-WE intervention)

How did AYCs experience participating in the intervention during the pandemic?

Young carers mentioned positive aspects of attending the meetings in general, which were connected to having contact with other AYCs, being positive to online meetings and helping to create meaning and routines during the pandemic.

"The experience has been very positive and has helped to cope with the pandemic, the activities were really helpful and taught me so much in lockdown."

(AYC participating in the ME-WE intervention)

Negative aspects mostly concerned the online form, online groups were not deemed to be as desirable to the AYCs as meeting face to face. Some AYCs experienced fatigue from the sheer amount of online activities that increased throughout the pandemic (e.g., online school classes) and the ME-WE groups in some situations only added to their sense of fatigue.

THE OPINION OF STAKEHOLDERS ON THE ME-WE MODEL

Success factors

Experience of the ME-WE intervention as a whole

Overall, in all six countries stakeholders were highly positive about the ME-WE Model.

- According to several participants, one of the most positive contributions of the ME-WE project was the development and provision of a **support programme which specifically targeted AYCs**. As professionals they felt that they therefore had something concrete to offer YCs whom they made contact with.

"Sometimes they forced us to think about our feelings and we were sometimes upset or depressed. "

(AYC participating in the ME-WE intervention)

- The ME-WE programme based on the DNA-V model was considered **highly relevant**, as it highlighted strengths and values in the lives of young carers.
- Participants felt that it was positive for AYCs to have an intervention where they can **share their story with other AYC**s, as their friends do not always understand what they are going through.
- Participants appreciated the **involvement of the target group** (AYCs or former AYCs) in the implementation process (for example, as research assistants in the NL) and the **cooperation between the research team and stakeholders**.
- The value of research to lead to **evidence-based support interventions** for AYCs was appreciated, as it was the international dimension of the study.
- **Facilitators** noted that, even though the ME-WE programme focuses on AYCs, it was **beneficial also for them**, for both their professional and personal lives.

"You don't teach this programme, you walk through this programme. It's not a programme that you teach a kid, it's a programme you walk through with a young person. When you said a lot of staff are saying that they got so much out of it, because that's the way it works, is that you go through it together"

(AYC participating in the ME-WE intervention)

Enhanced knowledge and awareness of AYCs

Stakeholders in different countries (CH, NL, SI) reported that - due to the ME-WE project- awareness on AYCs increased amongst different groups: teachers, other professionals, YCs, peers, parents, the general public and at a political level. This was

"Being confronted with the challenges experienced by AYCs makes the issue real. AYCs are everywhere. [...] YCs should be considered as a mainstream topic."

(AYC participating in the ME-WE intervention)

achieved by dissemination of information and facilitating network building among (other) organisations working with young carers. For example, in the Netherlands the ME-WE project enabled a better connection between schools/care support centres. In Sweden, it enabled increased collaboration between different municipal departments, namely between social services, health care, youth centres and schools. Even in Switzerland, a country that had the lowest number of recruited AYCs, the results in terms of awareness raising were impressive. For example, several students in health schools are now aware of the topic and as they work in contact with patients and families, they now will be able to respond if they come into contact with YCs. Also of importance is the awareness raising that has taken place at the political level (the Swiss National Health Department is now aware of the topic and this was viewed extremely positively by participants).

"What I also learned; I say very often, and I've said many times, you are young carers while now I think, oh dear, you are growing up as a young carer, but you are also growing up as; who else are you, you are so much more. So that has also helped me to look at my own work as a counsellor in a very different way, so that's also a big plus"

(Facilitator of the ME-WE intervention)

Changes in work with adolescent/young carers

In all countries, except the UK –given its specific, advanced context with regards to the awareness and policy and service responses to the situation of YCs- the majority of the stakeholders expressed that they had become more aware of the existence of YCs and YCs' life situations, and/or more aware of the likelihood that in their profession they often meet young carers without knowing it. These stakeholders explained that **their increased awareness had led them to change their way of working with young people.**

For example, the ME-WE project enabled professionals to:

- be **more attentive to any signals of a caring role**
- **discuss the topic more readily** with their colleagues and their broader professional networks.
- Use **tools not only to talk about but also talk with AYCs.** This includes providing alternatives in vocabulary to reach out to AYCs addressing that a label may be stigmatizing and caregiving may be considered as a normal part of life of youngsters (NL). It also includes explicitly asking questions on any challenges in the home situation in case of frequent absence at school (CH).
- In the UK, with a relatively strong societal awareness on AYCs and professionals experienced in supporting AYCs, changes in work procedures of stakeholders related to the ME-WE method further strengthening the professionals' skills. Similarly, In the Netherlands, Sweden and Italy some stakeholders also addressed that the ME-WE method has provided them with an **extra tool in their toolbox** to enhance their work with young carers, in particular, those in the adolescent phase.
- Some facilitators noticed that their view on AYCs changed with **more recognition of the other roles young people with caring tasks** have instead of merely focusing on their role as an AYC.

What can be improved

Information material and communication

Stakeholders pointed out that some of the information and recruitment materials lacked appeal to the AYCs and their families and that the project was a difficult "sell". The benefits of this particular intervention was not able to be communicated so clearly in all situations, since the intervention itself was being delivered as an evaluative study. It was recognized that the focus in the communication materials was perhaps too much on the research aspect of the ME-WE groups and not enough on what young carers could concretely get out of the groups.

Recruitment and engagement of AYCs

All countries reported challenges in recruiting AYCs. In this regard, issues related to the risk of stigmatization were mentioned most often: **many young carers do not want to be stigmatized due to the topic still being taboo**. This can be said to be especially true for adolescent young carers, who often simply want to fit in.

Stakeholders pointed out that **cultural aspects acted as a barrier and hindered the recruitment**. For instance, in Switzerland, the "family culture" entails that caring tasks and the resulting burdens are expected to remain "within the family". Joining an intervention and talking about what is going on at home might be seen as a betrayal of their own family. AYCs might also feel ashamed of the situation and be fearful of an intervention by child protection authorities. In Slovenia, caring is regarded as a part of normal family functioning as the family plays an important role in the architecture of the welfare system, acting as one of the main providers of care besides the State. Caring is also considered as a family obligation.

A second widely experienced issue relates to the availability of resources for recruitment such as limited time of school staff.

In IT, CH, SI, stakeholders stressed the **low awareness on AYCs in their country** – among professionals and young carers themselves - as an important obstacle to recruitment. In Switzerland, participating stakeholders reported that it is **challenging to conduct research before raising awareness about a topic**. Therefore, before conducting research, they argued that it is ideal to have an initial level of awareness about a topic among the general population, among professionals and at the political level. It was acknowledged that approaching this the other way around can be problematic at times. However, according to a participant, research also brings about awareness. It is therefore not so straightforward to say which process should take place first.

All countries also reported challenges related to the scientific study, namely the age-restriction, the exclusion criteria and the need to obtain guardians' consent to participate in the ME-WE intervention (particularly challenging for those young carers who had a parent with mental illness or addiction). Stakeholders noted that AYCs who are used to caring for others in the first place, might find it difficult to start focusing on themselves and their own needs. It was also pointed out that it takes courage to take part in an intervention. Some AYCs might not feel ready to discuss a difficult topic.

Some challenges were specific to the target group:

- In some countries, AYCs were in-between two different school systems (i.e., mandatory school and vocational or high school). In this situation, students experienced new teachers and social workers. They may not have had a have a person to go to as a point of reference if they wished to discuss issues that burden them.
- Moreover, young people in this age range have other priorities and might not be willing to deal with a difficult and sensitive topic.
- The target group is often extremely busy. Besides school and education, they also have their caring tasks, their hobbies and a private life. The intervention might have been seen by them as something that required even more time, which they often do not have. Taking part in the intervention might be seen as additional 'schoolwork' and AYCs may prefer to dedicate any free time to their hobbies, sports or other leisure activities.

The ME-WE intervention

Although participants recognised that it was necessary to have a strong structure for the intervention (in order to both achieve the programme's goals and to allow the international comparison) several reported that the structure might pose a challenge in itself. The main reason given was that they considered there is little freedom and flexibility in the organisation of the groups (e.g., regarding the target group and in the length of the meetings).

Participants also noted the fact that the intervention was a one-time intervention, with no other programmes post-intervention was also a limitation.

"How do we take care of the young people after the research study? It feels important that we offer them something where they can continue to receive support and help if needed. I think that, as we have made them open up and given them support, we also want them to continue to feel confident that we will not be another instance or adults who fail."

(Stakeholder involved in the ME-WE intervention)

In order to address this concern, in all six countries the project partners had discussions in their BLNs on how to best sustain the ME-WE Model post-project and this included an exploration among the key stakeholders about how to best continue to offer support to participants AYCs post ME-WE.

The impact of COVID-19

According to the stakeholders, COVID-19 had the following positive outcomes:

- The pandemic led to more discussions about mental health issues and the importance of protecting one's mental health. It also showed the need to look after children who are living in difficult situations, such as young carers.
- The online delivery of the ME-WE groups furthered the programme's inclusiveness, as it allowed AYCs in hard-to-reach areas, or those AYCs who are not enrolled in school or education to access the training. These geographically mixed groups of AYCs also led to an increased sense of integrity for the group members, as they did not know each other's teachers or families for example (SE).

On a negative note,

- If AYCs wanted to take part in the intervention they most likely had to do that at home. This might have posed several challenges, such as the lack of technical equipment or a lack of privacy from a family being in the same place and potentially hearing what is being said.
- Some respondents felt that the online modifications made it less easy to monitor the emotional well-being of the AYCs in the group sessions, as the AYCs could turn their cameras off at any time for any reason.
- Some facilitators found it challenging to switch to a fully online mode of the ME-WE -groups, due to unfamiliarity with facilitating sessions online and a lack of digital skills.

Suggestions for the future

Information material and communication

The main suggestion was to adapt the communication around the project, in order to make it more attractive. It was noted that AYCs need to see the benefits of the programme and they should see it as something special for them, as well as an opportunity to have fun and respite.

Caring should be presented in a positive way, as something to be proud of, rather than in a deficit-oriented way, as a problem.

"I think there is something problematic with the concept. How do you, as a youngster, want to identify yourself? […] Do you want to be a victim of difficult circumstances? […] As a carer you are something, and you do something competent. […] If we could find a concept that makes you want to… that attracts young people, that make them want to be a part of this, like 'I want to be a scout', 'I want to be an AIK member'…."

(Stakeholder involved in the ME-WE intervention)

Stakeholders called for a variation in the information (as all YCs are unique) and for a combination of different communication channels (films on social media, posters, brochures, information meetings in schools, youth centres, NGOs etc.)

Hiring a professional promoter or an influencer on social media, with the mission to be an ambassador for YCs could also prove successful.

Overall, the importance of the information material and the communication to be more youth-friendly and more accessible to the target group was emphasised.

Recruitment and engagement of AYCs

Participants highlighted the need for a systematic and broad approach to recruitment involving a variety of stakeholders that also includes youth workers, the health sector, social workers, employment agencies, influencers and families and aims to reach those AYCs who may be harder to reach and not in education or training (NEET).

In particular, they stressed the importance of further engaging professionals who already have positive and trusting relationships with youngsters (e.g., youth leaders, student coaches, school nurses, and school social workers), as they can employ a more personal approach to recruiting them.

The ME-WE programme

Stakeholders suggested to fine-tune the ME-WE intervention programme, in order for it to better meet young carers' needs and preferences.

1. The ME-WE intervention needs to be targeted at a **much wider age range**, from children in early school age (in recognition of the fact that young caring often begins in early childhood), to young adults.
2. A **continuation for AYCs after the last session** should be provided (e.g., continued contact with facilitators; a chat group; local/regional/national/international AYC meetings; to help AYCs connect to a community).
3. The **ME-WE training/education could be combined with other, more fun activities**.

"We'd like to do an hour of ME-WE and we'd get a bit of cooking, so we'd extend the session. That way, the project is an easier sell to the young people. Also, so that the talk continues over the activity. They're still thinking about it, they're still processing it, but they're doing an activity."

(Stakeholder involved in the ME-WE intervention)

4. A **variety of different types of support offer need to be provided**, as YCs have a range of different needs. It follows therefore that different YCs are likely to prioritise different types of interventions based on what each intervention has to offer and the benefits they bring about.
5. Sufficient **psychological support needs to be provided to AYCs (and facilitators) post groups**, as taking part in resilience training has the potential to bring a lot of emotions and issues to the surface.
6. The exclusion criteria (already receiving psychological/mindfulness-based therapy, medications) could be softened, to avoid rejecting some young people who might want to participate and whom could potentially benefit from the programme.
7. When offering future groups, consideration should be given to the engagement barriers that were found, for example: running groups at the quietest times in the academic year to mitigate the issue of time pressure; offering flexibility with the timings of groups (asking AYCs the most suitable times) and providing varied support options - both fully online and blended (online/face to face). The preferences of AYCs as to whether to receive the training inside or outside the school environment setting (e.g., in carer support centres) should be taken in consideration.
8. Exercises to be carried out in between the group sessions were advised (by several participants) to be either removed completely or signific

Recommendations for policy and practice

RAISE AWARENESS

There is clear indication that the ME-WE Model can be effective in fostering the resilience of AYCs and mitigating negative caring outcomes.

Yet, the challenges experienced in recruiting prove that, for the support to be taken up, it is crucial that the AYCs are recognised and identified by professionals in the youngsters' daily life environment. Hence, further work is needed for raising the awareness and the appropriate knowledge and competences among professionals so that they can really recognise and orient AYCs towards useful interventions such as the ME-WE Model.

Early recognition is crucial and schools have a key role in this regard, as they are often the sole contact point where -almost- all adolescents are present. A possible action point is to discuss the topic of informal care in thematic lessons in classes, preferably with attention for personal stories of (former) AYCs.

National governments can contribute to turning informal care into a subject for discussion in the classroom, but also outside the classroom by increasing the knowledge and awareness about young informal carers through national informal campaigns (as the recent social media campaign entitled #Deljezorg in the Netherlands).

With increased recognition of the issues and impacts of being an (A)YC, AYCs would more likely identify themselves as such, better recognise their own needs and be more inclined to reach out for support.

TRAIN PROFESSIONALS

It is essential for professionals working with youth (such as teachers), but also professionals with a high probability of 'meeting' young people with caring roles in their work (such as home care staff, primary health care physicians/GPs and pharmacists) to learn to recognize AYCs and to be able either to support them or to refer them to support services in their locality.

Health care professionals should adopt a **whole family approach** in their work, based also on the needs of AYCs' families at large, including children in the household. Professionals could initiate the conversation with AYCs to assess their needs. Depending on the assessment, young carers could be directed to low-threshold initiatives (such as joining the online AYCs community offered by the ME-WE app) or they could be offered more tailored support (such as the ME-WE Model).

CREATE A SUPPORT NETWORK

Any psychoeducational program targeted at AYCs should be supported by a large network of stakeholders that can involve the youngsters at local level, including stakeholders from the educational, health, social and leisure sectors, as well as policy makers.

Organising regional networking meetings can be of use here. In these types of meetings young informal carers could meet up with professionals to exchange knowledge and experiences about suitable support for young informal carers.

RECOGNIZE THAT TECHNOLOGIES ARE NOT A LUXURY BUT A GATEWAY TO ACCESS AND PROVIDE SUPPORT

The online delivery of the ME-WE programme exposed already in-place inequities present in the lives of vulnerable children like AYCs: more young carers than expected did not have access to computers, webcams and a reliable internet connection. Governments must view such technologies as critical in the lives of young carers. Far from being a luxury, sound technology facilities can act as a gateway to access support and prevent social exclusion.

The online mode of delivery also highlighted that practitioners themselves may not have technologies such as computers or high- speed internet at home. Governments should ensure that formal support services are more adequately financed and resourced with modern technology for its staff.

CO-DESIGN SUPPORT WITH YOUNG CARERS

The active participation of (A)YCs should underpin the development of all policy and practice for them. By listening to their experiences, it is possible to better understand and address their needs. YCs should be actively involved at all stages; from the identification of their needs and preferences, to the co-production of support interventions, including the recruitment and communication phases. YCs are experts from their lived experiences, and listening to their stories and their opinions is essential for successfully supporting and empowering them.

ENSURING THE SUSTAINABILITY OF THE ME-WE MODEL

A strong foundation for future interventions has been laid by the ME-WE Model.

The programme – with the adaptations suggested by the evaluation findings to better meet AYCs' needs - can be utilised by young carers around the world. It can be implemented in the form of physical group meetings locally, or as online meetings on the national level. It can also be delivered in a camp format (as exemplified in the Slovenian application of the ME-WE model).

The groups can be led by professionals from social services, student health programmes, or youth activity centres - preferably through a collaboration between these operators.

Given more time to prepare and without the external influencing factors such as a global pandemic, the programme is expected to have an easier replication.

It would appear important therefore not to lose the momentum that has been developed with regards to awareness and recognition and to capitalise on and expand the existing stakeholder network that the project has established.

The ME-WE project partners are eager to uphold the legacy of the ME-WE project: all six partner countries have been working in their BLNs and wider networks to sustain the learnings and the ME-WE Model when the project officially ends.

In Sweden, the Swedish Family Care Competence Centre, of which Linnaeus University acts as the research partner, secured the support of the National Board of Health and Welfare Sweden to reach out to all 290 municipalities across Sweden, targeting health, social care, youth centres, school staff and representatives from civil societies. The Swedish Family Care Competence Centre

will provide information and education on young carers and the ME-WE Model to municipalities, health care regions and organizations; support those who want to implement the ME-WE model including systematic follow-up work and evaluation; train the future facilitators and administrate the ME-WE app. Three municipalities have already been identified to pilot the ME-WE Model after June 2021.

In Switzerland, they are planning to integrate and to sustain the results of ME-WE into new projects. For instance, some of the ME-WE sessions can be integrated in Get-Togethers, groups of young carers between 15 and 25 meeting regularly and informally. The ME-WE app will be showcased in a web-based network map of support organisations for YCs and professionals.

In the UK, exploratory discussions with internal and external stakeholders have taken place to discuss the possibility for the network partners of Carers Trust to implement the ME-WE Model after June 2021.

In the Netherlands, in order to enable the use of the ME-WE intervention including the ME-WE mobile app after the end of the ME-WE project, a detailed information package including instructions and terms for use of the ME-WE groups and app was developed and made available online[7]. Promotional materials (e.g., information letter, social media post) were created in order to inform a wider audience about the ME-WE Model.

In Italy, the project partner Anziani e Non solo (ANS) plans to implement interventions for young carers according to the ME-WE model and to organize training for professionals aiming to replicate the model. ANS has committed to maintain the update of the Italian version of the ME-WE/young carers app and to disseminate it as a stand-alone self-development tool for AYCs.

In Slovenia, the NGO Sonček - which implemented the ME-WE Model in the framework of a 7 days summer camp for siblings - is eager continue to implement the ME-WE Model in the form of a Summer Camp for the next years.
The ME-WE programme will be available to interested stakeholders for non-commercial use.
The ME-WE /young carers app is available on Google Play and App Store in EU, EEA and EFTA states and the UK[8].

If you want to receive/deliver the ME-WE programme in your school, organization, centre, do not hesitate to contact the ME-WE project partners to agree on next steps[9].

Remember:
We all have a role to play to enable young carers to thrive!

By adopting the ME-WE Model in your daily work, you will help us ensure that many more AYCs will receive the chance to benefit from this co-created, and scientifically tested intervention for young carers to strengthen their resilience and improve their mental health and wellbeing.

"We should never underestimate the power of individuals to make a difference. You could be one of those people. You just might not know it yet."

(Project partner Prof. Saul Becker, University of Sussex, UK)

Endnotes

1. The Policy Briefs can be found on the ME-WE Project website: https://me-we.eu/internal-resources/
2. The ME-WE/young carers app can be found on Google Play (https://play.google.com/store/apps) and in App Store (https://www.apple.com/app-store/).
3. In Switzerland there was a low number of participant AYCs and they did not complete the evaluation questionnaire at the second and third data collection points. As a consequence of this lack of data, more learning came from the evaluation of contextual data, i.e., the online survey and focus group interviews with key stakeholders and former YCs.
4. The country-specific briefs can be found on the ME-WE Project website at: https://me-we.eu/internal-resources/
5. In Switzerland there was a low number of participant AYCs and they did not complete the evaluation questionnaire at the second and third data collection points.
6. In Switzerland there was a low number of participant AYCs and they did not complete the evaluation questionnaire at the second and third data collection points.
7. The ME-WE Package developed by the Dutch project partners can be found here: https://www.zorgvoorbeter.nl/nieuws/week-van-de-jonge-mantelzorger
8. The ME-WE/young carers app can be found on Google Play (https://play.google.com/store/apps) and in App Store (https://www.apple.com/app-store/).
9. The ME-WE project partners contacts can be found on the ME-WE Project website at: https://me-we.eu/partners/

Glossary

AYC	Adolescent Young Carer
BLN	Blended Learning Network
CH	Switzerland
IT	Italy
NL	The Netherlands
SE	Sweden
SI	Slovenia
UK	United Kingdom
WP	Work Package
YC	Young Carer

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More information: **www.me-we.eu**
#youngcarers

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