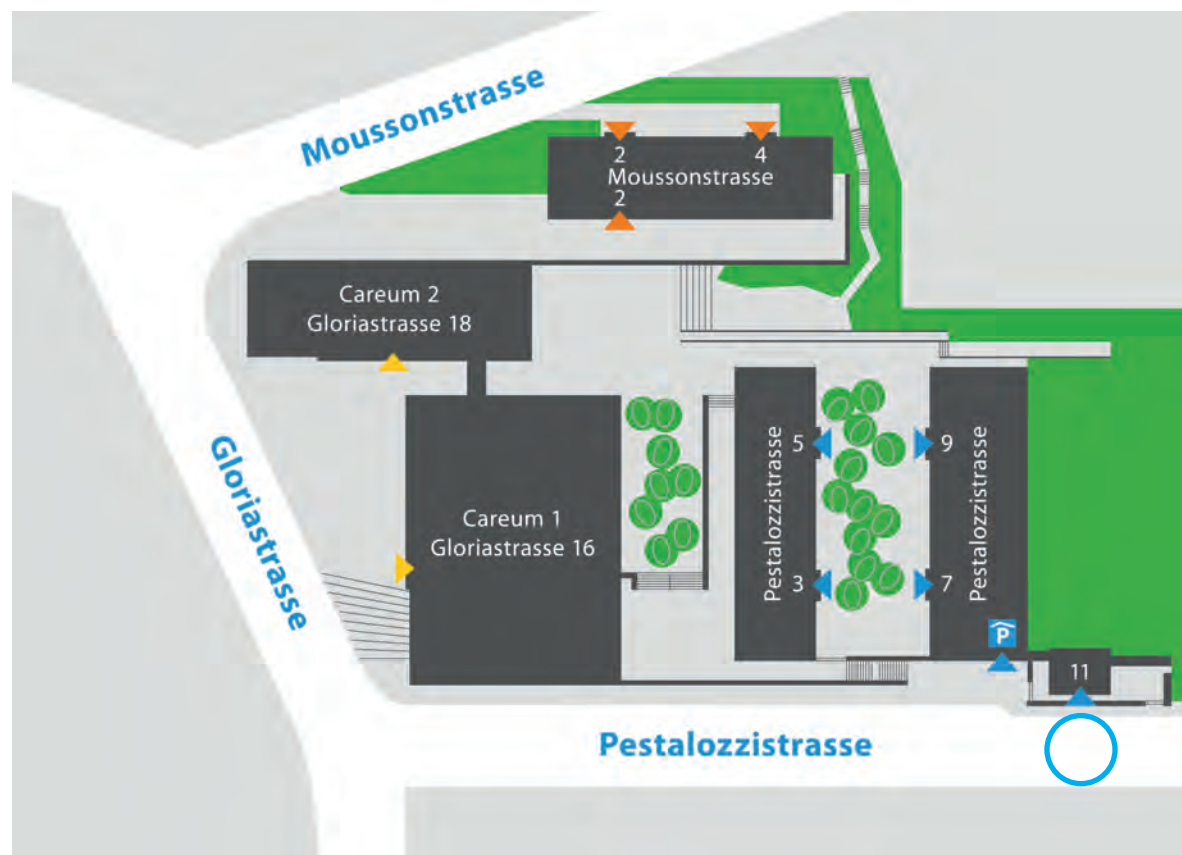


SNF End of Project Conference «Young Carers in Switzerland»

12. November 2019
Careum Auditorium
Pestalozzistrasse 11
8032 Zürich



So kommen Sie zum Careum Auditorium



Careum Auditorium
Pestalozzistrasse 11
8032 Zürich

Das Careum Auditorium befindet sich an zentraler Lage im Bildungsquartier von Zürich, Nähe Universität Hauptgebäude, in der Pestalozzistrasse 11.

Es ist nur wenige Meter von der Tramhaltestelle «Platte» entfernt.

Aufgrund der beschränkten Anzahl Parkplätze empfehlen wir Ihnen die Anreise mit dem öffentlichen Verkehr.

Anfahrt öffentliche Verkehrsmittel:

Tram Nummer 6 ab Hauptbahnhof bis Haltestelle «Platte»

Tram Nummer 5 ab Bellevue bis Haltestelle «Platte»

Anfahrt Auto:

Im Careum-Parkhaus steht nur eine beschränkte Anzahl Parkplätze zur Verfügung!

Careum Hochschule Gesundheit, Forschung, Pestalozzistrasse 5, CH-8032 Zürich
youngcarers@careum.ch, www.careum-hochschule.ch

Programm

SNF End of Project Conference «Young Carers in Switzerland»

Dienstag, 12. November 2019

Careum Auditorium

Pestalozzistrasse 11

8032 Zürich

Hashtag für Twitter
#youngcarersCH



careum Hochschule Gesundheit
Teil der Kalaidos
Fachhochschule

FN SNF
SCHWEIZERISCHER NATIONALFONDS
ZUR FÖRDERUNG DER WISSENSCHAFTLICHEN FORSCHUNG

**EURO
CARERS**
European Association Working for Carers

Young Carers in der Schweiz

Es ist noch immer zu wenig bekannt, dass auch Kinder, Jugendliche und junge Erwachsene pflegebedürftige Nahestehende unterstützen. Der Forschungsbereich der Careum Hochschule Gesundheit beschäftigt sich in einem mehrjährigen Forschungs- und Entwicklungsprogramm seit 2014 intensiv mit diesen jungen Menschen. Das Ziel unserer Forschung ist es, konkrete Unterstützungsmassnahmen zu erarbeiten und Fachpersonen zu sensibilisieren und zu vernetzen.

Es gibt viele Familien, die von physischen oder psychischen Erkrankungen, Beeinträchtigungen, Sucht oder altersbedingten Gebrechen betroffen sind. Oftmals sind dabei auch Kinder und Jugendliche entscheidend in die Betreuung und Pflege nahestehender Personen eingebunden, sei dies vorübergehend oder während mehrerer Jahre. Diese teilweise herausfordernden Situationen werden häufig weder vom sozialen Umfeld, noch von Fachpersonen oder der Öffentlichkeit wahrgenommen.

Nationale Datengrundlage erarbeiten

Kinder, Jugendliche und junge Erwachsene, die regelmässig Betreuungsaufgaben für nahestehende Personen übernehmen, werden international als «Young Carers» (unter 18 Jahren) bzw. «Young Adult Carers» (unter 25 Jahren) bezeichnet. Für die Schweiz fehlten bis vor kurzem verlässliche Daten zur Situation von Young Carers. Das vom Schweizerischen Nationalfonds geförderte Forschungsprojekt «Kinder, Jugendliche und junge Erwachsene als pflegende Angehörige in der Schweiz» schliesst diese Forschungslücke. Im Rahmen der Tagung werden unter anderem die Resultate vorgestellt.



Konferenzthemen

- «Learning from others» - Young Carers im internationalen Vergleich
- Ergebnisse zum Bewusstsein von Fachpersonen in der Schweiz
- Ergebnisse der nationalen Prävalenzstudie
- Unterstützungsbedürfnisse von Young Carers und ihren Familien
- Erfahrungsberichte von Young Carers
- Ansätze für die weitere Entwicklung einer nationalen Young Carers-Strategie

Simultanübersetzung

Die Referate und Diskussionen werden in Deutsch oder Englisch präsentiert. Sie werden simultan auf Englisch oder Deutsch übersetzt.

Anmeldung

Die Veranstaltung ist öffentlich und die Teilnahme kostenlos. Da die Platzzahl beschränkt ist, bitten wir Sie, sich rasch anzumelden unter: youngcarers@careum.ch

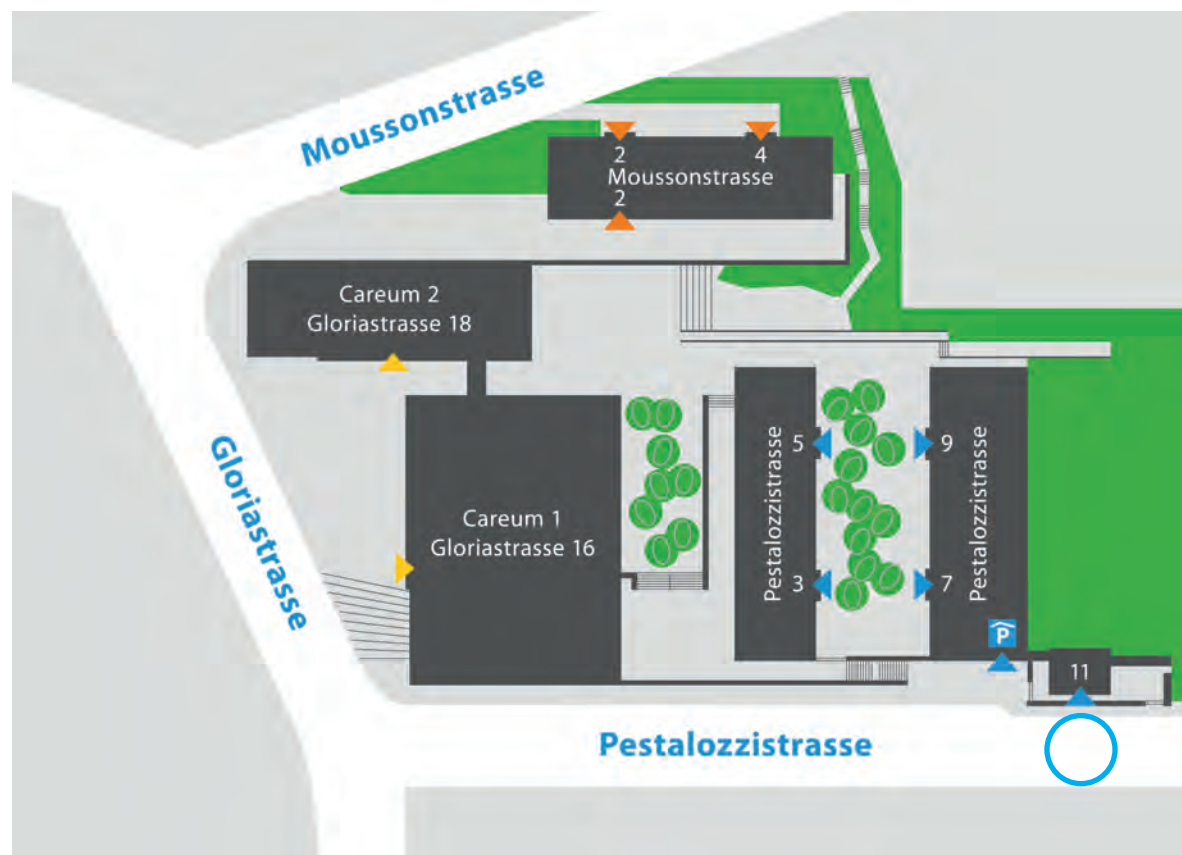
Hier mehr erfahren:



Programm 12. November 2019

ab 8.30	Registrierung und Kaffee
09.00–09.15	Begrüssung Prof. Dr. Agnes Leu, Direktorin Forschungsprogramm «Young Carers», Careum Hochschule Gesundheit, Zürich Prof. Dr. Saul Becker, University of Sussex, Grossbritannien
09.15–09.45	Eröffnung Francesca Centola, Eurocarers
09.45–10.30	Einblick in die nationalen Forschungsergebnisse Präsentation der Resultate des SNF-Projektes «Young Carers in Switzerland» Prof. Dr. Agnes Leu, Marianne Frech, Sarah Rabhi-Sidler, Fabian Berger Careum Hochschule Gesundheit, Zürich
10.30–11.00	Pause und Austausch
11.00–12.30	Young Carers im internationalen Vergleich Wie unterstützen andere Länder Young Carers? Laura Bennett, Carers Trust, Grossbritannien Licia Boccaletti, Anziani e non solo società cooperativa sociale, Italien Dr. Henk Herman Nap, Technische Universiteit Eindhoven, Niederlande Malla Heino, Carers Finland, Finnland Dr. Feylyn Lewis, University of Sussex, Grossbritannien / Vereinigte Staaten von Amerika Prof. Dr. Aurélie Untas, Université Paris Descartes, Frankreich
12.30–13.30	Mittagspause
13.30–14.15	Young Carers im Gespräch Moderierte Gesprächsrunde, Feedback und Fragen aus dem Publikum Fabienne, Lynn, Yvonne Oppliger, Fabian Berger, Prof. Dr. Agnes Leu, Prof. Dr. Saul Becker
14.15–15.15	Podiumsdiskussion mit Personen aus den Bereichen Bildung, Gesundheit und Soziales Was sind unsere nächsten konkreten Schritte? Dr. med. Thomas Ihde-Scholl, Chefarzt psychiatrische Dienste der Spitäler fmi AG und Präsident Pro Mente Sana Dagmar Rösler, Zentralpräsidentin Dachverband Lehrerinnen und Lehrer Schweiz Barbara Schmid-Federer, Präsidentin Schweizerisches Rotes Kreuz Kanton Zürich David Welten, Berater Pro Juventute Dr. med. Gian Bischoff, Kinderarzt und Mitglied der Jugendhilfekommission der Bildungsdirektion Zürich Prof. Dr. Agnes Leu, Prof. Dr. Saul Becker
15.15–15.45	Take Home Messages und Verabschiedung Prof. Dr. Saul Becker, Prof. Dr. Agnes Leu

How to get there



Careum Auditorium
Pestalozzistrasse 11
8032 Zürich

The Careum Auditorium is located at Pestalozzistrasse 11 – in the educational district at the heart of Zurich. It's only a few steps away from the tram stop "Platte".

Given the limited number of parking spaces, we recommend you arrive by public transport.

Arrival by public transport:

Tram number 6 from main station to stop "Platte".
Tram number 5 from Bellevue to stop "Platte".

Arrival by car:

There is only a limited number of parking spaces in the Careum parking lot.

Careum School of Health, Research, Pestalozzistrasse 5, CH-8032 Zürich
youngcarers@careum.ch, www.careum-hochschule.ch

Program

SNSF End of Project Conference «Young Carers in Switzerland»

Tuesday, 12th November 2019
Careum Auditorium
Pestalozzistrasse 11
8032 Zürich

Hashtag for Twitter
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careum School of Health
Part of the Kalaidos University
of Applied Sciences

FN SNSF
SWISS NATIONAL SCIENCE FOUNDATION

**EURO
CARERS**
European Association Working for Carers

Young Carers in Switzerland

There is still too little known about children, adolescents and young adults supporting family members or other close relationships/friends in need of care. Since 2014, the research department of the Careum School of Health has been working intensively with these young people in a research and development program lasting for several years. The aim of our research is to raise the awareness of professionals of the topic, enlarge their occupational networks and to develop concrete support instruments.

There are many families affected by physical or mental illnesses, impairments, addiction or age-related ailments. Often children and adolescents are also directly involved in the care and support of loved ones, either in the short term or for several years. These sometimes challenging situations that young people find themselves in are often not noticed by others around them or by professionals.

Development of a national data base
Children, adolescents and young adults who regularly take care of people close to them are internationally referred to as “young carers” (under 18 years) or “young adult carers” (under 25 years).

Until recently, Switzerland lacked a reliable data on the situation of young carers. The research project “Young carers and young adult carers in Switzerland” funded by the Swiss National Science Foundation closes this research gap.

The results will be presented at our national young carers conference.



- Conference themes**
- “Learning from others – international comparison of young carers’ support and legal framework
 - Results on awareness among professionals in Switzerland
 - Results of the national prevalence study
 - Support needs of young carers and their families
 - Testimonials from young carers
 - Approaches for the further development of a national young carers’ strategy

Simultaneous translation
The presentations and discussions will be presented in German or English and will be interpreted simultaneously into English or German.

Registration
The event is open to the public and participation is free of charge.
As the number of places is limited, please do not hesitate to register soon by emailing: youngcarers@careum.ch

Learn more:



Program 12 November 2019

from 8.30	Registration and coffee
09.00–09.15	Welcome Prof Dr Agnes Leu, Director, Young Carers Research Program, Careum School of Health, Zurich Prof Dr Saul Becker, University of Sussex, United Kingdom
09.15–09.45	Opening Francesca Centola, Eurocarers
09.45–10.30	Insight into the national research results Presentation of the results of the FSNF project “Young carers and young adult carers in Switzerland” Prof Dr Agnes Leu, Marianne Frech, Sarah Rabhi-Sidler, Fabian Berger Careum School of Health, Zurich
10.30–11.00	Break and networking
11.00–12.30	Young carers research and policy – an international comparison How do other countries support young carers? Laura Bennett, Carers Trust, United Kingdom Licia Boccaletti, Anziani e non solo società cooperativa sociale, Italy Dr Henk Herman Nap, Technische Universiteit Eindhoven, Netherlands Malla Heino, Carers Finland, Finland Dr Feylyn Lewis, University of Sussex, United Kingdom / United States of America Prof Dr Aurélie Untas, Université Paris Descartes, France
12.30–13.30	Lunch
13.30–14.15	Young carers testimonials Moderated discussion, feedback and questions from the audience Fabienne, Lynn, Yvonne Oppliger, Fabian Berger, Prof Dr Agnes Leu, Prof Dr Saul Becker
14.15–15.15	Panel discussion with experts from the fields of education, healthcare and social services What are our next concrete steps? Dr Thomas Ihde-Scholl, chief physician, psychiatric services, fmi AG, and President Pro Mente Sana Dagmar Rösler, president of the Swiss Federation of Teachers Barbara Schmid-Federer, president of the Swiss Red Cross, Canton of Zurich David Welten, consultant Pro Juventute Dr Bischoff, pediatrician and member of the Youth Welfare Commission, Directorate of Education, Zurich Prof Dr Agnes Leu, Prof Dr Saul Becker
15.15–15.45	Take home messages and farewell Prof Dr Saul Becker, Prof Dr Agnes Leu



Advocating for and with young carers across Europe

Francesca Centola, Careum, Zurich, November 12th 2019



SWISS NATIONAL SCIENCE FOUNDATION



About Eurocarers



European network working with and for informal carers.

Informal carer: a family member, friend who provides care - **usually unpaid** - to someone with a chronic illness, disability or other long lasting health or care need, **outside a professional or formal framework.**

Members: Research institutes and carers' organisations (70 members from 27 States)→ research-based advocacy

Mission: Ensure that the significant contribution made by informal carers to our societies is recognised and safeguarded through adequate support.



Informal carers across Europe: A precious resource...

- 80% of care in Europe is provided by informal carers.
- Economic value of unpaid informal care in EU Member States range from 50% to 90% of the overall costs of formal Long-term Care provision
- Replacing informal by formal care by 2070 would increase the share of GDP devoted to Long-term Care by 130% on average.

Unpaid carers save the UK £132 billion a year – the cost of a second National Health System

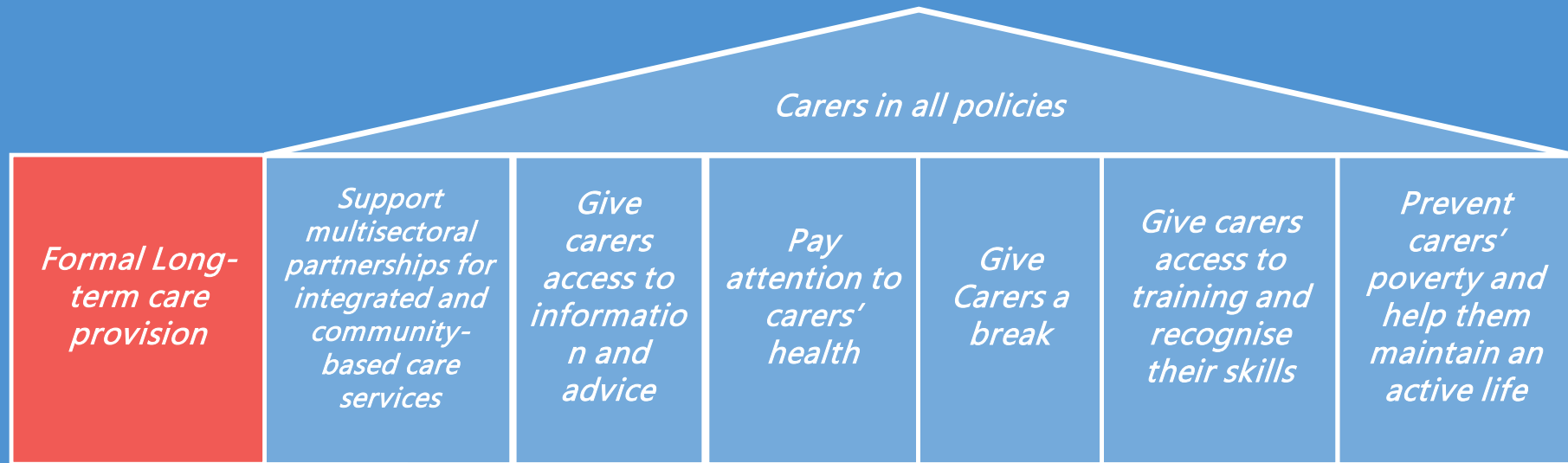
 **Without the vital contribution of informal carers, our welfare systems would be unsustainable!**

...under growing pressure



- Negative impact on participation in labour market
- Negative impact on health
- Social exclusion and poverty

Supporting carers is a win-win strategy!



Assess carers' needs

Identify carers

Define carers

A European strategy to support and empower informal carers

Young carers: a 'hidden army' of carers

Young carers: definition and numbers

Young carers are children and young persons under 18 who care, unpaid, for a family member with an illness or disability, mental health condition or addiction.

They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult.

Young adult carers
18– 25 years

Adolescent young carers
15- 17

Italy
7,3 % boys
6,9% girls
(15-24
years)

UK
8% young
carers (11-
18 years)

Sweden
7% young
carers (14-
16 years)

Switzerland
7,9% young
carers (10-
15 years)

The
Netherlands
6% young
carers (13-17
years)

Why are young carers invisible?

- ✓ Problem in self-identification
- ✓ Fear of being judged
- ✓ Stigma
- ✓ Concern not to cause more stress/worry to family
- ✓ Discouragement/denial by caree
- ✓ Lack of diagnosis of caree
- ✓ Uncertainty about who to talk to
- ✓ Believe that nothing will change if they disclose their caring responsibilities
- ✓ Desire to escape from caring situation


In many cases, service providers (and policymakers) are unaware, rather than unwilling to support young carers

- ✓ Patient-focused approach within healthcare
- ✓ Time pressure
- ✓ Service providers do not know what support is available for young carers



Young carers remain unidentified and they do not receive the support they need

Positive and negative impact of caring



Coping is difficult, but I feel proud!

➤ **Positive:** earlier maturity, a sense of meaning, self-esteem, empathy.

➤ **Education**

Under-achievement, absence and drop-outs → low employability in the long term.

➤ **Health and well-being**

The pressure associated with caring can be considered as a risk factor for mental ill-health.

➤ **Social exclusion**

Less dedicated time for personal development and leisure, victim of social stigma and bullying → higher life course social exclusion.

“Every Child has the Right to...”

Why support young carers? The human rights argument



REALITY

Every child has the right to...

...education

...rest and leisure

...the enjoyment of the highest attainable standard of health

...to an adequate standard of living

...to express their views

“School was a challenge; I'd often have done a shift before getting there, exhausted. Homework time was difficult, finding time for anything for me was impossible.”

Do you feel like a child?
“Not really.” What do you feel like? “An adult”

“I get really tired and sometimes I feel really down. I do like being a carer, but I want to be able to do things for me too”.

Why support young carers? The economic argument

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

In UK, the likelihood of young carers being NEET for six months or more is twice that of their peers (Audit Commission).

In Italy, caring responsibilities are the first reason of inactivity of the young NEET between 15 and 29 years (Youth Guarantee Report).

- ✓ Poor **mental health** is a **cost** for societies
- ✓ **Investing in young people is a social investment**

Nothing about us without us!



The Eurocarers Young Carers Working Group

Goal: to combine our efforts and resources, so that young carers' voices are heard, and policies and practices are put in place all across Europe to support them.

I feel like I do something important. Not only for myself, for my country, but for so many people in different countries.

As a young carer I often felt different and like an outsider. Network like this makes me feel included and part of something bigger than my own story.

It is important to have a working group at an EU level because we can exchange experience and practice from our country.

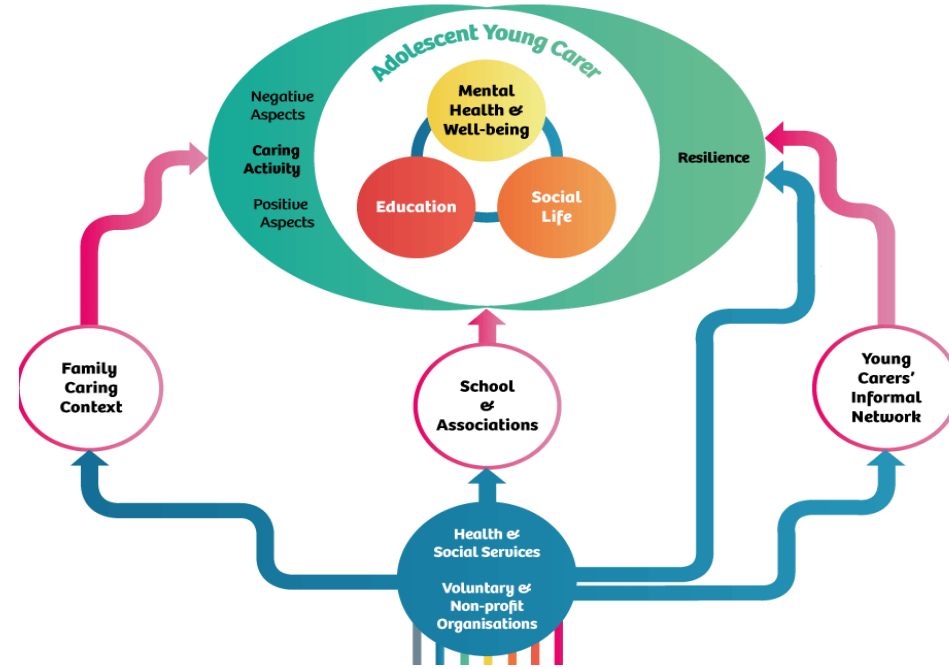
Research: Focus on the ME-WE project

(Psychosocial Support for promoting mental health and wellbeing among adolescent young carers in Europe)

Project duration: January 2018 – March 2021

Overall goal: mitigate the risk factor of being an adolescent young carer by empowering the young with **improved resilience** and **enhanced social support** (from family, schools, peers, services).

Resilience: the process of positive adaptation within the context of significant adversity

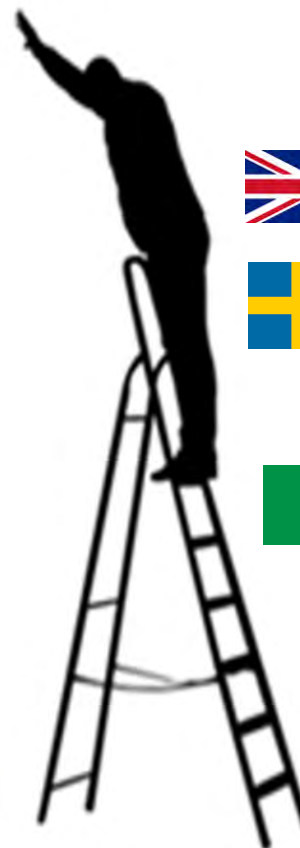




The ME-We Project consortium



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The ME-WE project objectives & activities

Objective 1: Systematise knowledge on AYCs

Profiles, needs and preferences

National policy, legal and service frameworks

Good practices, social innovations & evidence

Objective 2: Co-design, develop and test with AYCs an effective framework of interventions

Participatory co-design

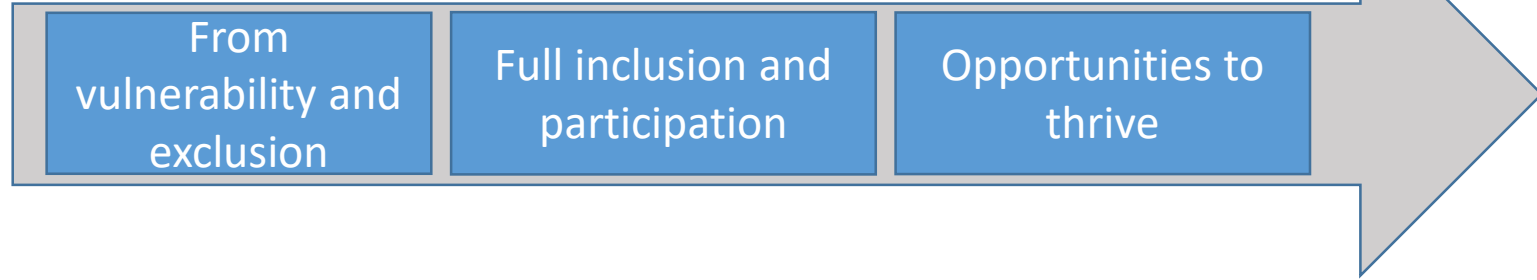
Implementation

Evaluation and impact

Objective 3: Carry out wide knowledge translation actions

Dissemination & translation of research into practice

The vision of the ME-WE project consortium: Empowering young carers to reach their full potential



A focus on the negative impacts of caring serves as a strong motivator to urge society to act, *however*,

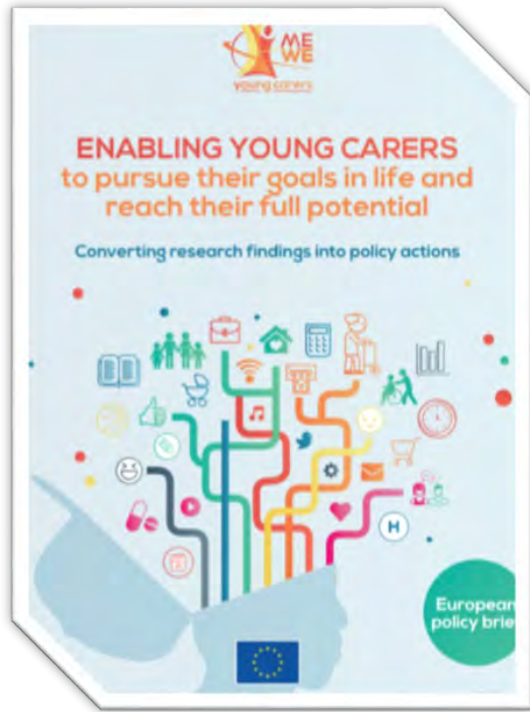
We must not overlook the positives of caring, both individually and as a society.

Young carers have a **right to self-determination, including the right to care if they desire to do so.**

Society's mission should be to provide young carers with recognition and support and to protect them from **inappropriate caring responsibilities.**



Translating research findings into policy actions: the ME-WE policy briefs



No “one size fits all” solution exist
Adaptable recommendations

Broad policy priorities:

Identify young carers

Support young carers

Listen to young carers

Identify

Young carers' experience

If you are not identified, then you have no choice!

More awareness would have taught me that I deserve a space in my family.



What can be done?

Screening at schools and at health settings

Trainings for professionals

Raising awareness among professionals and general public (to normalize caring)

Even if you don't care for, you always care about.

Young carers' experience

To have the chance to stand up for what you want, you first need to know what you want!



Not good at realising own needs → unable to ask for them to be met

What can be done?

At school: Flexibility + extra, tailored support.

Supporting mental health of young carers (peer support, respite breaks, courses to increase resilience)

Reducing the care burden

- ✓ Provide more adequate and intensive **formal care** services to the cared-for person
- ✓ **Assess** the health and social needs of care recipients, carers and the family as a unit (**whole family approach**)
- ✓ Provide support based on **specific needs** at specific time
- ✓ **Act early** (prevention!)
- ✓ Adopt an interdisciplinary and interprofessional **collaborative approach**

Listen to

Young carers' experience

- It is frustrating not to be listened to → you give up
- No one asked the rights questions
- No adult asking "How are you?" or seeing the unmet needs behind dysfunctional behaviours (e.g. eating disorder, sexual behaviour,...).

*If professionals
had listened to us,
we would have
felt less alone!*



What can be done?

Adults asking "What do you want me to do to help you?"

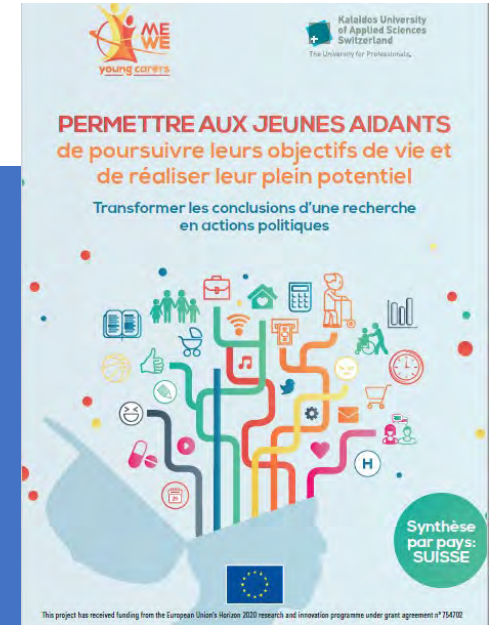
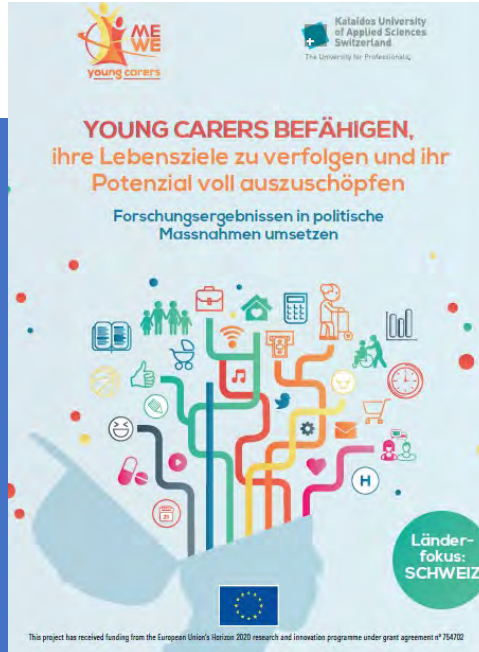
Professionals have to provide alternatives and come up with solutions decided together with young carers →

Co-design services

Young carers should be recognised as an important target group for policy makers and relevant stakeholders.

*Professionals should ask
right questions and not
stop to the first answer*

*If they had asked
me, I would have
stopped earlier
the struggle with
myself*



Focus on Switzerland



The Swiss context: legislative & policy framework



State of play

No specific legislation.

No definition of young carers.

Only indirect support to young carers (child protection).



There is a solid legal system with a lot of protection for children.

Legislation and services are regionally flexible→
Me-too-effect.



Focus of child protection system is on protection.

Families do not reach out for help from child protection services.

No evaluation of the outcomes of child protection interventions.

Lack of coordination between different legal systems.

Differences between how cantons implement the UN Convention on the Rights of the Child.

Future needs

No need to introduce a specific legislation for young carers
YET integrate young carers into existing legislation/policy.

Include a definition of young carers in legislation.

Change the law to include a preventative approach.

More data to understand how child protection measures are working.

Address the structures and conditions allowing professionals to work well together.

Ensure that policy changes/recommendations at Federal level are translated at cantonal level.

The Swiss context: visibility & available support



State of play

Caring is perceived as something to be kept private

Lack of awareness among professionals

Patient-focused approach

Difficulty to identify adolescent young carers. They fall through the gaps between children and adult services

Young carers do not exist as specific social group

Gaps between different systems

There are good support programmes for youth but they are not known

Support services are underfunded

Young carers are not an homogenous group

Future needs

Caring needs to become the focus for public policy and intervention (the personal is political!)

Empower professionals to identify and support young carers

Adopt a whole family approach

Make special efforts to identify and support AYC's

Include young carers in existing interventions

Need for integrated work

Bring support programmes to target groups (via a better communication)

Allocate more funding for support services

Support needs to be co-designed with young carers and tailored to the needs of each individual



Implement a **strategy to support carers of any age** (life-course perspective, because in every life-phase one can be a carer).

Define young carers.

Extend/amend existing non-specific legislation/policy so that young carers can be identified, recognized and supported.

Include young carers among the target groups of service providers' activities.

Strengthen **the focus on prevention**, not just protection.

Always adopt a **human rights perspective** (e.g. when assessing the best interest of the child)

Further research

Large-scale awareness-raising

Rosalyn Carter, Former First Lady of the United States once said: "There are four kinds of people in the world - those who have been carers, those who currently are carers, those who will be carers and those who will need carers."

What next?

The 3rd International Young Carers Conference

16-17 November 2020, Brussels



Call for abstract mid-November
(deadline end of February)

Submissions can focus on a research, a practice, a
policy initiative, legislation or an experience.

<https://eurocarers.org/2020-iycc/>

We all have a role to play to empower young carers to reach their full potential and enjoy the human rights they are entitled to!

Thank you!



*A simple action
can change the
life of young
carers!*

Contact details



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European Association Working for Carers



@Eurocarers_info
#young carers

Edy-Care Project: <https://eurocarers.org/edycare/>

Me-We Project: <http://me-we.eu/>



**YOUNG CARERS BEFÄHIGEN,
ihre Lebensziele zu verfolgen und ihr
Potenzial voll auszuschöpfen**

Forschungsergebnissen in politische Massnahmen umsetzen



**Länder-
fokus:
SCHWEIZ**



Psychosoziale Unterstützung zur Förderung der psychischen Gesundheit und das Wohlergehen von Young Carers in Europa

Das Me-We Projekt (2018-2021) bringt eine Reihe von Universitäten, Forschungseinrichtungen und die Zivilgesellschaft aus sechs verschiedenen europäischen Ländern zusammen, darunter Eurocarers, das europäische Netzwerk, das informelle Betreuer in allen Altersgruppen vertritt. Das Projekt zielt darauf ab, die psychische Gesundheit und das Wohlbefinden von Young Carers zu verbessern, indem es ihre Widerstandsfähigkeit (der Prozess der positiven Anpassung im Kontext großer Schwierigkeiten) stärkt.

**Linnaeus Universität
(Hauptpartner)**

Schweden



Eurocarers

Belgien



Universität Sussex

Vereinigtes
Königreich



Carers Trust

Vereinigtes
Königreich



Kalaidos Fachhochschule Schweiz

Schweiz



The Netherlands Institute for Social Research

Niederlande



**The national Centre of Expertise for Long-term
Care in the Netherlands (Vilans)**

Niederlande



Anziani e non solo

Italien



**National Institute of Health and Science on Ageing
(INRCA)**

Italien



Universität Ljubljana

Slowenien



Für weitere Informationen: www.me-we.eu

#youngcarers

Die Unterstützung der Europäischen Union bei der Erstellung dieses Dokuments stellt keine Billigung des Inhalts dar. Dieser widerspiegelt lediglich die Ansichten der Autoren und Autorinnen. Die Organe und Einrichtungen der Europäischen Union können nicht für den Inhalt verantwortlich gemacht werden.



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Zusammenfassung

Die Kindheit wird gemeinhin als eine geschützte und verantwortungsfreie Lebensphase angesehen, in der Erwachsene in der Verantwortung stehen und Betreuung und Pflege leisten, währenddessen die Kinder in erster Linie Empfänger¹ von Betreuung und Pflege sind. Für viele Kindern und Jugendliche in Europa ist dies jedoch nicht der Fall. Denn sie betreuen – manchmal sogar sehr intensiv – eine unterstützungsbedürftige nahestehende Person, sei es beispielsweise wegen Krankheit, Unfall, Beeinträchtigung oder Sucht. Dabei müssen sie Verantwortung übernehmen, die eigentlich von Erwachsenen gestemmt werden sollte. Wir nennen solche Kinder und Jugendlichen «Young Carers»².

ANZAHL DER YOUNG CARERS IN EUROPA

Obwohl derzeit die Datenlage zur Anzahl der Young (Adult) Carers in Europa noch dürftig ist, haben einige nationale Statistiken und Pilotprojekte dazu beigetragen, eine erhebliche und noch weitgehend unbekannte Bevölkerungsgruppe aufzudecken.

Die Volkszählung 2011 für das Vereinigte Königreich (England und Wales) ergab, dass es 177.918 Young Carers unter 18 Jahren gibt. Die Anzahl der Young Carers steigt im Laufe der Zeit: 27.976 mehr als 2001 (ein Anstieg von 19% über 10 Jahre).

In Italien gibt es nach den neuesten nationalen Statistiken 391.000 Young Carers und Young Adult Carers (15-24 Jahre), was 6,6 % der Gesamtbevölkerung entspricht.*

In der Schweiz sind 7,9% der Kinder im Alter von 10-15 Jahren Young Carers. (Leu et al. (2019); Leu & Becker, 2019).

In den Niederlanden geben uns Forschungsprojekte folgende geschätzte Zahlen: Young Carers machen 6% der Bevölkerung im Alter von 13-17 Jahren aus.

In Schweden führen laut einer Umfrage 7% der Kinder im Alter von 14-16 Jahren eine beträchtliche Anzahl von Betreuungsaufgaben durch.

In Irland ergab die Volkszählung 2016, dass 3.800 Kinder unter 15 Jahren sich um andere kümmern, was 1,9 % aller betreuenden Angehörigen ausmacht. Die Hälfte dieser Kinder (1.901), die unbezahlte Betreuung erbringen, waren 10 Jahre und jünger.

Volkszählung und offizielle Statistiken sind sehr wichtig. Dennoch übersehen sie oft Young Carers oder unterschätzen ihre Anzahl (der Erwachsene, der die Befragung ausfüllt, ist sich vielleicht nicht bewusst oder wollte nicht mitteilen, dass es in der Familie einen Young Carers gibt). Als Bestätigung dafür haben inoffizielle Daten aus einer BBC-Umfrage von 2018 ergeben, dass es in England 800.000 Young Carers gibt (gegenüber 166.000, die über die Volkszählung identifiziert wurden).

*Istat, Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea, données 2015 (en italien).

Während das Phänomen der informellen Betreuung – also der meist unbezahlten Betreuung und Unterstützung durch ein Familienmitglied oder eine nahestehende Person ausserhalb des beruflichen Rahmens – in ganz Europa an Dynamik gewinnt, ist über die Situation der unter 18-jährigen betreuenden Angehörigen wenig bekannt. Young Carers sind für Behörden und Dienstleister in der Tat noch weitgehend unsichtbar. Dieses Versäumnis, sie zu identifizieren und zu unterstützen, kann sich negativ auf ihre (psychische) Gesundheit, ihre Bildungserfahrung, ihre Beschäftigungsfähigkeit und ihre soziale Integration auswirken. Die negativen Auswirkungen auf individueller Ebene können zu langfristigen

negativen Folgen für die Gesellschaft als Ganzes führen.

Häufig sind sich politische Entscheidungsträger und Dienstleistende **nicht bewusst**, mit welchen Herausforderungen Young Carers konfrontiert sind. Darum kennen und ergreifen sie auch kaum mögliche Massnahmen, um solche Situationen zu verhindern.

Dieser Bericht zielt darauf ab, das Bewusstsein für das Thema zu schärfen und die Wissenslücke zu schliessen. Es werden im Folgenden die Ergebnisse des europäischen Forschungs- und Innovationsprojekts Me-We - Psychosoziale

1. On diesem Bericht wird aus Gründen der besseren Lesbarkeit das generische Maskulinum verwendet. Weibliche und anderweitige Geschlechteridentitäten werden dabei ausdrücklich mitgemeint, soweit es für die Aussage erforderlich ist.

2. Zur Definition vgl. Seite 5.

Unterstützung zur Förderung der psychischen Gesundheit und des Wohlbefindens von Adolescent Young Carers in Europa erläutert. Dieses wurde im Rahmen des EU-Programms Horizon 2020 finanziert. Dieses Dokument stützt sich zwar direkt auf konkrete Forschungsergebnisse, hat aber zum Ziel, die politischen Auswirkungen der Ergebnisse von Me-We zu reflektieren und zum Nachdenken anzuregen. Daher sollte es nicht als wissenschaftlicher Bericht betrachtet werden.

Im Me-We Projekt (2018-2021) arbeiten prominente Universitäten, Forschungsinstitute und Organisationen aus sechs verschiedenen europäischen Ländern zusammen – einschliesslich das europäische Netzwerk Eurocarers,

welches die Interessen betreuender und pflegender Angehöriger jeden Alters vertritt. Das Projekt zielt darauf ab, die psychische Gesundheit und das Wohlbefinden betreuender Jugendlichen (so genannte „Adolescent Young Carers“) zu verbessern, indem ihre Resilienz gestärkt wird (Widerstandsfähigkeit, um Krisen erfolgreich zu meistern).

Zu diesem Zweck wurden eine Online-Umfrage, eine Literaturrecherche und eine Reihe von Interviews mit wichtigen Experten und Expertinnen durchgeführt. Zum ersten Mal überhaupt wird im Rahmen unseres Me-We Forschungsprojekts ein Querschnittsvergleich von Young Carers in sechs europäischen Ländern vorgenommen. Auf diese werden auch Unterschiede sichtbar, die zwischen diesen Ländern bestehen.

Das gesammelte Wissen wird derzeit genutzt, um gemeinsam mit Adolescent Young Carers und anderen relevanten Interessengruppen Rahmenbedingungen für primäre Präventionsmassnahmen zu entwickeln. Diese Massnahmen werden in den sechs Projektländern umgesetzt und anschliessend evaluiert.

Die Ausgestaltung des Me-We Projekts geschieht vor dem Kontext der laufenden Debatten über die Zukunft der europäischen Versorgungssysteme – denn die Gesellschaft wird immer älter. Die Umsetzung richtet sich nach den Zielen der Strategie „Europa 2020“ in den Bereichen Bildung und Beschäftigung. In der Einführung des Berichts wird auf die Forschungslage und bereits vorhandene Daten Bezug genommen, um zu beleuchten, welche Auswirkungen die Betreuungsrolle auf junge Menschen hat und welchen **dringenden Handlungsbedarf** es gibt.

Die Einführung ist allgemein gehalten, wobei sich die folgenden Abschnitte speziell auf die Schweiz konzentrieren. Um einen Überblick über die wichtigsten Ergebnisse in allen Projektländern zu erhalten, verweisen wir auf den europäischen Bericht ([hier verfügbar](#)³).

Die Kapitel 1, 2 und 3 konzentrieren sich auf die Ergebnisse des Me-We Projekts, die sich aus dem ersten Projektjahr ergeben, bestehend aus einer Online-Umfrage (Kapitel 1), einer Analyse der gesetzgeberischen und politischen Rahmenbedingungen (Kapitel 2) sowie einer Überprüfung von bestehenden Unterstützungsmassnahmen (Kapitel 3).

Die vollständigen Studienergebnisse werden in den Jahren 2020 und 2021 in Peer-Review-Journals veröffentlicht.

Kapitel 4 führt die Me-We Erkenntnisse, bisherige Forschungsarbeiten und das aktuelle politische Umfeld zusammen mit dem Ziel, politische Prioritäten und mögliche Handlungsoptionen zu identifizieren.

Jede dieser Empfehlungen wird von unserer **Kernvision** geleitet: Young Carers sollen in der Lage sein, ihre Lebensziele zu verfolgen und ihr volles Potenzial zu entfalten, ohne von ihrer Betreuungsverantwortung negativ beeinflusst zu werden.

Das erste Projektjahr war darauf ausgerichtet, Einblicke zu gewinnen in:

- ▶ Profile, Bedürfnisse und Präferenzen von Adolescent Young Carers in sechs europäischen Ländern (Italien, Niederlande, Slowenien, Schweden, Schweiz und Grossbritannien);
- ▶ die rechtlichen-, politischen- und dienstleistungsbezogenen Rahmenbedingungen, die es zur Unterstützung von Adolescent Young Carers in den sechs Ländern gibt (mit Fokus auf die Art und Weise, wie in der Praxis gearbeitet wird, der Lenkung ihrer Entwicklung, deren Stärken und Einschränkungen); und
- ▶ die erfolgreichen Strategien zur Unterstützung von Adolescent Young Carers

**Wer ist für
die Hilfe ver-
antwortlich?**

3. Die Quellenangaben finden Sie bitte in der Online-Version. Dies gilt auch für die nachfolgenden Links.

Einleitung

DIE HERAUSFORDERUNGEN EINES YOUNG CARERS

Wer sind Young Carers?

Young Carers sind Kinder und Jugendliche unter 18 Jahren, die ein Familienmitglied oder eine nahestehende Person, die von chronischer Krankheit, Unfall, Beeinträchtigung, Gebrechlichkeit oder Sucht betroffen ist, pflegen, betreuen oder unterstützen. Sie übernehmen regelmässig wesentliche und/oder umfangreiche Betreuungsaufgaben mit einer Verantwortung, die normalerweise mit Erwachsenen in Verbindung gebracht wird (Becker, 2000⁴).

Young Carers im Alter von 15-17 Jahren werden als **“Adolescent Young Carers”** (AYCs) bezeichnet. Sie verdienen besondere Aufmerksamkeit, da sie sich in einer wichtigen Übergangsphase ihrer Entwicklung befinden, nämlich im Übergang von der Kindheit ins Erwachsenenalter. Diese Übergangsphase ist nicht nur für biologische und psychosoziale Aspekte entscheidend, sondern wirkt sich auch auf die Positionierung potenziell gefährdeter Jugendlicher in rechtlicher, politischer, gesundheitlicher und sozialer Hinsicht aus.

Die Gründe, warum Kinder zu Betreuungspersonen werden, sind vielfältig. Sie richten sich (unter anderem) nach dem kulturellen Hintergrund, dem Pflichtbewusstsein, dem Mangel an alternativen Möglichkeiten, nach Liebe und Einfühlungsvermögen für die betreute Person und dem Mangel an finanziellen und praktischen Ressourcen innerhalb der Familie (Leu & Becker, 2019).

Betreuung kann auf einem Kontinuum dargestellt werden, das mit «caring about» beginnt (geringe Betreuungsverantwortung, Routinestufen der Betreuung und wenig Hinweise auf negative Auswirkungen), hin zu «taking care of» (Erhöhung der Betreuungsaufgaben und -verantwortlichkeiten) bis hin zu «caring for» (hohe Betreuungsverantwortung, erhebliche regelmässige Betreuung, Hinweise auf signifikante negative Auswirkungen) (Joseph et al., 2019).

Welche Aufgaben übernehmen Young Carers?

- ▶ Praktische Aufgaben (z.B. Kochen, Hausarbeit und Einkaufen);
- ▶ Körperliche Betreuung (z.B. Hilfe beim Aufstehen aus dem Bett);
 - ▶ Emotionale Unterstützung (z.B. Gespräch mit jemandem, der in Not ist);
- ▶ Persönliche Betreuung (z.B. Hilfe beim Anziehen);
- ▶ Verwaltung des Familienbudgets und Sammlung von Verschreibungen;
- ▶ Hilfe bei der Verabreichung von Medikamenten;
 - ▶ Jemandem helfen, zu kommunizieren;
 - ▶ Betreuung von Geschwistern

Die Auswirkungen der Young Carers Rolle

Psychische Gesundheit und Wohlbefinden

Es gibt einige positive Auswirkungen in Zusammenhang mit der übernommenen Betreuungs- und Pflegerolle, z.B. können Young Carers Zufriedenheit aus den Betreuungsaufgaben gewinnen und im Selbstwertgefühl, in der Empathie und der Reife gestärkt werden (Banks et al., 2001; Cass et al., 2009; Cassidy et al., 2014; Heyman & Heyman, 2013; Joseph et al., 2009; Robson et al., 2006). Dennoch kann es erdrückend sein, die Herausforderungen, die das Leben an sie stellt, mit den Betreuungsaufgaben in Einklang bringen zu müssen. Der mit der Young Carers Rolle einhergehende Druck wird als Risikofaktor für psychische Erkrankungen gewertet (Aldridge & Becker, 2003; Ali et al., 2015; De Roos et al., 2017; Greene et al., 2016).

Ausbildung

Young Carers sehen sich besonderen Barrieren in Bezug auf Schule und Ausbildung ausgesetzt: Diese können zu häufigen Verspätungen, Absenzen bis hin zum Schulabbruch führen (Becker & Sempik, 2018; Kaiser & Schulze, 2014; Moore et al., 2009). Ebenso kann es schwierig sein, eine bezahlte Beschäftigung mit Betreuungsaufgaben zu vereinen.

4. Sämtliche Referenzen finden Sie hier: Leu, A., & Becker, S. (2019). Young Carers. In H. Montgomery (Ed.), Oxford Bibliographies in Childhood Studies. New York: Oxford University Press. Weitere Publikationen zum Thema Young Carers finden Sie hier: www.careum-hochschule.ch/Young-Carers/Publikationen/2019

Soziales Leben

Young Carers haben möglicherweise weniger Zeit für die persönliche Entwicklung und Freizeit und sind isoliert. Sie können auch Opfer von sozialer Stigmatisierung und Mobbing werden und sind während ihres gesamten Lebens häufiger sozialer Ausgrenzung ausgesetzt (Barry, 2011).

Trotz dieser genannten negativen Auswirkungen, sind Young Carers immer noch **zu wenig sichtbar** für politische Handlungsträger und Dienstleister.

Warum bleiben Young Carers unbemerkt?

- ▶ Young Carers identifizieren sich selbst nicht als Young Carers.
- ▶ Sie haben Angst, dass Sozialdienste oder Kinderschutzbehörden sie aus ihrer vertrauten Umgebung herausreißen.
- ▶ Sie haben Angst davor, von Kollegen, Lehrern oder Dienstleistern verurteilt oder missverstanden zu werden.
- ▶ Es kommt zu Stigmatisierung (insbesondere dann, wenn die unterstützungsbedürftige Person an einer Suchterkrankung leidet oder psychisch erkrankt ist).
- ▶ Sie sind sich unsicher, mit wem sie darüber sprechen sollen.
- ▶ Sie glauben, dass sich nichts ändern wird, wenn sie ihre Betreuungsverantwortung offenbaren.
- ▶ Leistungsanbieter (wie z.B. Spitex) richten ihr Angebot in der Regel an Personen, die Betreuung bedürfen, nicht an solche, die betreuen.
- ▶ Der breiteren Öffentlichkeit sind keine spezifischen Angebote für Young Carers bekannt (falls vorhanden).

“Wir ignorieren die Young Carers auf unsere Gefahr hin und auf die Gefahr der Zukunft dieser Kinder”

Prof. Saul Becker,
University of Sussex



Young carers bleiben unsichtbar und ihre Bedürfnisse werden nicht erfüllt.

WARUM MÜSSENSOLLEN WIR DIESES THEMA ANSPRECHEN?

Young Carers können ihre Menschenrechte nicht in vollem Umfang wahrnehmen

Die UN-Konvention über die Rechte des Kindes besagt, dass “jedes Kind unter anderem das Recht hat,...” auf Ruhe und Freizeit (Artikel 31), Bildung (Artikel 28 und 29), einen angemessenen Lebensstandard (Artikel 27), die eigene Meinung frei zu äussern (Artikel 12), und den höchstmöglichen Gesundheitsstandard zu geniessen (Artikel 24).

Young Carers sollen, wie alle anderen Kinder auch, die ihnen zustehenden Rechte geniessen können. Zu oft behindern jedoch die Herausforderungen, denen sie sich ausgesetzt sehen, diesen Prozess. So reichen die gleichen Wettbewerbsbedingungen möglicherweise nicht mehr aus, um die Chancengleichheit für Young Carers zu gewährleisten. Sie zählen zu einer besonders vulnerablen Gruppe von Kindern, Jugendlichen und jungen Erwachsenen und sollten als solche anerkannt werden. Jedoch sollten sie nicht nur von der universellen Umsetzung ihrer Rechte profitieren können, sondern auch von zusätzlichen und massgeschneiderten Unterstützungsmassnahmen, deren Umfang und Intensität in einem angemessenen Verhältnis zur erlebten Benachteiligung sind. Dies steht im Einklang mit dem internationalen Menschenrechtsgesetz, das die Staaten verpflichtet, positive Massnahmen zu ergreifen und ihrer Verpflichtungen nachzukommen, den Gleichbehandlungsgrundsatz einzuhalten. So kann argumentiert werden, dass Staaten, die es versäumen, positive Massnahmen zur Unterstützung von Young Carers zu leisten, es versäumen, ihre Rechte zu schützen und zu fördern.

DIE UNTERSTÜTZUNG VON YOUNG CARERS IST AUS ÖKONOMISCHER SICHT SINNVOLL

Vorzeitiger Schulabbruch verursacht hohe individuelle, soziale und wirtschaftliche Kosten.

Junge Menschen mit einem Bildungsabschluss auf Sekundarstufe I oder tiefer sind häufiger von Arbeitslosigkeit betroffen, sind eher von Sozialleistungen abhängig und haben ein höheres Risiko auf soziale Ausgrenzung. Ihr Lebensunterhalt, ihr Wohlbefinden und ihre Gesundheit werden ebenso negativ beeinflusst, wie ihre Teilnahme an demokratischen Prozessen.

Neben den individuellen Kosten beeinträchtigt der Schulabbruch die wirtschaftliche und soziale Entwicklung und ist ein grosses Hindernis für das Ziel der Europäischen Union, intelligentes, nachhaltiges und integratives Wachstum zu erreichen. Dies wird in der Strategie „Europa 2020“ ausdrücklich anerkannt, die zum Ziel hat, die durchschnittliche Schulabbruchsquote in der EU auf unter 10% zu senken.

Schlechte psychische Gesundheit ist ein Kostenfaktor für die Gesellschaft.

Auf internationaler Ebene wächst die Erkenntnis darüber, wie wichtig frühzeitige Intervention und Prävention sind, um schlechte gesundheitliche Auswirkungen zu vermeiden. Wie die Weltgesundheitsorganisation betont, bringen die Förderung und der Gesundheitsschutz von Kindern und Jugendlichen kurz- und langfristig nicht nur Vorteile für ihre Gesundheit, sondern auch für Wirtschaft und Gesellschaft. Denn gesunde (junge) Erwachsene sind in der Lage, einen grösseren Beitrag zur Arbeitnehmerschaft, zur Familie und Verwandtschaft und zur Gesellschaft insgesamt zu leisten.

Investitionen in junge Menschen sind eine soziale Investition. Wie von der EU im Sozialinvestitionspaket anerkannt, können durch frühzeitige Massnahmen sozioökonomische Ungleichheiten an der Wurzel angegangen, der Kreislauf der Benachteiligungen durchbrochen und damit die Chancengleichheit gefördert werden.

ZWISCHEN UNTERSTÜTZUNG UND EMANZIPATION – DAS YOUNG CARERS DILEMMA

Bevor wir fortfahren, lohnt es sich, ein ethische Dilemma bezüglich der Situation von Young Carers näher zu betrachten: “Es gehört eigentlich nicht dazu, dass Kinder und Jugendliche Betreuungsverantwortung übernehmen. Entsprechend ist die Unterstützung von Young Carers im Wesentlichen zum Nachteil ihrer Interessen”. Nachfolgend werden die verschiedenen Argumente aufgezeigt, die von denen vorgebracht wurden, die diese widersprüchlichen Ansätze befürworten.

Die Vision des Me-We Konsortiums

Die Wahl

sollte das Rückgrat jeder Entscheidung über betreuende Angehörige sein. Menschen sollten das Recht haben, frei zu wählen, ob sie Betreuende sein wollen – und bleiben – und inwieweit sie an der Pflege beteiligt sein wollen. Eine Wahl ist jedoch unwahrscheinlich, wenn keine professionelle oder informelle Pflegealternative zur Verfügung steht. Die flächendeckende Bereitstellung von erschwinglichen und qualitativ hochwertigen Langzeitpflegediensten ist daher eine Voraussetzung für die Selbstbestimmung von Young Carers. Gleichzeitig erkennen wir an, dass die Verfügbarkeit alternativer Optionen – obwohl sie zwingend erforderlich sind – manchmal nicht ausreicht, um eine Wahl zu ermöglichen. Tatsächlich können andere Faktoren (wie Schuldgefühl oder der familiären Verpflichtung) eine Rolle spielen und die persönliche Wahrnehmung der angebotenen alternativen Möglichkeiten beeinflussen. Geschieht die Übernahme der Betreuungsverantwortung jedoch aus einer gut informierten und unbeeinflussten Entscheidung sowohl des Betreuers als auch des Betreuungsempfängers, sollte die Gesellschaft die Aufgabe haben, die negativen Auswirkungen, die die Verantwortung für die Pflege auf Young Carers haben kann, zu verhindern und zu minimieren. So kann sichergestellt werden um sicherzustellen, dass sie ihre Lebensziele verfolgen und ihr volles Potenzial ausschöpfen können.

Vision 1: „Young Carers sollten nicht existieren und die politische Aufmerksamkeit sollte auf andere Themen gerichtet werden“	Vision 2: “Young carers sollten identifiziert und unterstützt werden”
<p>Indem wir Young Carers unterstützen und ihnen beibringen, wie sie damit umgehen sollen, akzeptieren wir effektiv die Übertragung von Betreuungsverantwortung von der Öffentlichkeit auf die Privat-sphäre.</p>	<p>Die Idee, dass Kinder frei von einer Betreuungsrolle sein sollten, ist absolut sinnvoll. Es ist jedoch unrealistisch, dafür zu sorgen, dass Kinder keine Betreuungsaufgaben mehr innehaben. Deshalb sollten wir lieber Massnahmen, Förderprogramme und Methoden bereitstellen, um die Betreuungslast der Young Carers zu vermeiden oder zu senken.</p> <p>Fakt ist: Es gibt «Young Carers», und es wird sie noch viele Jahre geben. Deshalb sollten wir uns darauf konzentrieren, wie wir sie unterstützen und ihren Bedürfnissen nachkommen können.</p>
<p>Wenn der betreuten Person angemessene Pflegeleistungen angeboten werden, könnte das Kind oder der junge Erwachsene mit dem normalen Prozess des Erwachsenwerdens fortfahren. Daher ist es wichtig, Ressourcen und Strategien einzusetzen, um den Betreuungsbedarf von Kindern insgesamt zu reduzieren (durch die Bereitstellung von Pflegedienstleistungen für die pflegebedürftige Person)” (Richard Olsen & Gillian Parker, Critical Social Policy, Issue 50)</p>	<p>“Wir erkennen, dass in einer idealen Welt, in der die freiwilligen und gesetzlichen Unterstützungsdienste in der Lage sind, umfassende oder unbegrenzte Unterstützung zu leisten, die Young Carers-Rolle massiv reduziert würde. Aber wir erkennen ebenso die aktuelle politische und wirtschaftliche Realität: In einem zunehmend unter Druck stehenden Sozialsystem, im Kontext von wirtschaftlicher Rezession, Unsicherheit und hohen Kosten für die soziale Betreuung wird erwartet, dass betreuende Angehörige ihre Unterstützung fortsetzen. In diesem Zusammenhang ist es wichtig, dass die Rolle der (erwachsenen und) jungen betreuenden Angehörigen voll anerkannt und wertgeschätzt wird“ (Jo Aldridge & Saul Becker, Critical Social Policy, issue 16.3).</p> <p>Wenn wir eine Null-Toleranz haben und so zu tun, als gäbe es keine Young Carers, dann werden wir sie erst sehen, wenn es zu spät ist. Nämlich dann, wenn ihr Unterstützungsbedarf eskaliert.</p>
<p>Aus menschenrechtlicher Sicht haben Kinder das Recht, Kinder zu sein und nicht betreuende Angehörige. Ein Unterstützungssystem würde dazu führen, dass sie in eine Betreuungsrolle verstrickt werden, von der sie frei sein sollten, und damit würden ihre Rechte verletzt.</p>	<p>Das Recht der Young Carers auf Selbstbestimmung umfasst das Recht zu betreuen, wenn sie dies selbst wünschen, unter Wahrung ihrer Interessen. Daher sollten Massnahmen darauf abzielen, Young Carers vor unangemessener Betreuung zu bewahren, d.h. vor Betreuungsaufgaben, die sich negativ auf die Gesundheit, das Wohlbefinden oder die Bildung des Kindes auswirken oder die unter Berücksichtigung der Umstände des Kindes als ungeeignet angesehen werden können.</p>

*Richard Olsen & Gillian Parker, Critical Social Policy, numéro 50

** Jo Aldridge and Saul Becker, Critical Social Policy, numéro 16.3

Kapitel 1:

Wie ist es, gleichzeitig Jugendlicher und Young Carer zu sein?



Wie ist es, in der Übergangsphase von der Kindheit ins Erwachsenenalter gleichzeitig eine Betreuungs- und Pflegerolle zu haben? Um sich dazu ein Bild zu verschaffen, führte das Me-We Konsortium von April bis Mitte November 2018 eine Online-Befragung in sechs europäischen Ländern durch (Italien, Niederlande, Slowenien, Schweden, Schweiz und Grossbritannien).

Ziel der Umfrage war es, den Umfang der Betreuungsaufgaben sowie dessen Auswirkungen auf das allgemeine Wohlbefinden und den Bildungsstand von Young Carers zu erhalten.

In der Schweiz waren von den 2.057 Befragten 485 betreuende Angehörige im Alter von 13-27 Jahren (geboren zwischen 1991 und 2005). Die Anzahl Adolescent Young Carers im Alter von 15 bis 17 Jahren betrug 85 (Betreuung

eines Familienmitglieds oder einer nahestehenden Person, einschliesslich derjenigen, die beides pflegen, d.h. es gab Überschneidungen). 19% gaben an jemanden zu betreuen, solange sie sich sich erinnern können.

78% der Adolescent Young Carers in der Schweizer Stichprobe waren weiblich. Dieses Ergebnis unterscheidet sich von früheren Schweizer Daten (Leu et al. (2019), deckt sich aber mit bestehender Literatur über den geschlechtsspezifischen Charakter der Pflege und den kulturellen, sozialen und familiären Erwartungen an die Pflege. 62 Adolescent Young Carers gaben an, dass sie Schweizer Bürger sind. 56% der Befragten leben in ländlicher Umgebung.

Die Mehrheit der Befragten (auch Nicht-Betreuende) berichteten, dass sie in einem Zweieltern-Haushalt leben (85%), 29,5% leben mit einem Bruder und 24% mit einer Schwester, was darauf hindeutet, dass eine grosse Anzahl von Befragten Einzelkinder sind. Mehrgenerationenhaushalte sind bei den Befragten in dieser Umfrage selten vorhanden: 5,5% leben bei einer Grossmutter und 4,5% bei einem Grossvater.

WEN BETREUEN YOUNG CARERS?

Von den 116 Befragten, die angaben, dass sie ein pflegebedürftiges Familienmitglied haben, berichteten 57 (50 %⁵), dass sie dieses Familienmitglied betreuen, pflegen oder dieses beaufsichtigen. Somit gibt es in der Schweizer Stichprobe 57 Young Carers, die sich um ein Familienmitglied kümmern, das Betreuung oder Pflege benötigt. Von den Young Carers betreuen 26 (57,8 %) nur ein Familienmitglied. Es gibt eine Reihe von Adolescent Young Carers, die sich um mehrere Familienmitglieder gleichzeitig kümmern: 9 AYC's (20 %) versorgen zwei Personen, 4 AYC's (8,9 %) drei Personen, 3 AYC's (6,7 %) vier Personen und 2 AYC's (4,4 %) fünf Personen und 1 AYC (2,2 %) sogar neun Personen.

Das „typische“ Profil eines Young Carers in der Schweiz ist ein Mädchen, das seine Mutter mit einer körperlichen Beeinträchtigung betreut. Grossmütter und Grossväter sind die zweit- bzw. dritthäufigsten Betreuungsempfänger.

5. Prozentsätze ohne missing values.

Die betreute Person kann auch ein Freund oder eine nahestehende Person sein. Von den 99 Befragten, die angaben, dass sie eine nahestehende Person im Pflege- oder Betreuungszustand haben, berichteten 46 Young Carers, dass sie sie betreuen. In den meisten Fällen ist die Betreuungsursache eine psychische Erkrankung. 18 AYCs betreuen ausschliesslich eine nahestehende Person (62 %). Es gibt nur wenige AYCs, die sich um mehrere nahestehenden Personen kümmern.

WIE VIEL UNTERSTÜTZUNG WIRD VON YOUNG CARERS GELEISTET?

Betreuungs- und Unterstützungsaufgaben können häusliche Aufgaben, Haushaltsführung, Körperpflege, emotionale Pflege, Geschwisterbetreuung und finanzielle/praktische Unterstützung umfassen. Im Vergleich zu ihren Altersgenossen üben Young Carers eine grössere Anzahl an Unterstützungsaufgaben aus. Daher haben sie andere Erfahrungen im täglichen Leben als ihre Kollegen. 24 % der gesamten Adolescent Young Carers Stichprobe erbringen viel Betreuungs- und Unterstützungsaufgaben (auf einer Multi-Dimensionalen Activities of Caring Checkliste (MACA⁶) Wert über 14), verglichen mit 20 % Nicht-Young Carers. 17 % Adolescent Young Carers leisten sehr viel Unterstützungsaufgaben (MACA-Wert über 18), verglichen mit 12 % Nicht-Young Carers.

Insgesamt leisten Mädchen im Vergleich zu Jungen mehr Betreuungs- und Unterstützungsaufgaben. Die Unterschiede sind jedoch statistisch nicht signifikant.

AUSWIRKUNGEN AUF DEN BILDUNGSSTAND

52 AYCs (64 %) gaben an, dass sie derzeit eine Ausbildung in der Berufsschule absolvieren. Dies spiegelt die schweizerische Stichprobenstrategie mit drei Berufsschulen wider. Weitere Schulen wurden in einer zweiten, späteren Rekrutierungsphase miteinbezogen, um die Zielmarke von 200 AYCs im Alter von 15-17 Jahren zu erreichen. 15 % berichteten, dass sie in der Schule Schwierigkeiten haben, weil sie sich um jemanden kümmern. Ebenso gaben 14 % an, dass ihre schulische Leistung aufgrund der Betreuungsaufgaben negativ beeinflusst wurde. 15 % gaben an, dass sie aufgrund ihrer Betreuungsrolle gemobbt, gehänselt oder verspottet wurden.

Diese Ergebnisse unterstreichen die Notwendigkeit, den Bildungssektor bei der Identifizierung und Unterstützung von Young Carers zu beteiligen.

ALLGEMEINES WOHLBEFINDEN

Bei Adolescent Young Carers wurde festgestellt, dass sie häufiger ein niedrigeres Wohlbefinden aufweisen als ihre Altersgenossen ohne Betreuungs- und Unterstützungsaufgaben. Auf einer Skala von 50 (extrem gutes Wohlbefinden) und 10 (geringes Wohlbefinden), haben Nicht-Young Carers einen Mittelwert von 34,9. Adolescent Young Carers weisen einen Mittelwert von 30,5 auf. Diese Diskrepanz von 4,4 ist statistisch hoch signifikant und kann auch als besorgniserregend angesehen werden.

GESUNDHEITLICHE AUSWIRKUNGEN DER BETREUUNGSROLLE

Young Carers in der Schweiz berichten im Vergleich zu anderen europäischen Ländern (mit Ausnahme von Grossbritannien) über eine höhere Anzahl an gesundheitlichen Schwierigkeiten durch Betreuungs- und Unterstützungsaufgaben: 40 % der Adolescent Young Carers melden körperliche Gesundheitsprobleme aufgrund ihrer Betreuungsrolle. 33 % berichten von psychischen Problemen.

Um die Gründe für dieses besonders bedeutsame Ergebnis zu erklären, sind weitere Untersuchungen erforderlich.

SCHWERE AUSWIRKUNGEN AUF DIE PSYCHISCHE GESUNDHEIT DURCH BETREUUNG: SELBSTVERLETZUNG UND VERLETZUNG ANDERER MENSCHEN

Aufgrund ihrer Betreuungsrolle haben 21 % der Adolescent Young Carers mit dem Gedanken gespielt, sich selbst zu verletzen und 5 % haben darüber nachgedacht, andere zu verletzen. Von diesen 5 % haben 50 % darüber nachgedacht, die betreute Person zu verletzen.

Der Anteil der Adolescent Young Carers, die daran gedacht haben, sich selbst zu verletzen, ist höher als in den anderen untersuchten Ländern, mit Ausnahme von Grossbritannien (8-11 %). Auch hier sind weitere Untersuchungen erforderlich, um die Gründe für diesen Unterschied zu ermitteln.

6. Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child: care, health and development*, 35(4), 510–520.

Dieses Ergebnis zeigt, dass Adolescent Young Carers einem **erheblichen Risiko von psychischer Belastung** ausgesetzt sind. Dies unterstreicht die Notwendigkeit, Angehörige der Gesundheitsberufe, insbesondere der Psychiatrie, für die Identifizierung und Unterstützung von Adolescent Young Carers zu sensibilisieren.

WEITERE INFORMATIONEN

In der Schweiz erhalten 15 % der Adolescent Young Carers eine direkte formelle Unterstützung. Im Vergleich zu anderen in dieser Studie untersuchten Ländern erhalten in der Schweiz weniger Familien von Adolescent Young Carers finanzielle Unterstützung. Dies lässt die Vermutung zu, dass die sozio-ökonomische Position der AYC-Familien in der Schweiz höher ist als in anderen Ländern. Um den wirklichen Grund dieses Unterschieds zu klären, bedarf es weiterer Forschung.

Während Adolescent Young Carers möglicherweise nicht die Möglichkeit haben, für ihre Betreuungsrolle auf spezielle formelle Unterstützungsleistungen zurückzugreifen, berichteten viele (61 %) über die Anwesenheit eines Freundes oder einer Freundin, der/die über ihre Betreuungsrolle informiert ist und ihnen Unterstützung anbietet. Diese Erkenntnis ist angesichts der Widerstandsfähigkeit und der Schutzfaktoren, die mit der Betreuungsrolle verbunden sind, wichtig: Adolescent Young Carers können informelle Unterstützung als wertvoll empfinden, wenn es keine formalen speziellen Dienste oder Leistungen gibt.

Was die Aussenwahrnehmung ihrer Betreuungsrolle betrifft, gaben die befragten Young Carers an, dass **es wahrscheinlicher ist, dass ein Freund oder eine Freundin über ihre Betreuungsrolle Bescheid weiss, als dass jemand in der Schule oder ein Arbeitgeber informiert ist**. Dies deckt sich mit den Ergebnissen anderer Länder in dieser Studie.

Kapitel 2:

Anerkennung, Schutz, Unterstützung: Welche rechtlichen Rahmenbedingungen existieren für Young Carers?

Ziel war es, die rechtlichen, politischen und dienstleistungsbezogenen Rahmenbedingungen zu untersuchen, mit denen Young Carers in sechs europäischen Ländern (Grossbritannien, Italien, Niederlande, Schweden, Schweiz und Slowenien) unterstützt werden sollen. Dabei ging es vor allem darum zu erforschen, welche Rahmenbedingungen vorhanden sind und wie diese sich in der Praxis auswirken, welche Stärken und Schwächen sie haben und aus welchem Antrieb sie entwickelt wurden. Zu diesem Zweck wurden eine Literaturrecherche sowie Interviews mit Experten und Expertinnen (entweder in juristischer, akademischer oder staatlicher Position) zum Thema Young Carers in den genannten sechs Ländern durchgeführt.

GESETZGEBUNG, POLITIK UND DIENSTLEISTUNGEN

In der Schweiz gibt es keine spezifische Gesetzgebung zum Schutz und zur Unterstützung der Young Carers und ihrer Familien. Ebenso fehlt eine Definition von Young Carers im Gesetz.

Das derzeitige System bietet (lediglich) indirekte Unterstützung für Young Carers, hauptsächlich durch Rechtsvorschriften zum Kinderschutz und zur sozialen Betreuung:

- ▶ Die [Bundesverfassung der Schweizerischen Eidgenossenschaft](#) besagt, dass Kinder und Jugendliche das Recht auf besonderen Schutz ihrer Integrität und auf Förderung ihrer Entwicklung haben. Sie können ihre Rechte auch persönlich ausüben, soweit es ihre Urteilsfähigkeit zulässt.
- ▶ [Schweizerisches Zivilgesetzbuch](#), Kindes- und Erwachsenenschutzrecht.
- ▶ Übereinkommen über die Zuständigkeit, das anzuwendende Recht, die Anerkennung, Vollstreckung und Zusammenarbeit auf dem Gebiet der elterlichen Verantwortung und der Massnahmen zum Schutz von Kindern ([Haager Kindesschutzübereinkommen, HKsÜ](#)).
- ▶ [Bundesgesetz über die Alters- und Hinterlassenenversi-](#)

[cherung](#), Art. 29 septies AHVG: Betreuungsgutschriften.

Was die Änderungen in der Gesetzgebung betrifft, so hat sich der **Paradigmenwechsel** von einem Wohlfahrtsansatz zu einem rechtsbasierten Ansatz vollzogen. Dies hat auch dazu geführt, dass Kinder jetzt besser über ihre Rechte informiert sind.

Es gibt politische Rahmenbedingungen, die sich speziell an Young Carers richten:

- ▶ [Aktionsplan für betreuende und pflegende Angehörige](#)

Am 5. Dezember 2014 veröffentlichte der Bundesrat den Bericht über die „[Unterstützung für betreuende und pflegende Angehörige](#)“. Dies ist das Ergebnis eines politischen Vorstosses des Schweizer Parlaments und des Bundesrates im Rahmen der [Agenda Gesundheit 2020](#) und zeigt eine wachsende Dynamik rund um die betreuenden Angehörigen in der politischen Landschaft in der Schweiz. Die im Bericht aufgeführten Massnahmen – bessere Information, Erholung, Vereinbarkeit von Beruf und Familie – sollen in Zusammenarbeit mit den Kantonen, Gemeinden und privaten Organisationen umgesetzt werden.

Im Jahr 2014 wurden Young Carers nicht in den Aktionsplan aufgenommen. In einer Petition des Parlaments wurde jedoch auf ihren Ausschluss eingegangen und sie werden nun ausdrücklich erwähnt.

- ▶ [Förderprogramm zur Entlastung von pflegenden und betreuenden Angehörigen](#). Die Forschung richtet sich an betreuende Angehörige jeden Alters. Young Carers werden explizit miteinbezogen. Das Programm wird den Interessengruppen in den Kantonen, Gemeinden, Unternehmen und Organisationen mit Modellen guter Praxis zur Verfügung gestellt, damit diese ihre eigenen Programme entwickeln, fördern oder selbst entsprechende neue Angebote einbringen können.

Die Experten erwähnten auch nicht-spezifische Rahmenbedingungen, die die Young Carers und ihre Familien indirekt unterstützen können:

- ▶ [Kinder- und Jugendpolitik](#)
- ▶ [Gesundheitsförderung Schweiz](#) ist eine von Kantonen und Versicherungen getragene Stiftung. Mit einem gesetzlichen Auftrag versehen, koordiniert und bewertet sie die von den Kantonen umgesetzten Massnahmen im Bereich der Gesundheitsprävention und -förderung. Vier Module und acht Prinzipien können von den Kantonen als Grundlage für ihre kantonalen Aktionsprogramme verwendet werden.
- ▶ Im Kanton Waadt bietet die Organisation [Espace Proches](#) den betreuenden Angehörigen Erholungs- und Beratungsdienste an.
- ▶ In fast allen Kantonen gibt es wahrscheinlich öffentliche Dienstleistungsangebote für Jugendliche und ihre Familien.

STÄRKEN UND SCHWÄCHEN VON GESETZGEBUNG, POLITIK UND DIENSTLEISTUNGEN

Die Experten wurden gebeten, die wichtigsten Stärken oder Schwächen von Gesetzgebung, Politik und Dienstleistungen zu bewerten.

Wichtigste Stärken

- ▶ Die Gesetzgebung ist sehr klar.
- ▶ Es gibt ein solides Rechtssystem, das sehr viel Schutz für Kinder bietet.
- ▶ Das Kinderschutzsystem ist in der Schweiz sehr gut etabliert und funktioniert in einer interdisziplinären Art und Weise.
- ▶ Gesetzgebung und Dienstleistungen sind regional flexibel und ermöglichen Lösungen, die dem regionalen Kontext entsprechen (Flexibilität). Die Vielfalt der Lösungen macht Innovationen einfacher.
- ▶ Das föderalistische System bewirkt einen Nachahmungseffekt: Führt ein Kanton Best Practice durch, werden andere Kantone diese früher oder später übernehmen.
- ▶ Die im Schweizerischen Zivilgesetzbuch verwendete Terminologie „Kindeswohl“ lässt Raum für Interpretation. Das kann eine Schwäche sein, es ist aber auch eine Chance, denn es ermöglicht das Handeln und Reagieren auf individuelle Situationen und individuelle Umstände.

Wichtigste Grenzen

- ▶ Young Carers sind in der Schweiz keine bestimmte soziale Gruppe und daher richten sich Förder- und Unterstützungsprogramme auch nicht an sie.
- ▶ Gesetze, politische Rahmenbedingungen und sogar einige Organisationen, die mit betreuenden Angehörigen arbeiten, verwenden keine altersgerechte Sprache für junge Menschen, so dass die Informationen möglicherweise für Young Carers nicht zugänglich sind, die nicht über ein angemessenes Bildungsniveau verfügen.
- ▶ Mangelnde Koordination zwischen den verschiedenen Rechtsordnungen (z. B. Sozialversicherungssystem, Familienrecht, Medizinrecht, Kinderschutz, usw.).
- ▶ Die politischen Bestimmungen für betreuende Angehörige sind für Young Carers nicht relevant, da sie sich auf die Förderung eines Gleichgewichts zwischen Arbeit und informeller Pflege beziehen. Young Carers, die eine Schule, ein Studium oder eine Ausbildung absolvieren, werden dabei nicht berücksichtigt.
- ▶ Trotz der Empfehlungen des Bundes zur Umsetzung der UN-Kinderrechtskonvention gibt es Unterschiede zwischen den Kantonen.

In Bezug auf die Kinderschutzhilfe wurden die folgenden Grenzen festgestellt:

▶ Die Identifizierung von Young Carers ist eine Herausforderung.

Die Kinderschutzhilfe wird nur dann einbezogen, wenn die Probleme eines Young Carers offensichtlich sind. Da Young Carers sich nicht selbst melden, sollten Fachleute (aus den Bereichen Bildung, Soziales und Gesundheit) die Behörden (z. B. Kinderschutzdienste) informieren. Da jedoch Fachpersonen wenig für die Situation von Young Carers sensibilisiert sind, können sie sie gar nicht identifizieren.

▶ Fokussierung auf Schutz statt auf Prävention oder Empowerment.

Kinderschutzmassnahmen können nur dann ergriffen werden, wenn das Wohl des Kindes gefährdet ist. Es reicht nicht aus, dass das Kindeswohl eingeschränkt erreicht wird. Bevor die Kinderschutzdienste eingreifen können, muss ein Schwellenwert überschritten werden. Der Schwerpunkt liegt daher darin, Kinder dann zu schützen, wenn Probleme bereits eskaliert sind, und nicht darauf, sie zu verhindern.

Nach Ansicht einiger Experten steht der Schwerpunkt auf Schutz im Gegensatz zur Notwendigkeit, Young Carers zu stärken und zu erkennen, dass Betreuungsverantwortung auch positive Ergebnisse bringen kann (nicht nur etwas, vor dem man sich schützen muss).

▶ Familien greifen nicht auf die Hilfe der Kinderschutzdienste zurück.

Kinderschutzhilfen können für Familien beängstigend sein, da ihre Aufgabe darin besteht, zum Schutz von Kindern einzugreifen. Es scheint, dass es keinen Mittelweg zwischen „Unsichtbarkeit“ von Young Carers und „Missbrauch“ (und

damit dem Eingreifen von Kinderschutzdiensten) gibt.

Die schwierige Vergangenheit des Kinderschutzes in der Schweiz (siehe Fokus auf die Bestimmung des Kindeswohls) hat dazu geführt, dass Young Carers und ihre Familien aus Angst vor einer Trennung nicht um Hilfe bei den Diensten bitten.

► **Keine Auswertung der Ergebnisse von Kinderschutzmassnahmen.**

Die Ergebnisse der Massnahmen der Kinderschutzbehörden werden nicht wirklich ausgewertet. Es ist daher unklar, ob diese Massnahmen für Young Carers und ihre Familien geeignet sind.

ZUKÜNFTIGE BEDÜRFNISSE

Nachdem die Experten die Stärken und Schwächen des derzeitigen Systems identifizierten, wurden sie über Änderungen in der Gesetzgebung, Politik und/oder Dienstleistungen befragt.

Ein erstes Dilemma, das es zu lösen galt, war die Möglichkeit, nach dem Vorbild von Grossbritannien eine spezifische Gesetzgebung für Young Carers zu erlassen (siehe Kasten

Fokus auf das britische Modell).

Die Experten waren sich einig, dass das britische Modell aus verschiedenen Gründen nicht in den Schweizer Kontext passen dürfte:

- Eine spezifische Gesetzgebung wäre aufgrund der föderalen Struktur ein langwieriges und kompliziertes Projekt. **Young Carers haben keine Zeit zu warten.** Daher ist es sinnvoller, Young Carers in Strategien und Programme einzubeziehen, die bereits existieren oder sich in der Entwicklung befinden.
- Es ist nicht notwendig, eine spezifische Gesetzgebung für Young Carers zu haben, da es nicht für jede Gruppe von Menschen in Not spezifische Gesetze gibt.
- In der Schweiz gibt es bereits viele bestehende Rechtsvorschriften, die die Grundlage für neue Rahmenbedingungen oder Dienstleistungen für Young Carers bilden können, wie z. B. das Kinderschutzgesetz und die UN-Kinderrechtskonvention. Die Einführung von Rechtsvorschriften, die sich speziell an Young Carers richten, würde eine Überregulierung bedeuten.
- Eine spezifische Gesetzgebung reicht nicht aus, um sicherzustellen, dass Young Carers in der Praxis unterstützt werden (in Grossbritannien ist beispielsweise zu sehen, dass die Unterstützung und der Schutz, die Young Carers in der Praxis erhalten, nicht unbedingt den Zielen der Gesetzgebung entsprechen).

FOKUS : ERMITTLUNG DES „WOHL DES KINDES“.

Die Konvention über die Rechte des Kindes (Convention on the Rights of the Child, CRC) besagt, dass das Wohl des Kindes bei allen Massnahmen, die Kinder betreffen, im Vordergrund steht.

Der Begriff „Wohl des Kindes“ beschreibt im weitesten Sinne das Wohlbefinden eines Kindes. Dieses Wohlbefinden wird durch eine Vielzahl von individuellen Umständen, wie z. B. das Alter, den Reifegrad des Kindes, die Anwesenheit oder Abwesenheit von Eltern, die Umgebung und Erfahrungen des Kindes, bestimmt.

In der Schweiz gibt es eine Debatte über die Kinderschutzbehörden: Einige sind der Ansicht, dass Kinder nicht „Eigentum“ ihrer Eltern sind und der Staat zur Intervention verpflichtet ist, während andere der Meinung sind, dass die Kinderschutzbehörden zu viel Macht haben. Dies ist auf unterschiedliche Interpretationen des Prinzips „Wohl des Kindes“ zurückzuführen.

Der Rückbezug auf das Wohl des Kindes wurde häufig angewandt, um ein Eingreifen des Kinderschutzes bei der Trennung von der Familie zu rechtfertigen, was als eine bewährte Vorgehensweise angesehen wurde. Die Kinderschutzdienste haben Kinder im Namen des Kinderschutzes aus ihren Familien herausgerissen unter Umständen, die aus heutiger Sicht als schwere Verletzungen der Rechte dieser Kinder und ihrer Familien angesehen würden.

Es ist wichtig, dass die Auslegung und Anwendung des Prinzips in Übereinstimmung mit den Konventionen über die Rechte des Kindes (Convention on the Rights of the Child, CRC) und anderen internationalen Rechtsnormen erfolgt. Darüber hinaus bedarf es situationsgerechter Lösungen, die das Thema von Fall zu Fall angehen, da **das Wohl eines Kindes für jedes Kind anders sein kann!** Daher ist eine stärkere Beteiligung der Young Carers selbst (und ihrer Familien) an den sie betreffenden Entscheidungen erforderlich.

Unter Berücksichtigung der bereits erwähnten Überlegungen sind sich die Experten einig, dass es ratsamer ist, Young Carers nicht in eine spezifische Gesetzgebung aufzunehmen, sondern sie in die bestehende Gesetzgebung bzw. Politik zu integrieren. **Diese muss erweitert und geändert werden, damit Young Carers erkannt und angemessen unterstützt werden können.**

Unter anderem empfehlen die befragten Expertinnen und Experten:

- ▶ Das Problem der Young Carers muss systematisch angegangen werden. Es bedarf weiterer Daten, um Lösungen zu finden, um diese Kinder und Jugendlichen sichtbar zu machen, um zu verstehen, wie Kinderschutzmassnahmen funktionieren, und um die Entscheidungsträger und Gesetzgeber im Hinblick auf die zukünftige Unterstützung von Young Carers zu informieren.
- ▶ Starkes politisches Engagement und Unterstützung durch z. B. gemeinnützige oder nichtstaatliche Organisationen.
- ▶ Änderung des Gesetzes in Bezug auf die rechtlichen Pflichten zum Kinderschutz, um sicherzustellen, dass ein präventiver Ansatz in der Praxis zum Tragen kommt.
- ▶ Integration des Themas (Adolescent) Young Carers in der nationalen politischen Rahmenbedingungen für betreuende Angehörige des Bundesamtes für Gesundheit in der Schweiz. Neben Änderungen des nationalen Programmes sollten auch Änderungen auf kantonaler Ebene vorgenommen werden.
- ▶ Weitere Rechtsvorschriften und politische Rahmenbedingungen, um die Strukturen und Bedingungen zu schaffen, die es Fachleuten ermöglichen, gut zusammenzuarbeiten (unter Berücksichtigung des Rechts auf Privatsphäre).
- ▶ Eine Definition von Young Carers hinzuzufügen.



DILEMMA

Brauchen wir eine spezifische Gesetzgebung und politische Rahmenbedingungen für Young Carers? Oder wäre die Beibehaltung unspezifischer Rechtsvorschriften ein besserer Ansatz?

Die Antwort hängt von länderspezifischen Aspekten ab, wie beispielsweise „wie wirksam ist die aktuelle unspezifische Gesetzgebung bzw. die politischen Rahmenbedingungen bei der Anerkennung, Identifizierung, dem Schutz und der Unterstützung von AYCs“? Die Antwort sollte auf einem grundlegenden Verständnis der lokalen Gegebenheiten beruhen. Unsere Studie zeigt, dass die Unterstützung und der Schutz, den die AYCs in der Praxis erhalten, nicht immer den Zielen der bestehenden Gesetzgebung und Politik entsprechen. Ohne ein genaues Verständnis der lokalen Gegebenheiten können Annahmen über die Wirksamkeit bestehender gesetzlicher und politischer Rahmenbedingungen dazu führen, dass AYCs nicht erkannt und alleine gelassen werden.

Brauchen wir Rechtsvorschriften oder sind Absichtserklärungen und das Engagement der verschiedenen Stakeholders ausreichend?

Damit es ein Engagement geben kann, ist es notwendig, dass sich verschiedene Stakeholders (Fachleute, Familien, betreuende Angehörige, Organisationen, der Staat) **bewusst sind** und anerkennen, dass Kinder und Jugendliche eine Rolle in der Betreuung und Unterstützung von Angehörigen übernehmen und dass dies negative Auswirkungen haben kann. Damit ihr Engagement wirksam ist, müssen die Beteiligten **wissen, wie sie AYCs effektiv unterstützen können**. Damit das Engagement umgesetzt werden kann, benötigen die Beteiligten ausreichende Kapazitäten und die erforderlichen **Ressourcen**. Wenn einer oder mehrere dieser Faktoren fehlen, dann ist das vielleicht die Rolle, die die Gesetzgebung und Politik spielen sollten.

FOKUS AUF DAS ENGLISCHE MODELL.

Nur Grossbritannien verfügt über eine **spezifische Gesetzgebung zu diesem Thema**, die junge Menschen mit Betreuungsverantwortung ausdrücklich anerkennen oder definieren. Daher kann es sich lohnen, dieses System genauer zu untersuchen. In England fallen Bestimmungen für Young Carers unter den Care Act 2014 und den Children Act 1989 (geändert durch den Children and Families Act, 2014). Diese verfolgen das Ziel, einen präventiven und **ganzheitlichen Familienansatz** zur Identifizierung, Bewertung und Unterstützung zu erreichen.

Recht auf Bedarfsanalyse und Unterstützung. Der neue rechtliche Rahmen definiert Young Carers, legt eine allgemeine Verpflichtung fest, die Bedürfnisse von Young Carers gegenüber den lokalen Behörden zu bewerten, und verpflichtet sie, angemessene Massnahmen zu ergreifen, um festzustellen, inwieweit es in ihrem Gebiet Young Carers gibt, die Unterstützung benötigen (d. h. aktiv nach ihnen suchen). Der Children and Families Act 2014 gibt Young Carers und Young Adult Carers in England das Recht auf eine Bewertung durch eine Fachperson und die Berücksichtigung ihrer Bedürfnisse (wenn die Bewertung zeigt, dass dies notwendig ist). Die Bedarfsanalyse eines Young Carers muss eine Bewertung darüber beinhalten, ob es für die Young Carer angemessen ist, die betreffende Person zu betreuen bzw. weiterhin zu betreuen. **Unangemessene Betreuungsaufgaben** sollten als solche angesehen werden, die einen Einfluss auf die Gesundheit, das Wohlbefinden oder auf die Schulbildung des Kindes haben können oder die aufgrund der Umstände des Kindes als ungeeignet angesehen werden können. Beide Gesetze erwähnen erstmals ausdrücklich die Young Carers. In der vorherigen Gesetzgebung wurden Young Carers als gefährdete Gruppe erwähnt, aber das Recht auf Bewertung war von zwei Voraussetzungen abhängig: Die angebotene Betreuung musste umfangreich und regelmässig sein. Was mit regelmässiger und substantieller Betreuung gleichgesetzt wurde, war der örtlichen Interpretation überlassen. Dies bedeutete, dass je nach Bereich jemand für eine Bewertung in Frage kommen konnte, während jemand in einem anderen Bereich nicht in Betracht gezogen wurde. Mit den neuen Rechtsvorschriften besteht eine klare Rechenschaftspflicht und Verantwortung für die Identifizierung von Young Carers und für die Unterstützung der ganzen Familie durch die Zusammenarbeit in den Bereichen Erwachsenen- und Kinderschutz, Gesundheit und Sozialfürsorge.

Die Gründe für die neue Gesetzgebung: Investitionen in das Wohlbefinden und die Prävention der betreuenden Angehörigen sind eine lohnende Investition! Der Hauptgrund, warum der englische Gesetzgeber beschlossen hat, die Gesetzgebung zu ändern - für betreuende Angehörige im Allgemeinen - ist das Verständnis, dass **Investitionen in das Wohlbefinden und die Präventionsarbeit der betreuenden Angehörigen eine lohnende Investition waren**, die letztendlich die Kosten für den Staat senkte. Ein Bericht von Carers UK und der Sheffield University aus dem Jahr 2015 ergab, dass betreuende Angehörige Grossbritannien jährlich 132 Milliarden Pfund einsparen. Das Versagen bei der Früherkennung und Unterstützung führte zu einer Eskalation der Bedürfnisse, mit negativen Folgen nicht nur für einzelne Betreuer, sondern auch negative und kostspielige Auswirkungen auf die Gesundheit und das Wohlbefinden der betreuenden Angehörigen, ihre Bildungs- und Berufsaussichten und auf die Finanzen des Staates. Bei den Young Carers gab es Hinweise auf den sehr geringen Prozentsatz, die eine Bedarfsanalyse erhielten. Wie die National Young Carers Coalition in einem [Briefing](#) 2013 feststellte: „Wir sind fest davon überzeugt, dass die Reform des Gesetzes für Young Carers nicht nur die Identifizierung und Unterstützung von Young Carers verbessern würde, was sich positiv auf ihre langfristigen Ergebnisse auswirken würde, sondern dass die Gesetzesreform auch die Belastung der lokalen Behörden verringern würde, indem sie das Risiko einer unangemessenen Betreuung verhindert und einen klaren Rahmen für die Unterstützung der ganzen Familie schafft, und zwar zu letztlich niedrigeren Kosten für den Staat“.

Paradigmenwechsel: ein Ansatz für die ganze Familie: Darüber hinaus hatte die Regierung Beweise dafür erhalten, dass sich das Erwachsenen- und Kinderrecht nicht aufeinander bezogen, was die Arbeit mit der ganzen Familie verhinderte. Young Carers wurden isoliert unterstützt, ohne dass ihre Familien ebenfalls die richtige Unterstützung erhielten. Nur sehr wenige Young Carers wurden identifiziert und von den Sozial- und Gesundheitsdiensten für Erwachsene zur Unterstützung empfohlen. Nur 4-10 % der Überweisungen an die Dienste für Young Carers stammten aus der Erwachsenensozialfürsorge*. Dies war alles andere als wirkungsvoll. Daher kam es zu einem Paradigmenwechsel: Die getrennte Unterstützung von Young Carers und deren Familien ging in einen „whole family approach“ über.

Die treibende Kraft für die Änderung der Gesetzgebung: Bei der **Sensibilisierung und der Kampagne für den Wandel** haben die **Nichtregierungsorganisationen** eine Schlüsselrolle gespielt. Des Weiteren haben sie eine strategische Rolle bei der Steuerung und Gestaltung des öffentlichen Diskurses und der politischen Entwicklungen übernommen, indem sie mit den politischen Entscheidungsträgern, Politikern und Young Carers selbst zusammengearbeitet haben. Damit sie diese Rolle wahrnehmen können, haben sie auf länderspezifische Forschungsergebnisse zurückgegriffen.

*https://www.childrensociety.org.uk/sites/default/files/tcs/nycc_key_points_briefing_on_young_carers_the_care_bill.pdf

Kapitel 3:

Erfolgreiche Strategien zur Verbesserung der psychischen Gesundheit und des Wohlbefindens von Young Carers

FOKUS AUF DIE SCHWEIZ

Die Projektpartner befragten 10 Schweizer Experten aus den Bereichen Wissenschaft, Politik, Gesundheit und Soziales zum Thema „Young Carers“ und verwandte Themen. Im Mittelpunkt der Interviews stand die Sichtbarkeit der Young Carers in der Schweiz und deren Unterstützung.

Sichtbarkeit und Sensibilisierung von Young Carers

Nach Ansicht der Experten ist in der Schweiz die Sichtbarkeit, das Bewusstsein und das Verständnis für Young Carers auf lokaler, regionaler und nationaler Ebene eher gering. Daher ist eine stärkere Anerkennung und Sensibilisierung von Young Carers und ihren Bedürfnissen bei Fachleuten und Familien erforderlich. Der Begriff „Young Carer“ ist in der Regel nicht bekannt. Nur Fachleute auf diesem Gebiet verwenden ihn (interessanterweise neigen sie dazu, den englischen Begriff zu verwenden). Die Vorstellung, dass ein Kind die Betreuung seiner Eltern, Geschwister, Grosseltern usw. übernimmt, wird praktisch nicht anerkannt. Nur wenige Personen sprechen über das Thema, das Stigma bleibt bestehen. Young Carers identifizieren sich selbst oft nicht als Young Carers, selbst wenn sie es tun, sprechen sie nicht darüber, sie halten es geheim, aus Angst, stigmatisiert zu werden. Sie befürchten, dass die Behörden aufmerksam werden könnten und sie von der Familie getrennt werden. Einige Experten betonen, dass Kinder mit Migrationshintergrund offener sind, über ihre Betreuungserfahrung zu sprechen, da in ihrer Kultur die Betreuung von Familienmitgliedern oder Nahestehenden ein häufig vorkommendes Phänomen ist. Ein Experte stimmte dieser Aussage nur teilweise zu und wies darauf hin, dass - wenn der Begriff „Young Carer“ in der Gesellschaft negativ konnotiert wird – möglicherweise auch Kinder aus Migrantenfamilien nicht mehr offen für Gespräche über ihre Betreuungserfahrungen sein

würden. Generell waren sich die befragten Experten einig darüber, dass **ein mangelndes Bewusstsein unter Fachleuten** mit unterschiedlichem Hintergrund (Gesundheitswesen, Bildung, Sozialwesen) besteht. Die einzige Ausnahme existiert bei Kindern und Jugendlichen, die sich um jemanden mit einer psychischen Erkrankung kümmern. In diesem speziellen Fall besteht bereits eine gewisse Sensibilität. Es existiert nur wenig bedeutende Medienberichterstattung über Young Carers. Wenn es welche gibt, liegt der Fokus auf jüngeren Kindern. Es braucht Veränderung und mehr Sensibilisierung für das Thema Young Carers. Dazu veröffentlichte die Young Carers Research Group unter der Leitung von Professor Agnes Leu eine Reihe von Forschungsergebnissen, was in Zukunft zu einer verbesserten Sichtbarkeit von AYC führen soll. Dank dieser Entwicklungen ist es wahrscheinlich, dass die Schweiz in der nächsten Iteration der von Leu und Becker⁷ vorgeschlagenen Klassifizierung zur Sensibilisierung und zur politischen Reaktionen auf Young Carers (derzeit auf Stufe 5 – „emerging“) höher aufsteigen wird.

Vorhandene Unterstützungsmöglichkeiten

Young Carers sind in der Schweiz nicht eine bestimmte soziale Gruppe, weshalb es keine spezifischen Massnahmen für sie gibt. Die Unterstützung von (A)YCs erfolgt über Kinderschutzwege und einige allgemeinere Massnahmen (für Kinder und Jugendliche im Allgemeinen). Es gibt viele Plattformen für Jugendliche, wie unter anderem [Pro Juventute](#), eine gemeinnützige Stiftung, die sich für die Rechte und Bedürfnisse von Kindern und Jugendlichen in der Schweiz einsetzt. Es gibt einige neue, vor allem lokale Programme, die speziell auf die Unterstützung von (A)YCs ausgerichtet sind, wie z. B. Sensibilisierungsaktivitäten in Schulen, in welchen Fachleute das Thema „Young Carers“ mit Schülern diskutieren. Spezielle Programme sind vor allem für Young

7. Leu, A., & Becker, S. (2017). A cross-national and comparative classification of in-country awareness and policy responses to <young carers>. *Journal of Youth Studies*, 20(6), 750–762. doi:10.1080/13676261.2016.1260698

Carers etabliert, die sich um Eltern mit psychischen Erkrankungen kümmern. So setzt sich die Stiftung [Kinderseele Schweiz](#) dafür ein, dass sich Kinder von psychisch kranken Eltern genauso gut wie nicht betroffene Kinder entwickeln können. Sie beraten die Betroffenen, ihr soziales Umfeld und Fachleute leisten Hilfe. Im Bereich der psychischen Gesundheit könnte der sogenannte „Open Dialogue Approach“ - bei dem Experten direkt mit der ganzen Familie arbeiten (Family Approach) - den Vorteil haben, Young Carers zu identifizieren und die Pflegelast zu reduzieren. Dieser Ansatz ist jedoch unterentwickelt und in der Schweiz noch nicht ausreichend akzeptiert.

Evaluation der verfügbaren Unterstützung und zukünftiger Bedürfnisse

Die Experten bewerteten das derzeitige Unterstützungssystem für Young Carers und identifizierten auf der Grundlage dieser Analyse die wichtigsten Bedürfnisse.

► **Betreuungsrolle als alltägliches Phänomen**

Eine grosse Herausforderung stellt die Wahrnehmung dar, dass **Betreuung etwas ist, das privat gehalten, und verborgen bleiben muss**, aus Angst vor Stigmatisierung oder Trennung von der Familie. Daher ist es wichtig, das Problem sichtbar zu machen und jegliches Stigma zu beseitigen, das damit verbunden ist, ein Young Carer zu sein. Der Schwerpunkt sollte auf der Tatsache liegen, dass **die Betreuung Teil der menschlichen Erfahrung ist** und dass damit positive Aspekte verbunden sind. Die Bereitstellung von Betreuung hilft, Fähigkeiten zu entwickeln, wie das Angehen von Situationen und Konflikten und das Aufbauen von Beziehungen zu anderen.

► **Befähigung von Fachpersonen**

Es ist wichtig, Fachpersonen aus allen Bereichen (Bildung, Soziales und Gesundheitswesen) zu befähigen, damit sie Young Carers besser identifizieren und unterstützen können. Ihnen müssen praktische Hilfsmittel (z. B. Richtlinien, Checklisten) zur Verfügung gestellt werden.

► **Integriertes Arbeiten**

Derzeit gibt es Lücken zwischen dem Gesundheits-, dem Bildungs- und dem Sozialsystem. Dies sind alles sehr unterschiedliche Bereiche mit wenigen Verbindungen und zu geringer Koordination untereinander. Die befragten Experten forderten eine erhöhte Integration, indem sie alle relevanten Akteure einladen, um das Thema zu diskutieren, sichtbar zu machen und gemeinsam Lösungen zu finden (im Sinne dessen, was mit dem Thema Kinder von Eltern mit einem psychischen Gesundheitsproblem getan wird).

► **Ganzheitlicher Ansatz unter Einbezug der Familie**

Dienstleistungsanbieter, die mit pflegebedürftigen Erwachsenen arbeiten, konzentrieren sich lediglich auf den Erwachsenen, nicht auf das Netzwerk, das sich um sie herumbewegt. Dadurch bleiben Young Carers unerkannt. Die Experten forderten einen Familienansatz, der die Belas-

tung der (A)YCs reduzieren soll.

► **Individuelle, personalisierte Unterstützung**

Die Experten betonten die Notwendigkeit, die Vielfalt der Familien zu akzeptieren. Young Carers sind keine homogene Gruppe. Jedes Kind hat seine eigene Geschichte. Anstatt ein Konzept zu entwickeln, das allen gerecht wird, ist es daher besser, persönliche Unterstützung zu bieten, die auf die individuellen Bedürfnisse zugeschnitten ist. *„Aber es gibt immer mehr Kinder, unter denen eine sehr grosse Vielfalt herrscht. Diese Vielfalt kann nicht durch die Standardisierung von Programmen abgedeckt werden. Und auch nicht, indem eine Sensibilisierungskampagne für jede einzelne Lebenssituation durchgeführt wird, sondern vielmehr, indem den Menschen, die mit ihnen arbeiten, beispielsweise erklärt wird: Hey, wenn man eine Klasse hat, gibt es sicherlich 4,5,6 Kinder, einige sind arm, andere haben einen Migrationshintergrund, die dritten haben einen Elternteil zu Hause, um den sie sich kümmern müssen, die vierten haben ein behindertes Geschwisterkind, die fünften haben eine Flucht hinter sich. Schauen Sie sich diese Kinder genau an und beurteilen Sie individuell, was diese Kinder brauchen“.*

► **Einbeziehung von Young Carers in bestehende Massnahmen und Programme**

Anstatt Programme zu entwickeln, die sich spezifisch an Young Carers richten, empfahlen die Experten, sie in das allgemeine Angebot miteinzubeziehen. Uneinigkeit gab es über den Umfang der Unterstützung: Ein Experte meinte, dass Jugendliche von der Schweizer Gesellschaft nicht ausreichend unterstützt werden. Im Gegenzug dazu betont ein anderer Experte, dass sowohl die Vielfalt des Angebots, die Hilfe für Jugendliche als auch die Zahlen, durchaus respektabel seien.

► **Verbesserung der Kommunikation, der Werbung und des Zugangs zu Unterstützungsprogrammen**

Die Experten äusserten Bedenken darüber, wie bekannt die Förderprogramme in der Bevölkerung sind. *„Ich denke wirklich, dass wir uns in einer sehr guten, sehr günstigen Situation in der Schweiz oder in Mitteleuropa im Allgemeinen befinden. Es gibt viele Angebote, aber was ich bemerke, oder was ich denke, ist, dass die Kommunikation oder manchmal auch die Zugänglichkeit von Angeboten für die Interessengruppe das grösste Problem darstellen, so dass es nicht sehr viel nützt, wenn wir über wahnsinnig gute Programme verfügen, wenn man sie gleichzeitig nicht an die Zielgruppe bringt. Ich denke wirklich, dass der grosse Fokus auf der Kommunikationsarbeit liegen müsste“.*

► **Besondere Anstrengungen zur Identifizierung und Unterstützung der Adolescent Young Carers unternehmen**

Die Experten erkannten an, dass die Schwierigkeiten der Identifizierung im Vergleich zu Young Carers bei Adolescent Young Carers noch grösser ist, da sie sich im Übergang vom Kind zum Erwachsenen befinden. Sie sehen in der Regel keine Kinderärzte mehr und besprechen ihre Lebenssituation nicht mit ihrem Hausarzt. Sie haben die regulären neun Schuljahre abgeschlossen und beginnen dann in der Regel eine Lehre, das Gymnasium oder eine weiterführende Schule.

► Mehr Finanzierungen für präventive Massnahmen

Stiftungen und Organisationen, die Young Carers unterstützen könnten, sind teils privat und teils staatlich finanziert, jedoch sind diese klein und unterfinanziert. Nach Ansicht der Experten könnte, durch eine Änderung der Gesetzgebung, mehr getan werden, beispielsweise mehr finanzielle Mittel für Dienste, die präventive Arbeit leisten. Die Massnahmen sollten aus verschiedenen Quellen (Stiftungen, Regierungen, Geldgeber, Krankenkassen ...) finanziert werden, um sie unabhängig zu halten. Sie können aus dem Staatsbudget finanziert werden, jedoch sollte eine allgemeine Finanzierung gegenüber einer Einzelfinanzierung vorgezogen werden.

► Mitgestaltung der Unterstützungsmassnahmen durch Young Carers

Die Unterstützungsmassnahmen müssen in Zusammenarbeit mit Young Carers konzipiert werden, um sicherzustellen, dass sie ihren Bedürfnissen entsprechen. Um aktiv teilnehmen zu können, müssen Young Carers angemessen informiert werden.

ERFAHRUNGEN ANDERER LÄNDER

Die Me-We Forschungsstudie - mit ihrem länderübergreifenden Vergleich - ermöglicht es uns, einen Überblick über mögliche Strategien zur Identifizierung und Unterstützung für „Young Carers“ zu geben. Die Erfahrungen im Ausland können eine grosse Inspiration für die Schweizer Politik und andere Akteure sein (unter Berücksichtigung der Besonderheiten des Schweizer Kontextes, die im vorherigen Abschnitt hervorgehoben wurden).

Erfolgreiche Strategien zur Identifizierung von Young Carers

Es ist wichtig, dass Young Carers wahrgenommen werden und nicht selbst die Hand ausstrecken müssen. Daher können die folgenden Massnahmen angewendet werden:

Screening in Schulen und im Sozial-/ Gesundheitsbereich

- Schulen können eine wichtige Rolle bei der Früherkennung von Young Carers spielen. Um die Identifizierung zu erleichtern, könnten Tools wie MACA-YC18⁸ verwendet werden.
- Gesundheits- und Sozialfachpersonen könnten - wenn sie mit einem unterstützungsbedürftigen Erwachsenen in Kontakt treten - routinemässig fragen, ob das Netzwerk um die unterstützte Person herum Kinder umfasst und ob diese eigene Bedürfnisse äussern. Sie sollten den

Verlauf regelmässig kontrollieren (mit der Entwicklung der Krankheit und der damit in Verbindung stehenden Betreuung und Pflege).

Training für Experten

- Fachpersonen (aus dem Bildungs-, Gesundheits- und Sozialbereich) könnten an einem Training über „Young Carers“ teilnehmen um dabei mehr über die Herausforderungen, mit denen sie konfrontiert sind, über Massnahmen zur Identifizierung und Unterstützung sowie über wirksame Möglichkeiten zu erfahren. Eine solche Ausbildung für Fachleute könnte in die Grundausbildung aufgenommen werden.

Sensibilisierung der Fachpersonen und Öffentlichkeit

- Damit unbezahlte Pflege, Widerstandsfähigkeit und psychische Gesundheit oder Sucht weniger tabuisiert werden, könnte in der Schule darüber diskutiert werden.
- Die positiven Auswirkungen von Betreuungsaktivitäten könnten gefördert werden: die Bereitstellung von Betreuung ist ein Element, das zum Aufbau von Fähigkeiten wie zur Entwicklung der Fähigkeit, Situationen und Konflikte zu bewältigen und Beziehungen zu anderen aufzubauen, führt.
- Sensibilisierungswochen in Schulen, der Austausch individueller Geschichten in Vorträgen, Fernsehsendungen, Kampagnen im sozialen Netzwerk sind gute Möglichkeiten, das Bewusstsein zu verbessern und die Stigmatisierung zu reduzieren.

Erfolgreiche Strategien zur Unterstützung von Young Carers bei der Ausbildung

Um sicherzustellen, dass Young Carers Bildungsprogramme absolvieren und gute Leistungen erbringen können, ist die wichtigste Fördermassnahme die Gewährleistung von **Flexibilität**, was unterschiedliche Bedeutung haben kann:

- Mehr Verständnis von Lehrpersonen für Verspätungen, Absenzen, Vergessen der Hausaufgaben
- Bildungspläne und Lernaktivitäten, die sich stärker auf die Bedürfnisse von (A)YCs konzentrieren

Neben Flexibilität können die Schulen eine **zusätzliche, massgeschneiderte Unterstützung** einrichten, um Ausfälle zu vermeiden und einen reibungslosen Übergang zur Ausbildung oder zum Beruf zu gewährleisten. Eine solche könnte beispielsweise wie folgt aussehen:

8. Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child: care, health and development*, 35(4), 510–520.

- ▶ Berater, mit denen Young Carers persönlich sprechen können.
- ▶ Die Vermittlung lokaler Aktivitäten an Schüler wie (z. B. Sportverein, Jugendclub) und sie darüber zu informieren, dass es diese Angebote gibt.
- ▶ Anwenden von Sondermassnahmen bei Young Carers, die bereits für andere Gruppen bestehen (z. B. haben in einigen Schulen Kinder, die Spitzensport betreiben, einen Sonderstatus, der darin besteht, zusätzliche Zeit für ihre Prüfungen und andere bevorzugte Behandlungen zu erhalten). Diese Massnahmen könnten auf Kinder/Jugendliche mit Betreuungsverantwortung ausgedehnt werden.
- ▶ Psychologische Unterstützung in der Schule, um Young Carers bei der Bewältigung von Frustration, Wut und den Gefühlen, die durch Pflege- und Betreuungsaufgaben entstehen, zu unterstützen.
- ▶ Ausgabe einer Young-Carers-Karte, damit Young Carers nicht jedes Mal ihre Situation erklären müssen.
- ▶ Nachhilfeangebote
- ▶ Unterstützung von Young Carers bei der Entscheidung, welche Art von Schule sie besuchen wollen. Schaffung eines Bewertungs- und Zertifizierungssystems, um die von Young Carers erworbenen Soft Skills zu verbessern, die sich auf dem Arbeitsmarkt als sehr nützlich erweisen können.
- ▶ Flexible Arbeitsbedingungen für Young Carers vorsehen, z. B. durch Anreize für Arbeitgeber, die Telearbeitskräfte mit Teilzeitarbeitszeiten einstellen.

Erfolgreiche Strategien zur Verbesserung der psychischen Gesundheit von Young Carers

Im Folgenden werden Massnahmen zur Unterstützung der psychischen Gesundheit von Young Carers erläutert:

Peer/Group Support/Information

- ▶ Bildung von Gruppen von Young Carers, Peer-Support-Gruppen, um den Kindern die Erkenntnis zu vermitteln, dass sie nicht allein sind (dies kann sie zusätzlich befähigen).
- ▶ Young Carers die Möglichkeit geben, von der Erfahrung ehemaliger Young Carers zu profitieren (durch Mentoring oder Coaching).
- ▶ Verbesserung des Zugangs zu Informationen über verfügbare Unterstützungsangebote (z. B. Informationen von Lehrern, Hausärzten und Sozialarbeitern über lokale Aktivitäten zur Unterstützung der Young Carers).
- ▶ Young Carers genügend Raum geben, um ihre Emotionen und Frustrationen zu teilen, auch wenn sie nicht unbedingt praktische Unterstützung suchen, um ihre Situation zu „beheben“. Ein solcher Raum und eine solche Anerkennung können im beruflichen Kontext wichtig sein, zum Beispiel in der Schule, aber noch mehr in ihrer persönlichen Umgebung.

Young Carers Erholungspausen anbieten

- ▶ Organisation von Sommercamps, Schülerlagern, Kino, Café, Sportaktivitäten, um die Kinder und Jugendlichen aus dem „Schnellkochtopf“ zu entfernen.
- ▶ Young Carers eine Pause vom Betreuen geben, sie Spass haben und Kontakt mit Gleichaltrigen aufnehmen lassen.
- ▶ Unterstützung bei anfallenden Kosten, damit sie an diesen Aktivitäten teilnehmen können.

Steigerung der Widerstandsfähigkeit

- ▶ Young Carers den Zugang zur Unterstützung ermöglichen, um nützliche Bewältigungsstrategien zu finden. Die Stärkung der Widerstandsfähigkeit von Young Carers hat auch den Vorteil, dass sie deren Abhängigkeit von formalen Unterstützungsdiensten verringert, insbesondere in Zeiten von Budgetkürzungen und reduzierten Angeboten.
- ▶ Psychoedukation kann ein nützliches Instrument sein, um die Widerstandsfähigkeit zu erhöhen.

Erfolgreiche Strategien zur besseren Zusammenarbeit mit Young Carers

Young Carers sollen in alle Entscheidungen, die sie betreffen, einbezogen werden. Um aktiv an Entscheidungsprozessen teilnehmen zu können, müssen sie informiert werden. Ihre Rechte müssen ernst genommen und ihre Meinung gehört werden.

Die folgenden Strategien können implementiert werden:

- ▶ Jugendliche informieren, z. B. über die Krankheit der Eltern, darüber, welche Unterstützung sie erhalten können und wie sie darauf zugreifen können.
- ▶ Sicherstellen, dass das Pflege- und Gesundheitspersonal, Sozialarbeiter, Lehrpersonen und Eltern wissen, wie man mit Kindern und Jugendlichen respektvoll kommuniziert.
- ▶ Mitgestaltung der Unterstützungsmassnahmen durch Young Carers, um sicherzustellen, dass sie ihren Bedürfnissen gerecht werden. Eine massgeschneiderte Unterstützung kann zu Verbesserungen in der Familie und beim Kind führen und verhindern, dass die Probleme an die nächste Generation weitergegeben werden



NICHTS ÜBER UNS OHNE UNS!

Das Me-We Projekt wendet den von uns befürworteten **Co-Design-Ansatz** an, indem es die direkte Beteiligung der Endnutzer fördert (Adolescent Young Carers, Bildungs-, Sozial- und Gesundheitsfachpersonen, politische Entscheidungsträger) und die Zusammenarbeit zwischen den Beteiligten stärkt.

In Übereinstimmung mit dem Co-Design-Ansatz haben alle Projektpartner Blended Learning Networks (BLNs) eingerichtet, d. h. heterogene Gesprächsgruppen, an denen Adolescent Young Carers und relevante Interessengruppen beteiligt sind. Die Aufgabe dieser Akteure, die an einem Tisch sitzen, ist, die besten Lösungen zu finden (z. B. sind sie aktiv an allen Projektaktivitäten beteiligt, insbesondere an der Planung der Massnahmen und an der Entwicklung einer App für Jugendliche).

Ein weiterer Kanal, der die aktive Beteiligung von Young Carers an den Aktivitäten des Me-We Projekts gewährleistet ist die aktive Einbindung zur Eurocarers Young Carers Working Group. Die Eurocarers Young Carers Working Group ist eine Plattform, die Young Carers und ehemalige Young Carers aus verschiedenen Ländern zusammenbringt. Sie wurde

2017 gegründet und baut auf den unglaublichen Energien auf, die während der Internationalen Young Carers Konferenz (Mai 2017, Malmö, Schweden) geteilt wurden. Derzeit gibt es 27 Mitglieder aus 10 europäischen Staaten und eines aus Australien. Ziel ist es, die Bemühungen und Ressourcen zu bündeln, damit die Stimmen der Young Carers gehört und von Politik und Praxis in ganz Europa umgesetzt werden, um sie zu stärken und zu unterstützen. Vier Mitglieder der Eurocarers Young Carers Working Group gehören dem Internationalen Beirat und Ethikrat an, und sind mit den anderen Experten gleichgestellt. Darüber hinaus hatten die Mitglieder der Eurocarers Young Carers Working Group regelmäßig die Gelegenheit, ihre Perspektive und ihr Feedback zu den Projektaktivitäten zu geben.

Kapitel 4:

Umsetzung von Forschungsergebnissen in der Politik

EMPFEHLUNGEN IN BEZUG AUF DIE SCHWEIZ

Viele der in unserer Studie befragten Experten betonten, dass die Betreuung und Pflege von Angehörigen in der Schweiz als privates Anliegen betrachtet wird. Es ist wichtig, dieses Tabu zu brechen: Die Angehörigenbetreuung muss, anstatt **ein verstecktes, „privates“ Thema zu sein, zum öffentlichen Diskurs beitragen und zu einem der Schwerpunkte für politische Entscheidungsträger werden (das Persönliche ist politisch).**

In der Schweiz wächst das politische Interesse an betreuenden Angehörigen. Der vom Bundesrat 2014 veröffentlichte „Bericht über die Unterstützung für betreuende und pflegende Angehörige“ ist ein Beleg für diese Entwicklung. Der Bundesrat erkennt die wichtige Rolle der (unbezahlten) betreuenden Angehörigen in der Gesellschaft an. Angesichts einer alternierenden Bevölkerung und fehlender Ressourcen ist dies eine Rolle, die in Zukunft noch wichtiger werden wird, um den steigenden Bedarf an Langzeitpflege zu decken. Erste und dennoch wichtige Schritte auf dem Weg zur Anerkennung und Unterstützung betreuender Angehörigen wurden unternommen.

- ▶ Wir fordern die politischen Entscheidungsträger auf, innovativ zu sein und eine **Strategie zur Unterstützung von betreuenden Angehörigen jeden Alters** umzusetzen. Eine solche Strategie wird eine **lebenslange Perspektive** der Betreuung einnehmen, denn in jeder Lebensphase kann man ein betreuender Angehöriger sein.
- ▶ Wir empfehlen, **die bestehenden unspezifischen Gesetze zu erweitern bzw. zu ändern**, damit Young Carers identifiziert, erkannt und unterstützt werden können. Insbesondere empfehlen wir, **den Schwerpunkt auf die Prävention zu legen**, welcher derzeit fehlt.
- ▶ **Wir fordern die Akteure auf, Young Carers in ihre Aktivitäten einzubeziehen.** Wie von den Experten hervorgehoben, müssen die folgenden Punkte erfüllt sein, damit die Unterstützung wirksam ist:
 - › Es bedarf eines gemeinsamen Ansatzes, bei dem verschiedene Interessengruppen (aus den Bereichen Bildung, Soziales, Gesundheitswesen, NGOs, Politik) zusammenarbeiten.
 - › Es sollte ein ganzheitlicher Familienansatz verfolgt werden.

- › Die Unterstützung muss auf die spezifischen Bedürfnisse jedes Einzelnen zugeschnitten sein.
- › Young Carers müssen aktiv an der Gestaltung und Umsetzung ihrer Unterstützung beteiligt sein.
- › Ein rechtsbasierter Ansatz sollte alle Entscheidungen der Akteure berücksichtigen (einschliesslich der Bestimmung des Kindeswohls).

Die Erfahrung anderer europäischer Länder zeigt uns, dass länderspezifische Forschung und die Präsenz von engagierten NGOs Schlüsselfaktoren für einen Wandel in Politik und Praxis für Young Carers sind (Becker & Leu, 2016). Deshalb

- ▶ fordern wir **weitere Untersuchungen zu Young Carers**, die es ermöglichen, bessere Entscheidungen über die Art der von Young Carers benötigten Unterstützung zu treffen und auf diese Weise evidenzbasierte Änderungen an der Gesetzgebung und Vorgehensweise vorzunehmen.
- ▶ betonen wir, dass dringend eine **umfassende Sensibilisierungskampagne** für Gesundheit, Bildung, Soziales, politische Entscheidungsträger und die Gesellschaft als Ganzes erforderlich ist. NGOs könnten dabei eine Schlüsselrolle spielen, wenn sie durch staatliche Mittel angemessen unterstützt werden.

Eine gemeinsame Anstrengung jedes Mitglieds unserer Gesellschaft wird sicherstellen, dass wir in unserer Vision **vorankommen: einer Vision, in der Young Carers die Menschenrechte, auf die sie Anspruch haben, in vollem Umfang geniessen können.**

EMPFEHLUNGEN AUF EUROPÄISCHER EBENE

Auf europäischer Ebene wird zunehmend anerkannt, dass Massnahmen zur Unterstützung und Stärkung von Young Carers ergriffen werden müssen. Das Europäische Netzwerk der Ombudspersonen für Kinder hat, in seiner am 21. September 2018 angenommenen [Erklärung zur psychischen Gesundheit von Kindern](#), die Bedeutung von Unterstützungsprogrammen zur Verbesserung und zum Schutz der psychischen Gesundheit von Young Carers hervorgehoben. Das Europäische Parlament fordert die Kommission und die

Mitgliedstaaten in dem am 15. November 2018 angenommenen [Bericht über Pflegedienste in der EU zur Verbesserung der Gleichstellung der Geschlechter](#) auf, die Anzahl von Young Carers zu ermitteln und die Auswirkungen dieser Rolle auf ihr Wohlbefinden und ihren Lebensunterhalt zu untersuchen. Auf der Grundlage der Forschungsergebnisse in Zusammenarbeit mit NGOs und Bildungseinrichtungen sollen die besonderen Bedürfnisse von Young Carers unterstützt und zu berücksichtigt werden. Die den Schweizer Entscheidungsträger empfohlenen Massnahmen können durch Massnahmen auf europäischer Ebene ergänzt werden.

- ▶ Unterstützung bei der **weiteren Erforschung** des Profils und der Bedürfnisse von Young (Adult) Carers; Sammlung von einem Einblick in die tatsächlichen Zahlen.
- ▶ Sicherstellen, dass **bestehende bewährte Verfahren** in ganz Europa verbreitet und sichtbar gemacht werden; Vergleiche mit dem anzustellen, was in anderen Ländern geschieht, um die Entwicklung von Verfahren und Rechtsvorschriften zu unterstützen.
- ▶ **Einbeziehung von Young Carers** in die EU-Jugendstrategie oder die EU-Agenda für die Hochschulbildung und andere relevante politische Dossiers.
- ▶ **Auf Young Carers zu hören.** In Anlehnung an die „Europe kids want“-Umfrage sollten Plattformen und Chancen für eine sinnstiftende Partizipation von Young Carers vorgesehen werden.
- ▶ **Nutzung der vorhandenen Instrumente** - d. h. Europäisches Semester, Die Europäische Säule sozialer Rechte (vgl. Abb. 2 nachfolgend), Europäischer Struktur- und Investitionsfonds, EU-Jugendstrategie, EU-Agenda für die Hochschulbildung, Europäische Plattform für Investitionen in Kinder, Youth Guarantee und Offene Methode der Koordinierung - zur Förderung der Entwicklung integrierter Ansätze für die Identifizierung, Unterstützung und soziale Integration von Young (Adult) Carers in ganz Europa.

Die Grundsätze	Relevanz für Young Carers
Grundsatz Nr. 1 Allgemeine und berufliche Bildung und lebenslanges Lernen	Pflegerische und betreuende Verantwortung kann einen negativen Einfluss auf die Bildung von Young Carers haben (reduzierte Leistungserbringung, Absenzen, Schulabbrüche).
Grundsatz Nr. 4 Aktive Unterstützung für Beschäftigung	Young Carers sind häufiger NEET (nicht in Ausbildung, Anstellung oder Schulungen) als ihre Gleichaltrigen.
Grundsatz Nr. 11 Betreuung und Unterstützung von Kindern	Young Carers sollten als Kinder mit weniger vorteilhaftem Hintergrund betrachtet werden und sollten besondere Unterstützung erhalten, damit sie gleiche Voraussetzungen haben, ihre Rechte in Anspruch zu nehmen.
Grundsatz Nr. 18 Langzeitpflege	Um eine gute Qualität der formellen Langzeitpflegeleistungen für die zu betreuende Person zur Verfügung stellen zu können, muss unangemessene Betreuung und Pflege vermieden werden.

Das Aufwachsen in betreuungs- und pflegeintensiven Kontexten hat (potenzielle) negative Auswirkungen (eingeschränkte Bildung, eingeschränkte Lebenschancen, beeinträchtigtes Wohlbefinden, Isolation). Es ist Aufgabe der politischen Entscheidungsträger, diese zu verhindern und zu minimieren und Young Carers zu ermöglichen, als Mensch zu gedeihen.

Die Lebenschancen von Tausenden von Kindern
in ganz Europa stehen auf dem Spiel

ES GIBT KEINE ZEIT ZU VERLIEREN.

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in ganz Europa stehen auf dem Spiel

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Weitere Informationen:
www.me-we.eu



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Transformer les conclusions d'une recherche en actions politiques





Soutien psychosocial pour la promotion de la santé mentale et du bien-être chez les jeunes aidants adolescents en Europe

Le projet Me-We (2018-2021) rassemble un éminent éventail d'universités, d'instituts de recherche et d'organisations de la société civile, dans six différents pays européens, dont Eurocarers, le réseau européen qui représente les aidants informels de tout âge. Le projet a pour objectif d'améliorer la santé mentale et le bien-être des jeunes aidants adolescents, en renforçant leur résilience (le processus d'adaptation positive dans un contexte de grande adversité).

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Eurocarers

Belgique



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Royaume-Uni



Carers Trust

Royaume-Uni



Kalaidos University of Applied Sciences

Suisse



The Netherlands Institute for Social Research

Pays-Bas



The national Centre of Expertise for Long-term Care in the Netherlands (Vilans)

Pays-Bas



Anziani e non solo

Italie



National Institute of Health and Science on Ageing (INRCA)

Italie



University de Ljubljana

Sllovénie



Pour plus d'informations: www.me-we.eu

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Résumé

Qui dit enfance, pense généralement à un moment de la vie protégé, libre de toute responsabilité, pendant lequel les adultes sont « responsables » et prennent soin d'un/e enfant qui est avant tout bénéficiaire de soins. Pourtant, pour un certain nombre d'enfants et d'adolescents en Europe, le constat est loin d'être vrai car ceux-ci se retrouvent obligés de s'occuper – parfois de manière très intensive – d'un membre de leur famille, d'une amie ou d'un ami qui a besoin d'un accompagnement (en raison d'une maladie, d'un handicap, d'une accoutumance...) et d'assumer des responsabilités qui devraient plutôt incomber à une personne adulte. Nous les appelons des jeunes aidants.

NOMBRE DE JEUNES AIDANTS EN EUROPE

Si nous ne disposons actuellement que de très peu de données sur le nombre d'aidants (jeunes ou jeunes adultes) en Europe, certaines statistiques nationales et des projets pilotes lèvent une partie du voile sur une catégorie de la population importante – mais largement méconnue.

Le recensement 2011 pour le RU (Angleterre et Pays de Galles) a révélé l'existence de 177.918 jeunes aidants âgés de moins de 18 ans. Ce nombre ne cesse d'augmenter avec le temps: 27.976 unités supplémentaires par rapport à 2001 (soit une augmentation de 19% sur 10 années).

L'Italie, d'après les statistiques nationales les plus récentes, compte 391.000 jeunes et jeunes adultes aidants (15-24 années), soit 6,6 % de la population totale. *

En Suisse, 7,9% des enfants âgés entre 10 et 15 ans occupent la fonction de jeunes aidants (Leu et al., 2019; Leu & Becker, 2019).

Des recherches menées aux Pays-Bas donnent les estimations suivantes: la cohorte de jeunes aidants constitue 6% de la population âgée entre 13 et 17 ans.

En Suède, une enquête révèle que 7% des enfants de 14 à 16 ans assument des responsabilités de soins importantes.

En Irlande, le recensement de 2016 montrait que 3.800 enfants âgés de moins de 15 ans assumaient des responsabilités de soins, soit 1,9 % de tous les aidants. La moitié de ces enfants (1.901) qui offraient des soins non rémunérés avaient moins de 10 ans.

Si les recensements et les statistiques officielles ont leur importance, ils ignorent souvent les jeunes aidants ou sous-estiment leur nombre réel (il est possible que l'adulte chargé de répondre au recensement ignore ou rechigne à révéler que sa famille compte un/e jeune aidant/e). Nous trouvons une confirmation de ce constat dans les données officielles d'une enquête réalisée en 2018 par la BBC qui révélait l'existence de 800.000 jeunes aidants en Angleterre (contre les 166.000 unités identifiées dans le Recensement).

*Istat, Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea, données 2015 (en italien).

Si le phénomène des soins informels – un accompagnement, d'habitude non rémunéré, fourni par un membre de famille, par une amie ou par un ami en dehors de tout cadre professionnel – prend de l'ampleur partout en Europe, on ne sait que peu de choses sur la situation des aidants âgés de moins de 18 ans. En effet, les jeunes aidants constituent souvent une population invisible aux yeux des autorités publiques et des prestataires de services et en conséquence ne reçoivent de leur part aucun soutien. Cette situation peut avoir un impact négatif sur leur santé (mentale), leur parcours scolaire, leur employabilité et leur inclusion sociale. Les conséquences négatives vécues au niveau individuel peuvent entraîner

des conséquences négatives durables pour la société dans sa totalité.

Si les prestataires de services ignorent les défis auxquels sont confrontés les jeunes aidants ou les mesures susceptibles de les prévenir ou de les surmonter, c'est davantage en raison de leur méconnaissance des problèmes que de volonté de ne pas y répondre.

La présente note a pour propos de sensibiliser à la problématique et de pallier cette méconnaissance, en faisant connaître les conclusions d'un projet novateur de recherche

européen financé par le biais du programme Horizon 2020 et appelé Me-We - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe (soutien psychosocial pour la promotion de la santé mentale et du bien-être chez les jeunes aidants adolescents en Europe). Si le présent document s'inspire directement des recherches et des preuves collectées dans ce cadre, son propos est de se pencher sur l'impact politique des conclusions de Me-We. En conséquence, il ne devrait pas être envisagé comme un rapport scientifique.

L'objectif de la première année du projet était de mener une étude approfondie sur:

- ▶ les profils, besoins et préférences des jeunes aidants adolescents dans six pays européens (Italie, Pays-Bas, Slovaquie, Suède, Suisse et RU);
- ▶ les cadres législatifs, les politiques et les services en place pour soutenir les jeunes aidants adolescents dans les six pays (l'accent étant placé sur leur travail pratique, les moteurs de développement, leurs forces et leurs limites); et
- ▶ les stratégies d'accompagnement des jeunes aidants.

A qui revient la responsabilité d'aider?

Le projet Me-We (2018-2021) rassemble un éminent éventail d'universités, d'instituts de recherche et d'organisations de la société civile, dans six différents pays européens, dont Eurocarers, le réseau européen qui représente les aidants informels de tout âge. Le projet a pour objectif d'améliorer la santé mentale et le bien-être des jeunes aidants adolescents, en renforçant leur résilience (le processus d'adaptation positive dans un contexte de grande adversité).

La recherche s'est faite via une enquête en ligne, une analyse bibliographique et une série d'interviews d'experts qui ont permis, pour la toute première fois, de réaliser une comparaison croisée sur le thème des jeunes aidants entre six pays européens. Elle a également révélé les différences contextuelles entre les pays visés.

Les connaissances ainsi recueillies servent pour l'instant à concevoir un cadre novateur d'interventions préventives primaires, avec les jeunes aidants adolescents eux-mêmes et d'autres parties concernées par la problématique. Ces interventions feront l'objet d'une mise en œuvre, puis d'une évaluation dans les six pays du projet.

Le projet Me-We s'inscrit dans un cadre plus large de débats en cours à propos de l'avenir des systèmes de soins européens – face à des sociétés vieillissantes – et de la mise en œuvre des objectifs de la stratégie Europe 2020 dans les domaines de l'enseignement et de l'emploi. La partie introductive de la présente note se base sur des recherches et des données préexistantes dans le but d'éclairer le rôle joué par les jeunes aidants dans le processus d'accompagnement, ainsi que l'urgente nécessité d'agir.

L'introduction reste générale, alors que les sections suivantes se concentrent plus précisément sur la Suisse. Si vous désirez un aperçu des principales conclusions dans l'ensemble des pays du projet, veuillez consulter la note européenne (disponible ici).

Les chapitres 1, 2 et 3 se concentrent sur les premières conclusions du projet Me-We, tirées lors de la première année d'activité par le biais d'une enquête en ligne, d'une analyse des cadres législatifs et d'un examen de mesures d'accompagnement existantes.

Les résultats de l'étude complète feront l'objet d'une publication dans des revues d'examen par les pairs en 2020 et 2021.

Le chapitre 4 jette une série de bases théoriques inspirées des conclusions de Me-We, des connaissances collectées lors de recherches passées et de l'environnement politique actuel, dans le but d'identifier une série de priorités politiques, ainsi que d'éventuelles pistes d'action.

Chacune de ces recommandations s'inspire de notre vision: les jeunes aidants devraient être à même de poursuivre leurs objectifs et de réaliser leur plein potentiel sans subir les conséquences négatives de leurs responsabilités de soins.

Introduction

LES DÉFIS DES JEUNES AIDANTS

Qui sont les jeunes aidants?

Les jeunes aidants sont des enfants ou des jeunes âgés de moins de 18 ans qui apportent ou envisagent d'apporter des soins, une aide ou un soutien à un parent, une amie ou un ami qui souffre d'une maladie chronique, d'un handicap, d'une faiblesse ou d'une dépendance. Ils effectuent, souvent de manière régulière, des tâches significatives ou substantielles de soins et assument un niveau de responsabilités qui convient à celui d'un adulte (Becker, 2000).

Les jeunes aidants âgés de 15 à 17 ans sont dénommés « **jeunes aidants adolescents** » et méritent une attention toute particulière car ils traversent une étape centrale, de transition, dans leur développement : ils passent de l'enfance à l'âge adulte. Cette phase de transition revêt une importance critique au-delà des considérations biologiques et psychologiques; elle influe également la position d'adolescents potentiellement vulnérables par rapport à la loi, à la politique, à la santé et au soutien social.

Les raisons qui expliquent pourquoi un ou une enfant assume le rôle d'aidant sont nombreuses. Citons (parmi d'autres) le contexte culturel, un sentiment de devoir, l'absence d'alternatives, le sentiment d'amour ou d'empathie envers le/la bénéficiaire de soins, le manque de ressources financières et pratiques au sein de la famille (Leu & Becker, 2019).

Il existe un continuum des soins apportés par des enfants, qui commence par se soucier (faible niveau de responsabilités de soins, comportements routiniers d'aide et peu de preuves de conséquences négatives), puis passe à s'occuper (augmentation des tâches et responsabilités de soins), pour arriver à se charger des soins (niveaux élevés de responsabilités de soins, aide régulière et significative, preuves de conséquences négatives importantes) (Joseph et al., 2019).

Que font les jeunes aidants ?

- ▶ Tâches pratiques (cuisine, tâches ménagères, courses)
- ▶ Soins physiques (aider une personne à sortir de son lit)
- ▶ Soutien émotionnel (parler à une personne déprimée)
 - ▶ Soutien personnel (aider quelqu'un à s'habiller)
- ▶ Gestion du budget familial et réception des prescriptions
 - ▶ Aide lors de la prise de médicaments
 - ▶ Aide en communication
 - ▶ Prise en charge des frères et sœurs

L'impact des soins

Santé mentale et bien-être

On constate que l'accompagnement peut avoir des conséquences positives. Ainsi, des jeunes aidants peuvent tirer satisfaction de l'expérience de prise en charge, au niveau de l'estime de soi, de l'empathie et de la maturité (Banks et al., 2001; Cass et al., 2009; Cassidy et al., 2014; Heyman & Heyman, 2013; Joseph et al., 2009; Robson et al., 2006). Cependant, force est d'ajouter que le/la jeune peut être dépassé/e par les défis que les responsabilités de soins accumulent dans son parcours de vie. La pression due aux tâches de soins est considérée comme un facteur de risque pour la santé mentale (Aldridge & Becker, 2003; Ali et al., 2015; De Roos et al., 2017; Greene et al., 2016).

Education

Les jeunes aidants affrontent des obstacles particuliers dans leur parcours scolaire et universitaire: ils risquent des retards ou des absences fréquentes, pouvant aller jusqu'à un abandon forcé des études (Becker & Sempik, 2018; Kaiser & Schulze, 2014; Moore et al., 2009). De même, il peut s'avérer ardu de combiner un emploi rémunéré et des responsabilités de soins.

Vie sociale

La possibilité existe que les jeunes aidants disposent de moins de temps pour leur développement personnel ou pour leurs loisirs, et qu'ils ressentent un isolement. Ils peuvent également être victimes de stigmatisations sociales, d'harcèlements et, plus fréquemment que d'autres, d'exclusion sociale dans leur parcours de vie (Barry, 2011).

Malgré ces conséquences négatives, les jeunes aidants restent trop souvent invisibles aux yeux des décideurs politiques et des prestataires de services.

Pourquoi les jeunes aidants restent-ils invisibles ?

- ▶ Les jeunes aidants ne s'identifient pas comme tels.
- ▶ Ils craignent d'être retirés de leur maison par les services sociaux ou par les services de protection de l'enfance.
- ▶ Ils craignent d'être jugés ou mécompris par leurs pairs, par les enseignants ou par les prestataires de services.
- ▶ Ils subissent des stigmatisations (principalement lorsque la personne aidée souffre d'une maladie mentale ou d'une accoutumance).
- ▶ Ils ne savent pas à qui s'adresser.
- ▶ Ils pensent que rien ne changera même s'ils parlent de leurs responsabilités de soins.
- ▶ Les prestataires de services ont tendance à se concentrer sur la personne aidée.
- ▶ La communauté plus large ignore quels sont les services destinés spécifiquement aux jeunes aidants (s'il en existe).

"Nous ignorons les jeunes aidants à nos propres risques et périls et sans nous soucier de l'avenir de ces enfants."

Prof. Saul Becker,
Université du
Sussex



Les jeunes aidants n'étant pas identifiés comme tels, leurs besoins restent sans réponse.

POURQUOI DEVONS-NOUS NOUS ATTAQUER À CETTE PROBLÉMATIQUE ?

Les jeunes aidants ne sont pas en capacité d'exercer pleinement leurs droits

La Convention des Nations Unies relative aux droits de l'enfance spécifie que « **chaque enfant a le droit de...** » - notamment – de se reposer et se détendre (Article 31), à l'éducation (Articles 28 et 29), à un niveau de vie suffisant (Article 27), d'exprimer librement son opinion (Article 12), de jouir du meilleur état de santé possible (Article 24).

Les jeunes aidants, à l'instar de tout autre enfant, devraient pouvoir jouir des droits qui leurs sont ouverts. Cependant, il arrive trop souvent que les défis auxquels ils sont confrontés les empêchent d'exercer ces droits et que les règles du jeu ne soient plus suffisamment équitables pour leur garantir l'égalité des chances. Les jeunes aidants constituent un groupe d'enfants particulièrement vulnérables et devraient être reconnus comme tels. Non seulement devraient-ils jouir de l'exercice universel de leurs droits, mais également bénéficier d'une politique supplémentaire et adaptée, ainsi que de mesures d'accompagnement d'une portée et d'une intensité équivalentes à leur niveau de désavantages. Cela s'inscrit dans le droit fil de la législation internationale en matière de droits de l'homme qui exige des États qu'ils adoptent des **actions positives** dans la poursuite de leurs obligations de respect du principe d'égalité. On peut avancer l'argument que l'absence d'actions positives par un État pour accompagner des jeunes aidants relève un défaut de protection et de promotion de leurs droits.

L'intérêt économique du soutien des jeunes aidants

Les abandons scolaires prématurés entraînent des coûts individuels, sociaux et économiques élevés.

Les jeunes aidants qui n'ont accompli que le premier cycle de l'enseignement secondaire ou moins risquent davantage d'être au chômage, de dépendre de prestations sociales ou de tomber dans l'exclusion sociale. Les conséquences négatives se feront sentir tant sur les gains qu'ils accumuleront tout au long de leur vie que sur leur bien-être ou leur santé, sans oublier les conséquences sur leur participation au processus démocratique.

Au-delà des coûts personnels, le décrochage scolaire entrave le développement social et économique de l'aidant/e, ce qui rend difficile la poursuite de l'objectif européen d'une croissance intelligente, durable et inclusive. Ce constat est explicitement reconnu dans la Stratégie Europe 2020, qui comporte l'objectif chiffré de réduction du taux moyen de décrochages scolaires sous 10 % dans l'Union Européenne.

Les problèmes de santé mentale coûtent aux sociétés.

Au niveau international, on reconnaît de plus en plus l'importance d'une intervention rapide et de la **prévention** pour éviter les problèmes de santé. Comme le souligne l'Organisation mondiale de la Santé, la promotion et la protection de la santé des adolescents sont bénéfiques non seulement pour la santé des adolescents eux-mêmes, à la fois à court et à long terme, mais aussi pour les économies et la société, les jeunes adultes en bonne santé étant mieux à même de prendre part à la vie professionnelle, à la vie de leurs familles et communautés, et à la société dans son ensemble.

Investir dans la jeunesse présente un investissement social. Comme le reconnaît l'Union Européenne dans le Programme d'Investissement Social, des interventions rapides permettent de prendre à la racine les inégalités socioéconomiques, de briser le cycle de désavantages et de promouvoir l'égalité des chances.

ENTRE SOUTIEN ET ÉMANCIPATION – LE DILEMME DES JEUNES AIDANTS

Avant de poursuivre, arrêtons-nous un instant sur le dilemme éthique des jeunes aidants: « Il n'appartient en fait pas aux enfants, ni aux jeunes d'assumer des responsabilités de soins et en conséquence soutenir les jeunes aidants va, par essence, à l'encontre de leurs intérêts supérieurs ». Voici quelques-uns des arguments avancés par ceux qui soutiennent chacune de ces approches contradictoires.

The vision of the Me-We consortium

Le choix devrait inspirer toutes les décisions concernant les aidants. Toute personne devrait avoir le droit de choisir librement si elle souhaite être – et demeurer – un aidant, et dans quelle mesure elle souhaite participer aux tâches de soins. Toutefois, il est peu probable que ce choix soit réel en l'absence d'une alternative de soins professionnels ou informels. L'offre universel de services de soins de longue durée à prix raisonnable et de bonne qualité est un prérequis de l'auto-détermination des aidants. Parallèlement, nous reconnaissons que la disponibilité d'options alternatives – bien qu'essentielles – peut parfois s'avérer insuffisante pour permettre un véritable choix. En effet, d'autres facteurs (comme le sentiment de culpabilité ou le sens de devoir familial) peuvent jouer un rôle et influencer la perception que l'on a des alternatives offertes. Ceci dit, quand les responsabilités de soins découlent d'un choix éclairé et indépendant posé par l'aidant/e et la personne aidée, la société devrait avoir pour mission de prévenir et de réduire au minimum l'impact qu'elles peuvent avoir sur les jeunes aidants, afin de permettre à ces derniers de poursuivre leurs objectifs de vie et d'atteindre leur plein potentiel.

Vision 1 : « Il ne devrait pas y voir de jeunes aidants, l'attention politique devrait se porter ailleurs »	Vision 2 : « Il convient d'identifier et d'accompagner les jeunes aidants »
<p>En soutenant les jeunes aidants et en leur apprenant à gérer leur situation, nous admettons de fait le transfert des responsabilités de soins du public vers la sphère privée, ce qui va à l'encontre tant des principes d'accès universel aux soins que des droits des jeunes aidants.</p>	<p>Si l'idée que les enfants devraient être exemptés de tout rôle de prise en charge fait sens dans l'absolu, il est irréaliste de penser que les enfants ne jouent plus aucun rôle dans le processus d'accompagnement. Nous devrions, dès lors, prévoir des interventions, des programmes et des méthodes de soutien pour prévenir et réduire la charge qui pèse sur les jeunes aidants.</p> <p>Les jeunes aidants sont parmi nous et ne devraient pas disparaître avant de nombreuses années; nous devrions donc nous concentrer sur leur accompagnement et sur le suivi de leurs besoins.</p>
<p>« Si la personne aidée reçoit les services dont elle a besoin, l'enfant ou le jeune adulte peut poursuivre un parcours normal. Il est donc important d'orienter les ressources et les stratégies vers l'objectif d'exempter les enfants de toute responsabilité de soins (en offrant les services à la personne qui a besoin d'un accompagnement). »*</p>	<p>« Nous admettons que, dans un monde idéal où les services d'accompagnement bénévoles et officiels sont désireux et capables de fournir une aide importante et illimitée, le rôle des jeunes aidants serait fortement réduit. Mais nous reconnaissons également les désagréables réalités politiques et économiques de l'époque actuelle et nous ajoutons que, les régimes de protection sociale étant soumis à une pression croissante et réduits à leur plus simple expression, et dans le contexte de récession économique, d'incertitudes et de marchandisation des services sociaux, il est probable que les aidants familiaux conservent leurs responsabilités. Il est donc important que le rôle des aidants (jeunes ou adultes) soit pleinement apprécié et valorisé. »**</p> <p>Si nous adoptons une politique de zéro tolérance – en ignorant la réalité de l'existence des jeunes aidants– nous ne nous apercevrons de leur présence que trop tard, lorsque leurs besoins en aide auront atteint une ampleur incontrôlable.</p>
<p>Du point de vue des droits de l'homme, les enfants ont le droit d'être des enfants, et non pas des aidants.</p> <p>Un système de soutien aurait pour effet de les piéger dans un rôle d'aidant, dont il convient de les libérer, et aurait pour conséquence de violer leurs droits.</p>	<p>Le droit à l'auto-détermination des jeunes aidants inclut le droit de fournir des soins, s'ils le désirent, pour autant que leur intérêt supérieur soit préservé. Dès lors, des mesures devraient être mises en place pour protéger les jeunes aidants des risques de responsabilités inappropriées (des responsabilités de soins qui auront un impact négatif sur la santé, le bien-être ou l'éducation de l'enfant, ou qui pourraient être considérées comme impropres à l'état d'enfant).</p>

*Richard Olsen & Gillian Parker, Critical Social Policy, numéro 50

** Jo Aldridge and Saul Becker, Critical Social Policy, numéro 16.3

Chapitre 1:

Comment est-ce d'être un adolescent et un aidant?

Image 1- L'enquête en ligne Me-We



Que se passe-t-il lorsqu'on parcourt un monde en mutation (cette période de transition de l'enfance vers l'âge adulte) tout en effectuant des tâches de soins? Pour mieux le comprendre, le consortium Me-We a réalisé une enquête en ligne dans 6 pays européens d'avril à la mi-novembre 2018.

L'objectif était d'évaluer l'importance des soins apportés par de jeunes aidants adolescents et leurs conséquences sur leur bien-être général et leur parcours éducatif.

En Suisse, sur les 2.057 personnes qui ont répondu à l'enquête, 485 étaient des aidants âgés de 13 à 27 ans (nés entre 1991 et 2005). L'échantillon suisse comptait 85 représentants de notre groupe cible (jeunes aidants adolescents âgés entre 15 et 17 ans) s'occupant soit d'un membre de la famille,

d'un/e ami/e ou des deux. 19% d'entre eux signalent n'avoir aucun souvenir d'une époque pendant laquelle ils n'assumaient aucune responsabilité de soins.

La majorité des jeunes aidants adolescents dans l'échantillon suisse (78%) est composée de femmes, contrairement aux données suisses collectées jusqu'alors (Leu et al., 2019), mais conformément à la littérature existante sur la nature genrée des soins ou sur les attentes culturelles, sociales et familiales en matière de prise en charge.

62 jeunes aidants adolescents ont indiqué avoir la citoyenneté suisse. 56% ont signalé résider dans des villages.

La majorité des répondants (non-aidants inclus) ont signalé vivre dans des ménages biparentaux (85%). 29.5% vivent avec un frère et 24% avec une sœur, ce qui signifie qu'un grand nombre de répondants pourrait être la seule personne dépendante au sein d'une famille. On recense très peu de ménages multigénérationnels parmi les personnes interrogées lors de l'enquête: 5,5% d'entre elles vivent avec une grand-mère et 4,5% avec un grand-père.

DE QUI LES JEUNES AIDANTS ADOLESCENTS S'OCCUPENT-ILS ?

Sur les 116 répondants ayant indiqué qu'un membre de leur famille connaissait des problèmes de santé, 57 (50%) ont signalé de prendre en charge, d'aider ou de s'occuper d'un membre de famille avec un problème de santé. Donc, l'échantillon suisse **compte 57 jeunes aidants adolescents qui s'occupent d'un membre de leur famille ayant des problèmes de santé**. Sur ce total, 26 (57,8%) prennent soin d'un seul membre de leur famille. Un certain nombre de jeunes aidants adolescents s'occupent de plusieurs membres de leur famille: 9 d'entre eux (20%) s'occupent de 2 personnes, 4 (8,9%) de 3 personnes, 3 (6,7%) de 4 personnes, 2 (4,4%) de 5 personnes, tandis qu'un jeune aidant adolescent (2,2%) a signalé prendre soin de 9 personnes.

Le profil « typique » du jeune aidant adolescent en Suisse est celui d'une **jeune fille** s'occupant de sa **mère qui souffre**

d'un handicap physique. Les grands-mères et grands-pères constituent respectivement les deuxièmes et troisièmes catégories qui bénéficient d'aide.

Le ou la bénéficiaire de soins peut également être un ami ou une amie. Sur les 99 des répondants ayant indiqué avoir un/e ami/e proche qui souffre d'un problème de santé, **46 jeunes aidants adolescents ont signalé lui apporter des soins.** Dans la majorité des cas, ce problème de santé s'avère être une maladie mentale.

18 jeunes aidants adolescents s'occupent que d'un/e ami/e (62%). Le nombre de jeunes aidants adolescents qui prennent en charge plusieurs amis proches est extrêmement bas.

QUELLE EST L'INTENSITÉ DES SOINS FOURNIES PAR LES JEUNES AIDANTS?

Qui dit « activités de soins » dit notamment tâches ménagères, gestion du ménage, soins à la personne, soutien émotionnel, prise en charge d'un frère ou d'une sœur et accompagnement financier et pratique. Si on les compare à leurs pairs non-aidants, les jeunes aidants adolescents réalisent un plus grand nombre d'activités de soins. Leur expérience de la vie quotidienne s'avère donc fortement différente des autres jeunes de leur âge, qui n'assument aucune responsabilité de soins. 24% de la cohorte totale de jeunes aidants adolescents dans l'échantillon exécutent un nombre élevé d'activités de soins, soit un score supérieur à 14 sur la liste des Activités Multidimensionnelles de Soins (MACA), contre 20% des non-aidants. 17% des jeunes aidants adolescents réalisent un nombre très élevé d'activités de soins, soit un score MACA supérieur à 18, contre 12% des non-aidants.

De manière générale, les jeunes filles réalisent un nombre plus élevé d'activités de soins que les garçons (même si les différences n'ont pas de signification statistique).

IMPACT SUR LE NIVEAU D'ÉDUCATION

52 jeunes aidants adolescents (64%) ont signalé participer à un stage d'apprentissage dans le cadre d'un établissement d'enseignement professionnel secondaire. Ce résultat reflète la stratégie adoptée lors de l'échantillonnage suisse (présence de trois écoles professionnelles). D'autres écoles ont été ajoutées lors de la phase suivante de recrutement afin d'atteindre l'objectif chiffré de 200 jeunes aidants adolescents âgés de 15 à 17 ans.

15% ont signalé connaître des difficultés scolaires en raison de leurs responsabilités de soins. De même, 14% ont indiqué que leurs responsabilités de soins ont un impact négatif sur leur réussite scolaire. 15% ont ajouté avoir fait l'objet

d'harcèlements, d'agaceries et de moqueries en raison de leur rôle d'aidants.

Ces conclusions montrent combien il est nécessaire d'associer le secteur pédagogique dans le processus d'identification et de soutien des jeunes aidants.

BIEN-ÊTRE GÉNÉRAL

Il apparaît que les jeunes aidants sont davantage susceptibles de signaler un état plus bas de bien-être que leurs pairs non-aidants. Sur une échelle de 10 à 50, 50 signifiant un niveau extrêmement élevé de bien-être et 10 un niveau bas de bien-être, les non-aidants atteignent une valeur moyenne de 34,9, contre 30,5 chez les jeunes aidants adolescents. Cette différence de 4,4 a une grande signification statistique et peut être considérée comme une source possible de préoccupations.

IMPACT DU RÔLE D'AIDANTS SUR LA SANTÉ

De manière générale, les jeunes aidants adolescents en Suisse ont signalé des niveaux plus élevés que dans les autres pays européens (à l'exception du RU) de problèmes de santé dus à leurs responsabilités de soins: 40% des jeunes aidants adolescents ont indiqué connaître des problèmes de santé physique en raison de leur rôle d'aidants et 33% des problèmes de santé mentale.

Une recherche plus approfondie s'impose pour expliquer les raisons de cette conclusion particulièrement importante.

GRAVES CONSÉQUENCES SUR LA SANTÉ MENTALE EN RAISON DES RESPONSABILITÉS DE SOINS: L'AUTOMUTILATION ET LE MAL À AUTRUI

En raison de leur rôle d'aidants, 21% des jeunes aidants adolescents ont envisagé de s'automutiler et 5% de blesser autrui (dont 50% ont pensé blesser leur bénéficiaire de soins).

La proportion de jeunes aidants adolescents qui ont envisagé de se faire du mal est plus élevée que dans les autres pays soumis à l'enquête (à l'exception du RU – 8-11%). A nouveau, une recherche plus approfondie s'impose pour analyser les raisons de cette différence.

Cette conclusion montre que les jeunes aidants adolescents sont sous la forte menace de souffrances mentales et qu'il est nécessaire d'associer des professionnels de santé, et plus particulièrement dans la discipline de santé mentale, au processus d'identification et de soutien.

ACCÈS À UN ACCOMPAGNEMENT FORMEL ET INFORMEL

En Suisse, 15% des jeunes aidants adolescents bénéficient d'une **aide officielle** personnelle. Un nombre moins élevé de leurs familles en Suisse reçoivent une aide financière par rapport aux autres pays visés par l'étude. On pourrait dès lors émettre l'hypothèse que la situation socio-économique des familles en Suisse serait plus avantageuse que dans les autres pays. Toutefois, une recherche plus approfondie s'impose pour analyser les raisons réelles de cette différence.

S'il est possible que les jeunes aidants adolescents ne puissent pas accéder à des services d'accompagnement officiel dans leur rôle d'aidant, ils sont nombreux (61%) à signaler la présence d'un/e ami/e au courant de leur position d'aidant/e et prêt à leur offrir de l'aide. Cette conclusion revête une certaine importance à la lumière des facteurs de résilience et de protection liés au statut des jeunes aidants: ceux-ci pourraient trouver une aide informelle précieuse en l'absence de services formels.

À la question de savoir si leur entourage était au courant de leur rôle d'aidant, les jeunes aidants adolescents de l'enquête ont répondu qu'ils présument, plus que probablement, avoir un/e ami/e susceptible de connaître leur rôle, plutôt qu'un compagnon/compagne d'école ou un/e employeur/employeuse. Cette conclusion est dans le droit fil des enseignements tirés dans les autres pays de l'étude.

Chapitre 2:

Reconnaissance, protection, soutien : que dit la loi à propos des jeunes aidants ?

L'objectif du présent chapitre est d'examiner le cadre législatif et politique, ainsi que la batterie de services disponibles en soutien des jeunes aidants adolescents dans les six pays européens, l'accent étant placé sur leur efficacité pratique, leurs forces et faiblesses, et les moteurs de leur développement. Dans ce but, nous avons analysé la littérature existante et mené une série d'entretiens avec des experts (actifs dans une fonction législative, universitaire ou gouvernementale) autour du thème des jeunes aidants (quatre entretiens réalisés en Suisse).

LES LÉGISLATIONS, LES POLITIQUES ET LES SERVICES

Il n'y a en Suisse aucune législation dont le propos spécifique est de protéger ou de soutenir les jeunes aidants et leurs familles. Nous n'avons trouvé dans la législation aucune définition des jeunes aidants.

Le système actuel se limite à un soutien indirect, dérivant principalement de la législation relative à la protection de l'enfance et à l'aide sociale :

- ▶ [Constitution fédérale de la Confédération suisse](#), qui précise que les enfants et les jeunes ont le droit à une protection particulière de leur intégrité et à l'encouragement de leur développement. Ils/elles peuvent eux/elles-mêmes exercer leurs droits dans la mesure où ils/elles sont capables de discernement;
- ▶ [Le Code civil suisse](#), législation relative à la protection de l'enfant et de l'adulte;
- ▶ [Convention](#) concernant la compétence, la loi applicable, la reconnaissance, l'exécution et la coopération en matière de responsabilité parentale et de mesures de protection des enfants ([Convention de La Haye sur la Protection des enfants](#));
- ▶ [Loi sur la sécurité sociale](#), et plus précisément l'Art. 29septies de la Loi fédérale sur l'assurance-vieillesse et les survivants, qui prévoit une aide financière pour les

familles (bonifications pour tâches d'assistance), ce qui soulage indirectement la charge pesant sur les jeunes aidants.

Pour ce qui concerne les modifications législatives, nous constatons un glissement de paradigme d'une approche fondée sur l'aide sociale vers une approche basée sur les droits, ce qui permet aux enfants d'être mieux informés de leurs droits.

Un cadre politique et une batterie de services s'adressent spécifiquement aux jeunes aidants :

- ▶ [Un plan d'action pour le soutien et la décharge en faveur des proches aidants](#)

Le 5 décembre 2014, le Conseil fédéral a publié le « Rapport sur le soutien aux proches aidants », suite à l'impulsion politique donnée par le Parlement suisse et le Conseil fédéral dans le cadre de la [Stratégie Santé 2020](#), qui témoigne d'un intérêt croissant pour la question des aidants dans le paysage politique suisse. Les mesures reprises dans le plan, qui prévoient une meilleure information, des temps de repos, la conciliation de l'activité professionnelle et de la prise en charge des proches, devront être mises en œuvre en coopération avec les cantons, communes et les organisations privées.

Si, en 2014, les jeunes aidants ne figuraient pas dans le plan d'action, une pétition du Parlement a pallié cette exclusion et ils y sont maintenant mentionnés de manière explicite.

- ▶ Le Programme de recherche fédéral « [Offres visant à soutenir et à décharger les proches aidants 2017-2020](#) ». Si la recherche vise les aidants de tout âge, le programme mentionne explicitement les jeunes aidants. Il fournira aux parties prenantes dans les cantons, dans les communautés et dans les autres organisations des bases de données fondées sur des preuves et des modèles de bonne pratique, afin que les acteurs concernés puissent mettre en place et promouvoir leurs propres programmes et introduire eux-mêmes de nouvelles offres adaptées.

Les experts ont également fait référence à une série de politiques et de services qui, s'ils ne sont pas propres au secteur, peuvent apporter un soutien indirect aux jeunes aidants et à leurs familles :

- ▶ [Politique de l'enfance et de la jeunesse](#).
- ▶ [Promotion Santé Suisse](#); il s'agit d'une fondation soutenue par les cantons et les assureurs. En vertu d'un mandat légal, elle initie, coordonne et évalue des mesures destinées à promouvoir la santé et à prévenir les maladies. Les cantons peuvent s'inspirer de ses 4 modules et de 8 principes comme bases de leurs programmes d'action cantonaux.
- ▶ Dans le Canton de Vaud, l'organisation [Espace Proches](#) offre des services de répit et de conseils aux aidants.
- ▶ Presque chaque canton devrait disposer de services publics destinés aux jeunes et à leurs familles.

FORCES ET LIMITES DES CADRES LÉGISLATIFS ET POLITIQUES ET DE L'OFFRE DE SERVICES

On a ensuite demandé aux experts de pointer les forces et limites qu'ils identifient dans les cadres législatifs et politiques et dans l'offre de services.

Principaux points forts

- ▶ La législation est très claire.
- ▶ Il existe un système législatif robuste qui protège les enfants.
- ▶ Le régime suisse de protection de l'enfance repose sur des bases solides et applique le principe de l'interdisciplinarité avec efficacité.
- ▶ Tant la législation que les services varient selon les régions, d'où des solutions adaptées aux contextes régionaux (flexibilité). L'existence de plusieurs solutions facilite les innovations.
- ▶ Le système fédéraliste donne également un « effet Me-too »: si un canton a un exemple de bonne pratique, les autres cantons finiront par l'adopter.
- ▶ La terminologie utilisée dans le Code civil suisse, comme « l'intérêt supérieur de l'enfant », est ouvert à interprétation. Si cela peut parfois être une limite, c'est également une opportunité qui permet d'agir et de réagir en fonction des situations et circonstances individuelles.

Principales limites

- ▶ Les jeunes aidants n'appartiennent pas à un groupe social spécifique en Suisse et ne sont donc visés directement par aucun programme de soutien.
- ▶ Les législations, le cadre politique et même certaines associations actives avec les aidants n'utilisent pas un

langage adapté à l'âge des jeunes aidants. Dès lors, il arrive que les informations ne parviennent jusqu'à eux lorsqu'ils n'ont pas encore atteint le niveau adéquat d'alphabétisation.

- ▶ Le manque de coordination entre les différents régimes législatifs (régime de sécurité sociale, droit de famille, droit médical, protection de l'enfance, etc.).
- ▶ Les dispositions politiques destinées aux aidants ne conviennent pas toujours aux jeunes aidants, notamment lorsqu'elles visent un objectif de conciliation entre la vie professionnelle et la prise en charge informelle, sans prendre en compte la situation de jeunes aidants qui suivent des études ou sont en apprentissage.
- ▶ Des variations apparaissent dans la manière dont les cantons appliquent la Convention des Nations Unies sur les Droits de l'Enfant, malgré les recommandations de mise en œuvre proposées par la Fédération.

Dans le cadre des services de protection de l'enfance, les limites suivantes sont apparues:

▶ Identifier les jeunes aidants reste un défi

Les autorités de protection de l'enfance n'interviennent que lorsque les problèmes rencontrés par les jeunes aidants sont évidents. Si les jeunes aidants ne s'adressent pas directement aux autorités, ce sont les professionnels (de l'enseignement, des soins de santé et de l'aide sociale) qui devraient signaler leur existence aux autorités compétentes (par exemple aux services de protection de l'enfance). Cependant, si les professionnels ignorent l'existence des jeunes aidants, ces derniers resteront invisibles.

▶ Privilégier la protection plutôt que la prévention ou la mise en capacité (empowerment)

Des mesures de protection de l'enfance ne sont possibles qu'en cas de menaces contre l'intérêt supérieur de l'enfant. Il ne suffit pas que son intérêt supérieur ne soit pas totalement respecté. Un seuil doit donc être atteint avant que les services puissent intervenir. Cela signifie qu'une mesure de protection ne peut être prise que lorsque les problèmes auront dégénéré, au lieu de prendre des mesures pour les prévenir avant qu'ils ne surviennent.

De même, certains experts avancent que l'accent placé sur la protection va à l'encontre de l'objectif nécessaire de mise en capacité des jeunes aidants et oublie que des responsabilités de soins peuvent également apporter des résultats positifs (et pas uniquement des effets dont il faudrait se protéger).

▶ Les familles ne sollicitent pas l'aide des services de protection de l'enfance

Les services de protection de l'enfance peuvent effrayer les familles, car leur rôle est d'intervenir pour sauvegarder l'enfant. Il ne semble exister aucun juste milieu entre l'invisibilité des jeunes aidants et la maltraitance (et en

conséquence l'intervention des services de protection de l'enfance).

La longue tradition de la protection de l'enfance en Suisse (comme en témoigne l'accent placé sur l'intérêt supérieur de l'enfant) a créé une situation qui dissuade les jeunes aidants et leurs familles de solliciter l'aide des services sociaux, de peur d'être séparés.

► **On n'évalue pas l'efficacité des interventions de protection de l'enfance**

Les interventions menées par les autorités de protection de l'enfance ne font l'objet d'aucune évaluation. Nul ne sait, donc, si ces interventions sont adaptées aux jeunes aidants et à leurs familles.

BESOINS FUTURS

Après avoir identifié les forces et les limites du système actuel, les experts ont été invités à proposer des changements dans les cadres législatifs et politiques ou dans les services.

Ils doivent, dans un premier temps, se positionner sur l'intérêt d'adopter une législation propre aux jeunes aidants, à l'image de ce qui s'est fait au RU (voir l'encart sur le modèle anglais).

D'après les experts, il est peu probable que le modèle britannique soit adapté au contexte suisse, et ce pour diverses raisons :

- Légiférer serait un processus long et compliqué, en raison de la structure fédérale du pays. Les jeunes aidants n'ont pas le temps d'attendre. En conséquence, il serait plus logique d'inclure les jeunes aidants dans les stratégies et programmes existants ou prévus.
- Une législation propre aux jeunes aidants n'est pas nécessaire, puisqu'il n'existe pas de loi spécifique pour chacune des catégories de personnes dans le besoin.
- La Suisse s'est déjà dotée d'un large corpus de dispositions légales pouvant former la base de nouveaux cadres ou services à destination des jeunes aidants, comme la législation de protection de l'enfance et la Convention des Nations Unies sur les Droits des Enfants. Introduire une nouvelle législation destinée spécifiquement aux jeunes aidants équivaldrait à sur-réglementer.
- Qui dit législation spécifique ne dit pas automatiquement soutien pratique des jeunes aidants (l'exemple britannique montre que le soutien et la protection dont bénéficient les jeunes aidants dans la pratique ne reflètent pas nécessairement les objectifs de la législation).

FOCUS : COMMENT DÉTERMINER « L'INTÉRÊT SUPÉRIEUR DE L'ENFANT » ?

La Convention relative aux droits de l'enfant (CDE) stipule que l'intérêt supérieur de l'enfant doit être une considération primordiale dans toutes les décisions qui concernent les enfants.

Le terme « intérêt supérieur » renvoie au bien-être de l'enfant. Celui-ci est déterminé par un large éventail de situations personnelles, comme l'âge, le niveau de maturité de l'enfant, la présence ou l'absence de parents, l'environnement et les expériences de l'enfant.

En Suisse, un débat fait rage sur la question des autorités compétentes pour la protection des enfants: si certaines sont d'avis que l'enfant n'est pas la « propriété » des parents et que l'Etat a une obligation d'intervention, d'autres pensent que les autorités de protection de l'enfant ont trop de pouvoir. Le conflit est la conséquence des divergences d'interprétations du principe « d'intérêt supérieur » de l'enfant.

Le concept a souvent été appliqué pour justifier l'intervention des services de protection de l'enfant lorsqu'ils éloignent l'enfant de ses parents, y voyant l'option la plus sûre. Il est arrivé que les services de protection de l'enfant enlèvent des enfants de la garde de leurs familles, prétextant une nécessité de protection dans une situation qui, aujourd'hui, semblerait constituer une grave violation des droits des enfants et de leurs familles.

Il est important que l'interprétation et l'application du principe se fassent conformément à la CDE et aux autres normes juridiques internationales. Qui plus est, des solutions adaptées aux situations particulières s'imposent, dans chacun des cas pris séparément, puisque l'intérêt supérieur d'un enfant peut être différent de celui d'un autre! Voilà pourquoi de nombreuses voix se font entendre pour une plus grande participation des jeunes aidants eux-mêmes (et de leurs familles) dans toutes les décisions qui les concernent.

À la lumière des constatations ci-dessus, les experts sont d'avis qu'au lieu d'introduire une législation spécifique pour les jeunes aidants, il est préférable d'intégrer ceux-ci dans les législations et politiques existantes. Le cadre existant devrait être étendu et amendé, de manière à reconnaître les jeunes aidants et à les soutenir de manière appropriée.

Les experts recommandent, notamment :

- ▶ Que la question des jeunes aidants soit systématiquement abordée. Nous avons besoin de plus de données pour trouver des solutions qui rendront ces enfants visibles, pour voir comment les mesures de protection de l'enfance fonctionnent et alimenter les décisions et législations relatives au soutien futur à apporter aux jeunes aidants;
- ▶ Que, par exemple, les organisations sans but lucratif ou non-gouvernementales apportent un soutien et un engagement politique robuste;
- ▶ Que des changements soient apportés à la législation relative aux obligations légales en matière de protection de l'enfance, pour garantir une application dans la pratique de l'approche préventive;
- ▶ Que la question des jeunes aidants (adolescents) soit intégrée dans la politique nationale de soins mise en œuvre par l'Office fédéral suisse de la Santé publique. Outre les changements à apporter au programme fédéral, des modifications s'imposent également à l'échelon des cantons;
- ▶ Que de nouvelles législations et un nouveau cadre politique soient mis en place pour s'attaquer aux structures et conditions d'une bonne coopération entre professionnels (en tenant compte du droit à la vie privée);
- ▶ Qu'on définisse le concept de jeunes aidants.

DILEMMES

Est-ce qu'on peut imposer une législation et une politique propre aux jeunes aidants? Ou ne faudrait-il pas plutôt maintenir des législations et politiques générales?

La réponse à cette question dépend des aspects propres aux divers pays, comme le niveau d'efficacité des législations ou politiques générales en place lorsqu'il s'agit de reconnaître, d'identifier, de protéger et de soutenir les jeunes aidants adolescents. Elle devrait se baser sur une analyse de la réalité locale. En effet, notre étude montre que le soutien et la protection que reçoivent les jeunes aidants adolescents dans la pratique ne reflètent pas toujours les objectifs des législations ou politiques en vigueur. Sans une analyse précise des réalités locales, le caractère hypothétique des analyses de l'efficacité des cadres législatifs et politiques en place risque de laisser involontairement les jeunes aidants adolescents sans assistance, faute de reconnaître leur existence.

Faut-il envisager une nouvelle législation ou peut-on se contenter de lois non-contraindantes et de l'engagement des différentes parties prenantes ?

Pour qu'il y ait un véritable engagement, chaque partie prenante (professionnels, familles, aidants, organisations, État) doit constater et reconnaître que des enfants et des jeunes peuvent assumer des responsabilités de soins et que celles-ci peuvent avoir un impact négatif.

Pour que l'engagement ait un véritable effet, les parties prenantes doivent savoir comment apporter un soutien efficace aux jeunes aidants adolescents. Pour que l'engagement soit exécuté, les parties prenantes doivent recevoir les ressources nécessaires et avoir les capacités appropriées.

En l'absence d'un ou de plusieurs de ces facteurs, il est envisageable que la législation ou la politique doivent intervenir.

LE MODÈLE ANGLAIS EN QUELQUES LIGNES.

Seul le RU s'est doté d'une **législation spécifique** qui reconnaît ou définit les jeunes en charge de responsabilités de soins. Dès lors, une analyse plus approfondie de ce système s'impose.

En Angleterre, les dispositions relatives aux jeunes aidants relèvent de la Care Act (Loi sur les soins) de 2014 et de la Children Act (Loi sur les enfants) de 1989 (amendée par la Children and Families Act (Loi sur les enfants et les familles) de 2014) qui se combinent pour offrir une **vision préventive, axée sur la totalité de la famille**, des principes d'identification, d'évaluation et de soutien.

Droit à l'évaluation des besoins et du soutien. Le nouveau cadre législatif définit les jeunes aidants, confère aux autorités locales **un devoir universel d'évaluer leurs besoins**, ainsi que l'obligation de prendre les **mesures raisonnables pour déterminer** dans quelle mesure la région couverte compte des jeunes aidants ayant besoin d'un soutien (par exemple en les recherchant activement). La Loi sur les Enfants et les Familles de 2014 donne aux jeunes aidants et aux jeunes adultes aidants en Angleterre le droit d'évaluer et de répondre à leurs besoins (si l'évaluation en montre la nécessité). L'évaluation des besoins des jeunes aidants doit également porter sur la pertinence pour le/la jeune aidant/e de s'occuper ou de continuer à s'occuper de la personne aidée. Il convient de considérer que les **responsabilités de soins**, si elles sont **non-appropriées**, sont susceptibles d'avoir un impact sur la santé, le bien-être et l'éducation du/de la jeune aidant/e, ou d'être impropres à la situation de l'enfant.

Les deux Lois contiennent la toute première référence spécifique aux jeunes aidants. Si, dans la législation précédente, les jeunes aidants étaient mentionnés comme un groupe vulnérable, le droit à l'évaluation dépendait de deux prérequis: les soins fournis devaient être importants et réguliers. Ce qui équivalait à des soins réguliers et importants restait ouvert à interprétation locale, et donc, dans une région donnée une personne pouvait être soumise à évaluation, sans l'être dans une autre.

La nouvelle législation prévoit la responsabilité claire d'identifier les jeunes aidants et de soutenir la totalité de la famille via une collaboration entre les services pour adultes et pour enfants, les services de santé et d'assistance sociale.

Justification de la nouvelle législation: Investir dans le bien-être des aidants et dans la prévention est un bon investissement!

La principale raison qui a incité le législateur anglais à changer la législation— de manière générale en faveur des aidants— est l'idée que **l'investissement dans le bien-être des aidants et dans la prévention est rentable**, car cela permet, en fin de parcours, de réduire le coût pour l'État. Un rapport rédigé en 2015 par Carers UK et l'Université de Sheffield révélait que les aidants économisent au RU 132 milliards de £ par an. Un défaut d'identification et de soutien précoce entraîne plus de besoins, ce qui a des conséquences négatives non seulement sur les aidants (impact négatif et onéreux sur la santé et le bien-être des aidants, sur leur parcours scolaire, sur leurs perspectives professionnelles), mais également sur les finances de l'État. Quand il s'agit de jeunes aidants, des preuves montrent qu'un pourcentage très bas de jeunes aidants voient leurs besoins évalués. Comme le précise la Coalition nationale des jeunes aidants, dans une note en 2013: « Nous sommes d'avis qu'une réforme de la législation concernant les jeunes aidants permettrait non seulement de mieux identifier et de mieux soutenir les jeunes aidants (ce qui aurait des conséquences positives à long terme), mais réduirait également la charge sur les collectivités locales en prévenant le risque de soins inappropriés et en offrant un cadre clair de soutien de toute la famille, et, ainsi, diminuerait les coûts pour l'État. »

Changement de paradigme: une approche basée sur la totalité de la famille

Qui plus est, le gouvernement a reçu l'assurance du manque de coordination entre les législations relatives aux adultes et celles qui concernent les enfants, ce qui empêche de travailler avec la famille dans son ensemble. Les jeunes aidants étaient les seuls à recevoir un soutien, sans que leurs familles ne puissent en bénéficier. Très peu de jeunes aidants étaient identifiés et signalés aux services sociaux ou de santé pour adultes, et seuls 4-10% des renvois vers les services pour jeunes aidants venaient des acteurs de l'aide sociale pour adultes*. Ce système ayant prouvé son inefficacité, un changement de paradigme est survenu: au lieu de soutenir les jeunes aidants séparément de leur famille, l'approche vise aujourd'hui la totalité de la famille.

Les moteurs du changement de législation

Les **organisations non-gouvernementales** ont joué un rôle central de **sensibilisation et de plaidoyer pour un changement**. Elles ont également eu une importance stratégique quand il s'est agi d'orienter et de façonner le discours public et l'évolution politique en interagissant avec les décideurs politiques, les élus et les jeunes aidants eux-mêmes. Pour y parvenir, elles se sont basées sur des **conclusions de recherches** portant sur leurs pays respectifs.

*https://www.childrensociety.org.uk/sites/default/files/tcs/nycc_key_points_briefing_on_young_carers_the_care_bill.pdf

Chapitre 3:

des stratégies réussies pour améliorer la santé mentale et le bien-être des jeunes aidants

FOCUS SUR LA SUISSE

Les partenaires du projet ont interrogé 10 experts suisses issus du milieu universitaire ou actifs dans les domaines de la politique, de la santé ou de l'aide sociale. Ils ont abordé la question des jeunes aidants adolescents et une série de sujets connexes. Les entrevues se sont concentrées sur la visibilité des jeunes aidants en Suisse et sur l'aide qui leur est offerte.

Visibilité et sensibilisation des jeunes aidants

Les experts constatent que les jeunes aidants en Suisse ne sont que peu ou pas du tout visibles, que rien n'est fait pour sensibiliser à leur problématique et qu'aucune analyse ne porte sur leur situation, que ce soit au niveau local, régional ou national. En conséquence, il est nécessaire de mener un travail de sensibilisation à propos des jeunes aidants et de leurs besoins dans les cercles professionnels et familiaux.

En règle générale, le terme « jeune aidant » est inconnu. Seules les spécialistes du domaine l'utilisent (il est, par ailleurs, intéressant de remarquer qu'ils utilisent le terme anglais).

On n'admet pratiquement pas qu'un/e enfant puisse s'occuper de ses parents, de ses frères et sœurs, de ses grands-parents... Peu de personnes en parlent et la stigmatisation fait toujours rage.

Les jeunes aidants ne se considèrent pas comme tels et, dans les rares cas contraires, ils taisent leur situation de peur d'être stigmatisés ou que les autorités le découvrent et les enlèvent de leur famille.

Certains experts soulignent que les enfants d'origine migrante parlent plus aisément de leur rôle d'aidant car, dans leur culture, il est courant qu'un/e jeune s'occupe des autres membres de sa famille. Toutefois, un des experts nuance: lorsque le terme « jeune aidant » revêt une connotation négative dans la société, même les jeunes aidants d'origine migrante ont tendance à taire leur état.

Les experts interrogés soulignent tous l'**absence de sensibilisation parmi les professionnels** (soins de santé, éducation, services sociaux). La seule exception concerne les enfants qui s'occupent d'une personne souffrant de maladie mentale, ce genre de situation étant un peu plus visible.

On parle peu des jeunes aidants dans les médias. Lorsque c'est le cas, il s'agit d'enfants plus jeunes.

Les choses vont probablement changer. En effet, le Groupe de Recherche sur les Jeunes Aidants élabore un corpus de preuves qui, avec un peu de chance, rehaussera la visibilité des jeunes aidants. Il est ainsi probable que la Suisse monte dans la prochaine édition du classement de Leu et Becker sur le niveau de sensibilisation nationale et sur les réponses politiques apportées aux « jeunes aidants » (actuellement elle se classe au niveau 5: émergent).

Aide disponible

En Suisse, les jeunes aidants ne représentent pas un groupe social spécifique. D'où l'absence d'interventions qui leur sont dédiées. L'aide aux jeunes aidants découle des canaux liés à la protection de l'enfance et de certaines interventions générales (s'adressant aux enfants et aux jeunes).

Il existe de nombreuses plates-formes pour les jeunes, comme [Pro Juventute](#), une fondation caritative de défense des droits et des besoins des enfants et des jeunes Suisses.

Une série de nouveaux programmes, locaux pour la plupart, visent par ailleurs l'aide aux jeunes aidants: activités de sensibilisation dans les écoles où des professionnels discutent de la question des jeunes aidants avec les élèves.

Il existe également des programmes spéciaux destinés aux jeunes aidants qui s'occupent d'un/e proche souffrant d'une maladie mentale. Par exemple, la fondation [Kinderseele Schweiz](#) veille à garantir que les enfants de parents souffrant de troubles de la santé mentale puissent s'épanouir comme les autres enfants. Elle guide les enfants concernés, leur entourage social et professionnel et leur offre de l'aide.

Dans le domaine de la santé mentale, la méthode du Dialogue Ouvert – des professionnels travaillant avec toute la famille (démarche familiale) – présente l'avantage d'identifier les jeunes aidants et d'alléger leur « charge » de travail. Toutefois, cette démarche n'est pas encore suffisamment développée, ni acceptée en Suisse.

Évaluation des aides disponibles et des besoins futurs

Les experts évaluent le système d'aide en place pour les jeunes aidants et basent leur analyse sur les principaux besoins identifiés.

Le travail d'aidant en tant que phénomène quotidien

L'un des grands défis concerne la perception **selon laquelle le rôle d'aidant relève de la sphère privée**, qu'il faut le taire par crainte d'être stigmatisé ou séparé de sa famille.

En conséquence, il est essentiel de rendre la question visible et d'éliminer toute stigmatisation du/de la jeune aidant/e. Il serait bon de mettre l'accent sur le fait **que les soins font partie de l'expérience humaine** et qu'ils accompagnent des aspects positifs (ils permettent d'acquérir des compétences, de développer la capacité d'affronter certaines situations et certains conflits et de nouer des relations avec autrui).

Responsabiliser les professionnels

Il est essentiel de **mettre tous les professionnels** (éducation, services sociaux et soins de santé) **en capacité** de mieux identifier et d'aider les jeunes aidants. Il faut leur fournir des outils pratiques (par exemple des orientations ou des tableaux de bord).

Un travail intégré

Actuellement, on observe des failles entre le système de soins de santé, le système éducatif et le système social. Il s'agit d'organismes très différents, qui entretiennent peu de relations.

Les experts réclament un travail mieux intégré: inviter tous les acteurs pertinents d'une région à une rencontre et à une discussion sur le thème afin de trouver des solutions communes (dans le droit fil de la procédure appliquée aux enfants dont les parents souffrent de troubles de la santé mentale).

Une approche familiale globale

Les services pour adultes, qui ont besoin de soins se concentrent exclusivement sur l'adulte et non pas sur le réseau qui gravite autour de lui. D'où l'absence de visibilité des jeunes aidants.

Les experts demandent une approche familiale, afin d'alléger la charge des jeunes aidants adolescents.

Une aide personnalisée

Les experts soulignent la nécessité d'accepter la diversité des familles. Les jeunes aidants ne constituent pas un groupe homogène. Chaque enfant a sa propre histoire. En conséquence, à la place de créer un concept unique pour tous, il est préférable d'offrir une aide personnalisée reposant sur les besoins individuels.

« Mais il y a de plus en plus d'enfants, ils présentent une diversité croissante et il est impossible de répondre à cette diversité avec des programmes normalisés. S'il est tout aussi impossible d'organiser une campagne de sensibilisation pour chaque situation personnelle, on peut dire aux personnes concernées que chaque classe compte probablement 4,5,6 enfants, dont l'un vit en situation de pauvreté, l'autre est d'origine migrante, un troisième doit prendre soin d'un proche à la maison, un quatrième a un frère ou une sœur handicapé/e, et les inviter à se pencher sur leurs besoins individuels. »

Intégrer les jeunes aidants dans les interventions et programmes existants

Au lieu de créer des programmes ciblés spécifiquement sur les jeunes aidants, les experts préconisent de les intégrer dans l'offre générale de services. Ils divergent sur le niveau d'aide offert actuellement: si un des experts pense que les adolescents ne reçoivent pas un soutien suffisant dans la société suisse, un autre est d'avis que la « gamme de services d'aide offerts aux adolescents est respectable, ainsi que le nombre de services ».

Améliorer la communication, la promotion et l'accès aux programmes d'aide

Les experts s'inquiètent du degré de visibilité des programmes d'aide dans l'opinion publique.

« Je suis d'avis qu'en règle générale, la situation en Suisse ou en Europe centrale est très bonne, très favorable. L'offre est pléthorique, mais je remarque, j'ai le sentiment que la communication ou parfois l'accès pour le groupe concerné est très problématique. Cela ne sert donc à rien de disposer d'excellents programmes s'ils n'atteignent pas le groupe cible concerné. Je pense qu'il faut véritablement se concentrer sur le travail de communication. »

S'atteler à identifier et à soutenir les jeunes aidants adolescents

Les experts reconnaissent qu'il est d'autant plus difficile d'identifier les jeunes aidants lorsqu'il s'agit d'adolescents car ils sont en phase de transition entre les services pour enfants et ceux pour les adultes. Ils ne consultent plus de pédiatres et ne parlent pas de leur situation à leur médecin traitant. Ils ont terminé les 9 années d'études générales et peuvent soit décrocher un contrat d'apprentissage, soit poursuivre des études.

Un meilleur financement des services de prévention

Si les fondations et les organisations, qui pourraient aider les jeunes aidants, sont en partie privées et en partie financées par l'État, elles sont de petite taille et sous-financées. Selon les experts, on pourrait améliorer la situation en changeant la loi en faveur d'un meilleur financement des services de prévention. Les interventions devraient être financées par plusieurs sources (fondations, gouvernement, donateurs, assurance-santé) afin de les rendre indépendantes. Elles peuvent être financées sur le budget de la protection sociale, mais dans le cadre d'un financement général et non pas ponctuel.

Concevoir l'aide aux jeunes aidants

L'aide doit faire l'objet d'une conception avec les jeunes aidants pour garantir qu'elle réponde à leurs besoins. Pour pouvoir participer activement, les jeunes aidants nécessitent une bonne information.

L'EXPÉRIENCE D'AUTRES PAYS

Le projet de recherche Me-We et son volet de comparaison transnationale, nous donne un aperçu des stratégies possibles pour l'identification et l'aide aux jeunes aidants. L'expérience d'autres pays est une source d'inspiration précieuse pour les responsables politiques et les prestataires de services suisses (tout en reconnaissant les spécificités du contexte suisse telles que soulignées dans la section précédente).

Des stratégies avérées d'identification des jeunes aidants

Il est préférable que les jeunes aidants soient identifiés par une personne autre qu'eux-mêmes, plutôt que de devoir attirer l'attention. En conséquence, les mesures suivantes sont conseillées:

Dépistage dans les écoles et dans les structures médicales et sociales

- ▶ Les écoles jouent un rôle essentiel dans l'identification précoce des jeunes aidants. Pour faciliter le processus, des outils tels que MACA-YC18 peuvent s'avérer particulièrement utiles.
- ▶ Les professionnels dans les structures médicales et sociales— lorsqu'ils rencontrent des adultes qui ont besoin de soins— devraient systématiquement demander s'il y a des enfants dans l'entourage et si ces derniers ont également certains besoins. Ils devraient également assurer un suivi régulier (au fil de l'évolution de la maladie et par conséquent des soins).

Former les professionnels

- ▶ Les professionnels (de l'éducation, de la santé et du domaine social) pourraient recevoir une formation sur les jeunes aidants (les défis auxquels ils sont confrontés, les mesures à prendre pour les identifier et les aider, les manières efficaces de les écouter). La formation des professionnels pourrait être intégrée dans leurs programmes de formation de base.

Sensibiliser les professionnels et l'opinion publique

- ▶ Un débat pourrait être organisé à l'école à propos des questions des soins non rémunérés, de la résilience ou de l'assuétude, afin que ces thèmes soient moins tabous.
- ▶ On pourrait promouvoir l'impact positif des activités de

soins (offrir des soins permet d'acquérir des compétences, de développer des capacités à affronter certaines situations et conflits et de nouer des relations avec autrui).

- Les semaines de sensibilisation à l'école, le partage de récits individuels lors de conférences, les programmes télévisés, les campagnes sur les réseaux sociaux constituent autant de bons instruments de sensibilisation et de lutte contre les stigmatisations.

très utiles sur le marché de l'emploi;

- Envisager des conditions de travail flexibles pour les jeunes aidants, notamment en donnant des incitants aux employeurs afin qu'ils engagent des aidants en télétravail et à temps partiel.

Des stratégies avérées de soutien aux jeunes aidants via l'éducation

Pour veiller à ce que les jeunes aidants terminent leurs études et aient de bons résultats, il convient surtout de faire preuve de flexibilité. Celle-ci peut prendre différentes formes:

- Les enseignants peuvent faire preuve de compréhension face aux retards, aux absences et aux devoirs non faits;
- Le programme éducatif et les activités d'apprentissage peuvent être davantage centrés sur les besoins des jeunes aidants adolescents.

Outre la flexibilité, les écoles peuvent mettre en place une aide supplémentaire, personnalisée, pour éviter les décrochages et garantir une transition fluide vers une formation supplémentaire ou vers l'emploi.

Par exemple :

- Disposer de conseillers que les jeunes aidants peuvent rencontrer face-à-face;
- Renvoyer les élèves vers des services d'aide (par exemple, des clubs sportifs, des clubs de jeunes) et les informer de l'existence de ces services d'aide;
- Appliquer des mesures spéciales, qui existent déjà pour d'autres groupes, aux jeunes aidants (par exemple, dans certaines écoles, les enfants qui pratiquent des sports de haut niveau jouissent d'un statut particulier, qui leur offre du temps supplémentaire pour les examens et d'autres traitements de faveur). Ces mesures pourraient être élargies aux enfants ou jeunes qui assument des responsabilités d'aidant;
- Envisager un suivi psychologique au sein de l'école afin d'aider les jeunes aidants (adolescents) à gérer leurs frustrations, leur colère et les émotions suscitées par leurs activités d'aidant;
- Octroyer une carte d'aidant afin que les jeunes ne doivent pas tout le temps expliquer leur situation;
- Proposer un service de mentorat;
- Accompagner les aidants pour qu'ils puissent opérer des choix éclairés concernant le type d'école à fréquenter. Concevoir un système d'évaluation (et de certification) pour valoriser les compétences interpersonnelles, que les jeunes aidants ont acquises et qui pourraient s'avérer

DES STRATÉGIES AVÉRÉES POUR VEILLER À LA BONNE SANTÉ MENTALE DES JEUNES AIDANTS

Des mesures peuvent être envisagées pour soutenir la santé mentale des jeunes aidants, par exemple :

Des groupes de soutien ou d'information par des pairs;

- ▶ Créer des groupes de jeunes aidants, des groupes de soutien par des pairs pour montrer aux enfants qu'ils ne sont pas seuls (cela peut également contribuer à les responsabiliser);
- ▶ Permettre aux jeunes aidants de profiter de l'expérience d'anciens jeunes aidants (grâce au mentorat et au coaching);
- ▶ Améliorer l'accès à l'information sur l'aide disponible (par exemple, informer les enseignants, les médecins traitants et les assistants sociaux sur les activités locales visant à soutenir les jeunes aidants);
- ▶ Donner suffisamment d'espace aux jeunes aidants pour qu'ils puissent partager leurs émotions et leurs frustrations, y compris lorsqu'ils ne demandent pas nécessairement d'aide pratique pour « résoudre » un problème. Cet espace et cette reconnaissance peuvent s'avérer utiles dans le cadre professionnel, à l'école par exemple, mais encore plus dans le contexte personnel;

Offrir des congés de répit aux jeunes aidants;

- ▶ Organiser des camps d'été, des camps scolaires, des sorties au cinéma ou au café, des activités sportives pour éloigner le/la jeune de la « cocotte-minute »;
- ▶ Offrir des congés aux jeunes aidants pour qu'ils s'amuse et nouent des contacts avec leurs pairs;
- ▶ Les aider financièrement afin qu'ils puissent participer à ces activités;

Améliorer la résilience;

- ▶ Permettre aux jeunes aidants d'accéder aux outils et à l'aide dont ils ont besoin pour trouver des stratégies d'adaptation utiles. Qui dit plus grande résilience des jeunes aidants dit moindre dépendance envers les services d'aide officiels, principalement en période de coupes budgétaires et de réduction des services disponibles;
- ▶ Proposer la psychopédagogie pour augmenter la résilience.

DES STRATÉGIES AVÉRÉES D'UN DIALOGUE EFFICACE AVEC LES JEUNES AIDANTS

Les jeunes aidants doivent participer à toutes les décisions qui les concernent. Il convient de les informer afin qu'ils puissent participer à tous les processus décisionnels. Leurs droits doivent être pris au sérieux et leurs opinions écoutées.

- ▶ Il est possible de mettre en œuvre les stratégies suivantes: informer les jeunes aidants adolescents à propos, par exemple, de la maladie dont souffre leur proche ou de l'aide qu'ils peuvent recevoir et la manière d'y accéder.
- ▶ Veiller à ce que les aides soignant/es, les professionnels de la santé, les assistants sociaux, les enseignants et les parents sachent comment communiquer avec les enfants ou jeunes de manière amicale et respectueuse.
- ▶ Concevoir les mesures d'accompagnement avec les jeunes aidants afin de garantir que celles-ci répondent à leurs besoins. Un soutien personnalisé peut améliorer la situation des enfants et des familles dans l'instant présent – et éviter de transmettre les problèmes à la génération suivante.



RIEN À NOTRE PROPOS SANS NOUS !

Le projet Me-We applique l'approche de **conception** que nous voulons promouvoir, en encourageant la participation directe des usagers finaux (jeunes aidants adolescents, professionnels de l'enseignement et des soins, décideurs politiques) et en stimulant la collaboration parmi les parties prenantes.

Dans le droit fil de l'approche de conception, tous les partenaires du projet ont mis en place des Réseaux d'Apprentissage Mixte, soit des « communautés de pratique » hétérogènes qui associent les jeunes aidants adolescents et des parties prenantes concernées. L'ensemble de ces acteurs, réunis autour d'une même table, doivent trouver les meilleures solutions (ils sont activement impliqués dans toutes les activités du projet, et plus précisément dans la planification des interventions et dans l'élaboration d'une application pour jeunes aidants adolescents).

Une autre manière de garantir la participation active des jeunes aidants dans les activités du projet Me-We a été de se rapprocher du Groupe de travail « Jeunes Aidants » d'Eurocarers.

Le Groupe de travail « Jeunes Aidants » d'Eurocarers est une plateforme qui rassemble des jeunes aidants, des aidants adultes et d'anciens jeunes aidants issus de différents pays. Il a été créé en 2017, dans le sillage de la Conférence Internationale sur les Jeunes Aidants (mai 2017, Malmö, Suède) où l'énergie des participants était palpable. Pour l'instant, le groupe compte 27 membres venant de 10 pays européens et un membre venant d'Australie. Son objectif est de combiner efforts et ressources, afin que la voix des jeunes aidants soit entendue et que des politiques et actions soient mises en place partout en Europe pour les responsabiliser et les accompagner.

Quatre membres du Groupe de travail « Jeunes Aidants » appartiennent également au Conseil consultatif et éthique international (International Advisory and Ethics Board), au même niveau que les autres experts. En outre, les membres du Groupe de travail ont souvent la possibilité de donner leurs points de vue sur les activités du projet.

Chapitre 4:

Traduire les résultats des études en politiques

RECOMMANDATIONS ADAPTÉES AU CONTEXTE SUISSE

La plupart des experts interrogés dans le cadre de notre étude soulignent que pour les familles suisses, les soins relèvent de la sphère privée. Il est essentiel de briser ce tabou: les soins, plutôt que d'être laissés à **la sphère « privée » et dans l'ombre, doivent être au centre des politiques et interventions publiques (la sphère personnelle est politique).**

En Suisse, l'intérêt politique pour les aidants informels va crescendo. Le Rapport « Le soutien aux proches aidants » –publié par le Conseil fédéral en 2014– en est la preuve. Le Conseil fédéral reconnaît le rôle essentiel que les aidants informels (non rémunérés) jouent dans la société. À la lumière du vieillissement de la population et de la pénurie de ressources, il est probable qu'à l'avenir, leur rôle sera d'autant plus important que la demande en soins de longue durée ira croissante. Des premières mesures ont vu le jour, qui représentent une étape importante sur le chemin vers la reconnaissance et le soutien des aidants non rémunérés.

- ▶ Nous exhortons les responsables politiques à innover et à mettre en place une **stratégie d'aide aux aidants indépendamment de leur âge**. Celle-ci devrait reposer sur une **démarche d'aide basée sur le parcours de vie**, chacun pouvant devenir aidant à un moment donné de sa vie.
- ▶ Nous préconisons **d'élargir et d'amender les politiques et législations non-spécifiques existantes** afin de mieux identifier, reconnaître et soutenir les jeunes aidants. Nous recommandons plus particulièrement de renforcer l'accent placé sur la prévention, qui est actuellement négligée.
- ▶ **Nous exhortons les prestataires de services à intégrer les jeunes aidants dans les groupes cibles visés par leurs activités**. Comme le soulignent les experts, pour que l'aide soit efficace, il convient de répondre aux exigences suivantes:
 - Mettre en place une approche intégrée de collaboration entre les différents acteurs (enseignants, assistants sociaux, professionnels de la santé, ONG, monde politique);

- Adopter une approche familiale axée sur la totalité de la famille;
- Adapter l'aide en fonction des besoins spécifiques de chaque individu;
- Faire participer activement les jeunes aidants à la conception et la mise en place de l'aide;
- Faire reposer chaque décision des prestataires de services (y compris la détermination de l'intérêt supérieur de l'enfant) sur une approche basée sur les droits.

L'expérience d'autres pays européens montre que les études spécifiques aux pays et la présence d'ONG de défense des droits sont les principaux moteurs du changement dans les politiques et pratiques concernant les jeunes aidants (Becker & Leu, 2016). En conséquence,

- ▶ Nous exigeons des **études approfondies sur les jeunes aidants**, qui permettront de prendre de meilleures décisions concernant le type d'aide dont ils ont besoin. Elles permettront également d'amender les législations et politiques sur base de preuves;
- ▶ Nous insistons pour qu'une **grande campagne de sensibilisation** des acteurs de l'aide sociale, de l'éducation et de la santé, des responsables politiques et de toute l'opinion publique soit organisée dans les plus brefs délais. Les ONG devraient jouer un rôle essentiel et pour ce faire, recevoir un financement public adéquat.

Les efforts conjoints des membres de nos sociétés nous permettront **d'avancer** dans la réalisation de notre vision: tous les jeunes aidants peuvent jouir pleinement de leurs droits.

RECOMMANDATIONS AU NIVEAU EUROPÉEN

Au niveau européen, il est de plus en plus admis qu'il est nécessaire de soutenir et de responsabiliser les jeunes aidants.

Le « Réseau européen des Défenseurs des Enfants – ENOC » – dans sa [déclaration sur la santé mentale chez les enfants](#), adoptée le 21 septembre 2018 – souligne l'importance des programmes de soutien visant à améliorer et à protéger la santé mentale des jeunes aidants.

Le Parlement européen, dans son [Rapport sur les services de soins dans l'Union européenne pour une meilleure égalité des genres](#) – adopté le 15 novembre 2018 – exhorte la Commission et les États membres à **entreprendre des recherches sur le nombre de jeunes aidants et sur l'incidence de leur mission d'aidants sur leur bien-être et leurs moyens de subsistance** et, sur la base de ces recherches, de soutenir les jeunes aidants et de répondre à leurs besoins spécifiques, en coopération avec les ONG et les établissements d'enseignement.

Les actions recommandées aux responsables politiques suisses peuvent être complétées par des actions au niveau européen:

- ▶ Soutenir des **études approfondies** sur le profil et les besoins des jeunes (adultes) aidants ; recueillir des informations sur leur nombre réel;
- ▶ Veiller à ce que les **bonnes pratiques actuelles soient diffusées** et garantir leur visibilité dans toute l'Europe; faire des comparaisons avec la situation dans d'autres pays pour encourager le développement des pratiques et des lois;
- ▶ **Intégrer les jeunes aidants** dans la Stratégie européenne pour la jeunesse ou dans la nouvelle stratégie européenne de l'UE pour l'enseignement supérieur, ainsi que dans d'autres dossiers politiques pertinents;
- ▶ **Écouter les jeunes aidants**; à l'image de l'enquête « The Europe kids want », envisager des plates-formes pour garantir une participation pertinente des jeunes aidants;
- ▶ **Utiliser les instruments disponibles** – par exemple, le Semestre européen, le Pilier européen des droits sociaux, les Fonds structurels et le Fonds européen pour l'investissement, la Stratégie européenne pour la jeunesse, la stratégie de l'UE pour l'enseignement supérieur, la Plateforme européenne pour l'investissement dans l'enfance, la garantie jeune et la Méthode ouverte de coordination – afin d'encourager le développement d'approches intégrées pour l'identification, le soutien et l'intégration sociale des jeunes (adultes) aidants de toute l'Europe.

Tableau 1 - Le socle européen des droits sociaux et son intérêt pour les jeunes aidants

Les principes	L'intérêt pour les jeunes aidants
Principe 1 Éducation, formation et apprentissage tout au long de la vie	Les responsabilités de soins peuvent avoir un impact négatif sur l'éducation des jeunes aidants (échecs scolaires, absence et décrochages)
Principe 4 Soutien actif à l'emploi	Les jeunes aidants ont plus de risques d'être des NEET (ni éducation, ni emploi, ni formation) que leurs pairs
Principe 11 Des services de garde d'enfants et d'aide aux enfants	Les jeunes aidants doivent être considérés comme des enfants issus de milieux défavorisés qui ont le droit à un soutien complémentaire, adapté afin de pouvoir bénéficier d'une égalité des chances et exercer leurs droits sociaux.
Principe 18 Les soins de longue durée	En offrant des services de soins officiels de longue durée et de bonne qualité aux personnes aidées, on peut éviter des soins inappropriés.

Il incombe aux responsables politiques de prévenir et de minimiser les (éventuels) effets négatifs du rôle de jeunes aidants (problèmes scolaires, moindres chances de réussite, bien-être perturbé, isolement) et de permettre aux jeunes aidants de s'épanouir et de se réaliser en tant qu'êtres humains.

Les chances de réussite de milliers d'enfants
de toute l'Europe en dépendent

IL N'Y A PAS DE TEMPS À PERDRE.



#youngcarers

More information:
www.me-we.eu



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Trasformare i risultati di una ricerca in azioni politiche





Supporto psicosociale per la promozione della salute mentale e del benessere dei caregiver adolescenti in Europa

Il progetto Me-We (2018-2021) riunisce importanti università, istituti di ricerca e organizzazioni della società civile di sei diversi paesi europei tra cui Eurocarers, la rete europea che rappresenta i familiari curanti di qualsiasi età. Il progetto intende migliorare la salute mentale e il benessere degli adolescenti che prestano cura e assistenza, rafforzando la loro resilienza (vale a dire il processo di adattamento positivo in un contesto di grande avversità).

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Svezia



Eurocarers

Belgio



Université du Sussex

Regno Unito



Carers Trust

Regno Unito



Kalaidos University of Applied Sciences

Svezia



The Netherlands Institute for Social Research

Paesi Bassi



The national Centre of Expertise for Long-term Care in the Netherlands (Vilans)

Paesi Bassi



Anziani e non solo

Italia



National Institute of Health and Science on Ageing (INRCA)

Italia



University de Ljubljana

Slovenia



Maggiori informazioni: www.me-we.eu

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Sintesi

L'infanzia è comunemente vista come una fase della vita protetta e libera da responsabilità, in cui gli adulti sono "responsabili" e si prendono cura dei bambini, i quali sono i principali beneficiari di questo tipo di cure. Tuttavia, per un certo numero di bambini e adolescenti in tutta Europa, questo è lontano dall'essere vero, poiché si trovano a dover fornire assistenza - a volte a livelli molto intensi - a un/una familiare o conoscente che necessita di sostegno (a causa di una malattia, disabilità, dipendenza, ecc.) e devono assumersi delle responsabilità che sarebbero più appropriate ad una persona adulta. Questi bambini e adolescenti vengono internazionalmente definiti "young carers" *.

NUMERO DI YOUNG CARERS IN EUROPA

Sebbene al momento vi siano dati molto limitati sul numero di bambini e giovani adulti con compiti di assistenza in Europa, alcune statistiche nazionali e alcuni progetti pilota hanno contribuito a svelare l'esistenza di questa importante - ma in gran parte sconosciuta - categoria di popolazione.

Il [censimento del 2011 per il Regno Unito \(Inghilterra e Galles\)](#) ha rivelato l'esistenza di 177.918 young carers di età inferiore ai 18 anni. Questo numero sta aumentando con il tempo: sono 27.976 in più rispetto al 2001 (un aumento del 19% in 10 anni).

In Italia, secondo le statistiche nazionali più recenti, ci sono 391.000 bambini e giovani adulti (15-24 anni) con compiti di cura e assistenza, corrispondenti al 6,6% dell'intera popolazione. *

In Svizzera, il 7,9% dei bambini di età compresa tra 10 e 15 anni è un Young Carer (Leu et al., 2019; Leu & Becker, 2019).

Nei Paesi Bassi, dei progetti di ricerca hanno fornito le seguenti stime: gli Young Carers rappresentano il 6% della popolazione di età compresa tra 13 e 17 anni.

In Svezia, secondo un sondaggio, il 7% dei bambini di età compresa tra 14 e 16 anni svolge una considerevole attività di assistenza.

In Irlanda, il censimento del 2016 ha mostrato che 3.800 bambini sotto i 15 anni hanno prestato assistenza a terze persone, rappresentando l'1,9% di tutti i fornitori di cure e assistenza. La metà di questi bambini (1.901) che forniscono assistenza non retribuita ha meno di 10 anni.

Censimenti e statistiche ufficiali sono molto importanti. Tuttavia, spesso trascurano gli Young Carers o ne sottovalutano il numero (l'adulto che compila il censimento potrebbe non essere consapevole / non voler rivelare che nella sua famiglia è presente un o una Young Carer). A conferma di ciò, un dato non ufficiale di [un'indagine della BBC del 2018](#) ha rivelato che in Inghilterra ci sono 800.000 Young Carers (contro i 166.000 identificati attraverso il censimento).

*Istat, Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea, dati 2015.

Mentre il fenomeno dell'assistenza informale - la prestazione di assistenza, di solito non retribuita, da parte di un/una familiare o conoscente al di fuori di un quadro professionale - sta prendendo piede in tutta Europa, si sa ancora poco sulla situazione dei giovani con meno di 18 anni che prestano assistenza. Gli young carers sono infatti ancora largamente invisibili alle autorità pubbliche e ai fornitori di prestazioni e di conseguenza non vengono identificati e supportati. Ciò può influire negativamente sulla loro salute (anche mentale), sul loro percorso formativo, sul loro inserimento professionale e sulla loro inclusione sociale. Gli effetti negativi a livello individuale possono comportare conseguenze neg-

ative di lunga durata per la società nel suo insieme.

Se politici e fornitori di prestazioni ignorano le sfide affrontate dagli young carers e le misure che possono prevenirle o aiutarli a superarle, è più per la loro scarsa **consapevolezza** di questo problema che per la mancanza di **volontà**.

Questo documento mira a sensibilizzare l'opinione pubblica sull'argomento e a migliorare la conoscenza sul tema, condividendo i risultati del progetto europeo di ricerca e innovazione Me-We - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young

Carers in Europe - finanziato dal Programma dell'Unione Europea Horizon 2020. Nonostante questo documento si basi su prove scientifiche, il suo obiettivo è quello di riflettere sull'impatto politico dei risultati del progetto Me-We. Pertanto, questo documento non dovrebbe essere considerato come un rapporto scientifico.

Il progetto Me-We (2018-2021) riunisce importanti università, istituti di ricerca e organizzazioni della società civile di sei diversi paesi europei – tra cui Eurocarers, la rete europea che rappresenta i familiari curanti di qualsiasi età. Il progetto

mira a migliorare la salute mentale e il benessere degli adolescenti che prestano cura e assistenza, rafforzando la loro resilienza (vale a dire il processo di adattamento positivo in un contesto di grande avversità).

A tal fine sono stati condotti un sondaggio online, una revisione della letteratura e una serie di interviste con esperti del settore. Come risultato, per la prima volta in assoluto, la ricerca ha reso possibili confronti incrociati sul tema degli young carers tra sei paesi europei. Lo studio ha anche messo in luce le differenze contestuali esistenti tra questi paesi.

Le conoscenze raccolte vengono attualmente utilizzate per la progettazione e lo sviluppo di un intervento innovativo di prevenzione, in collaborazione con gli stessi young carers e con altre persone interessate dal tema. Questo intervento sarà implementato e valutato nei sei paesi partecipanti al progetto.

Il progetto Me-We fa parte di un quadro più ampio e s'inserisce nel contesto dei dibattiti in corso sul futuro dei sistemi di assistenza europei - a fronte dell'invecchiamento della società - e sull'attuazione degli obiettivi della strategia Europa 2020 nei settori dell'istruzione e dell'occupazione. L'introduzione a questo documento si basa su ricerche e dati preesistenti per far luce sul ruolo di assistenza degli young carers e sull'urgente necessità di agire.

L'introduzione è di carattere generale, mentre le sezioni seguenti riguardano la Svizzera. Per avere una visione d'insieme dei principali risultati nei paesi partecipanti al progetto, si prega di consultare il policy brief europeo ([disponibile qui](#)).

I capitoli 1, 2 e 3 si concentrano sui primi risultati del progetto Me-We, provenienti dal primo anno di attività, raccolti tramite un sondaggio online, un'analisi dei quadri legislativi e politici e un'analisi delle misure di supporto esistenti.

I risultati completi dello studio saranno pubblicati in riviste scientifiche nel 2020 e 2021.

Il capitolo 4 formula delle teorie sulla base dei risultati del progetto Me-We, delle conoscenze derivanti da ricerche precedenti e dell'attuale contesto politico, al fine di identificare le priorità politiche e le possibili linee d'azione.

Ogni raccomandazione è ispirata dalla nostra visione: gli young carers dovrebbero essere in grado di perseguire i loro obiettivi e di raggiungere il loro pieno potenziale, senza subire le conseguenze negative derivanti dalla loro responsabilità di assistenza.

Il primo anno del progetto è stato dedicato all'approfondimento dei seguenti aspetti:

- ▶ i profili, le esigenze e le preferenze degli adolescenti con compiti di assistenza in sei paesi europei (Italia, Paesi Bassi, Slovenia, Svezia, Svizzera e Regno Unito);
- ▶ la legislazione e i quadri politici e relativi ai servizi esistenti per sostenere questi giovani nei sei paesi (con particolare attenzione al modo in cui vengono applicati nella pratica, alle forze motrici del loro sviluppo, ai loro punti di forza e ai loro limiti); e
- ▶ le strategie di successo per supportare gli young carers.

**Di chi è la
responsabilità
di prendersi
cura?**

Introduzione

LE SFIDE DELL'ESSERE YOUNG CARER

Chi sono gli young carers?

Gli young carers sono bambine, bambini e giovani sotto i 18 anni d'età che forniscono o intendono fornire assistenza o supporto ad un/una familiare o conoscente con una malattia cronica, una disabilità, una debolezza o una dipendenza. Svolgono, spesso su base regolare, compiti di assistenza significativi o sostanziali e si assumono un livello di responsabilità che di solito verrebbe associato ad una persona adulta (Becker, 2000).

Gli young carers di età compresa tra i 15 e i 17 anni sono chiamati a livello internazionale **"adolescent young carers"** (young carers adolescenti). Essi meritano un'attenzione particolare, poiché si trovano in una fase importante e transitoria del loro sviluppo: il passaggio dall'infanzia all'età adulta. Questa fase di transizione è critica non solo per considerazioni biologiche e psicosociali, ma anche perché influenza il posizionamento degli adolescenti potenzialmente vulnerabili nei confronti della legge, della politica, della salute e dell'assistenza sociale.

Le ragioni per cui i giovani si assumono responsabilità di cura e assistenza sono molteplici e comprendono (tra l'altro) il contesto culturale, il senso del dovere, la mancanza di opzioni alternative, l'amore e l'empatia per la persona bisognosa di assistenza, la mancanza di risorse finanziarie e materiali all'interno della famiglia (Leu & Becker, 2019).

L'assistenza fornita dai giovani può essere rappresentata su un continuum, che comincia con l'empatia - caring about (bassi livelli di responsabilità assistenziale, livelli abituali di assistenza e scarsa evidenza di risultati negativi), passando per l'occuparsi di qualcuno - taking care of (aumento dei compiti e delle responsabilità assistenziali), fino ad arrivare alla presa a carico dell'assistenza - caring for (alti livelli di responsabilità assistenziale, assistenza fornita in modo regolare e significativo, evidenza di risultati negativi significativi) (Joseph et al., 2019).

Cosa fanno gli young carers?

- ▶ Compiti pratici (ad es. cucinare, lavori domestici e fare la spesa);
- ▶ Assistenza di tipo fisico (ad es. aiutare qualcuno ad alzarsi dal letto);
- ▶ Sostegno emotivo (ad es. parlare con qualcuno che è in difficoltà);
 - ▶ Cura della persona (ad es. aiutare qualcuno a vestirsi);
 - ▶ Gestire il budget familiare e le ricette mediche;
 - ▶ Aiutare qualcuno a prendere le medicine;
 - ▶ Aiutare qualcuno a comunicare;
 - ▶ Prendersi cura di fratelli e sorelle

L'impatto del ruolo di assistenza

Salute mentale e benessere

Ci sono alcuni effetti positivi legati al ruolo di assistenza. Ad esempio, gli young carers possono trarre soddisfazione dalla loro esperienza e accrescere la loro autostima, empatia e maturità (Banks et al., 2001; Cass et al., 2009; Cassidy et al., 2014; Heyman & Heyman, 2013; Joseph et al., 2009; Robson et al., 2006). Tuttavia, dover conciliare le sfide della vita quotidiana con i compiti di assistenza può essere un'esperienza schiacciante. La pressione associata all'assistenza è considerata un fattore di rischio per la salute mentale (Aldridge & Becker, 2003; Ali et al., 2015; De Roos et al., 2017; Greene et al., 2016).

Formazione

Gli young carers devono affrontare particolari ostacoli in relazione alla scuola e all'istruzione superiore: possono essere spesso in ritardo, avere assenze frequenti e, infine, potrebbero essere costretti ad abbandonare la scuola (Becker & Sempik, 2018; Kaiser & Schulze, 2014; Moore et al., 2009). Allo stesso modo, può essere difficile conciliare il lavoro retribuito con le responsabilità di assistenza.

Vita sociale

Gli young carers potrebbero avere meno tempo per lo sviluppo personale e il tempo libero e potrebbero essere isolati. Possono anche diventare vittime di uno stigma sociale e di bullismo e possono essere più frequentemente soggetti all'esclusione sociale nel corso della loro vita (Barry, 2011).

Nonostante questi effetti negativi, gli young carers rimangono ancora troppo spesso invisibili agli occhi di chi prende decisioni politiche e ai fornitori di prestazioni.

Perché gli young carers rimangono invisibili?

- ▶ Gli young carers non si riconoscono come tali.
- ▶ Hanno paura di essere portati via da casa dai servizi sociali o dalle autorità di protezione dell'infanzia.
- ▶ Hanno paura di essere giudicati o fraintesi dai loro coetanei, dagli insegnanti o dai fornitori di servizi.
- ▶ Subiscono uno stigma (soprattutto se la persona assistita soffre di una malattia mentale o una dipendenza da sostanze).
- ▶ Non sanno con chi parlare.
- ▶ Credono che, anche se parlassero delle loro responsabilità di assistenza, non cambierebbe nulla.
- ▶ I fornitori di servizi tendono a concentrarsi sulla persona assistita.
- ▶ La comunità non è a conoscenza di servizi specifici per gli young carers (se presenti).



Gli young carers non vengono identificati e i loro bisogni restano insoddisfatti

“Ignoriamo gli young carers a nostro rischio e pericolo, e mettendo a rischio il futuro di questi giovani.”

**Prof Saul Becker,
University of Sussex**

PERCHÉ DOBBIAMO AFFRONTARE QUESTO PROBLEMA?

Gli young carers non possono godere appieno dei loro diritti

La Convenzione delle Nazioni Unite sui diritti dell'infanzia stabilisce che **“Ogni bambino ha diritto a...”** - tra le altre cose - riposo e tempo libero (articolo 31), educazione (articoli 28 e 29), un livello di vita adeguato (articolo 27), esprimere liberamente la sua opinione (articolo 12), godere del miglior stato di salute possibile (articolo 24).

Gli young carers, come tutti i bambini, dovrebbero poter godere dei diritti che spettano loro. Troppo spesso, tuttavia, le sfide che gli young carers devono affrontare ostacolano tutto ciò, e quindi le condizioni potrebbero non essere più sufficienti a garantire loro opportunità pari a quelle dei loro coetanei. Gli young carers sono un gruppo di bambini particolarmente vulnerabili e dovrebbero essere riconosciuti come tali. Essi dovrebbero non solamente beneficiare dell'attuazione universale dei loro diritti, ma dovrebbero anche essere soggetti a misure politiche e di sostegno supplementari e su misura, con una portata e un'intensità proporzionali al loro livello di bisogno. Ciò è in linea con il diritto internazionale in materia di diritti umani, che impone agli Stati di intraprendere **azioni positive** nel perseguimento del loro obbligo di rispettare il principio di uguaglianza. Si può sostenere che l'assenza di azioni positive a sostegno degli young carers da parte dello Stato sia un fallimento della protezione e della promozione dei loro diritti.

Sostenere gli young carers è interessante dal punto di vista economico

L'abbandono scolastico comporta elevati costi individuali, sociali ed economici. .

I giovani con un livello d'istruzione secondario inferiore o più basso sono maggiormente a rischio di finire in disoccupazione, di dipendere dalle prestazioni sociali, e hanno un rischio più elevato di esclusione sociale. I loro guadagni nell'arco della vita, il loro benessere e la loro salute ne risentono negativamente, così come la loro partecipazione ai processi democratici.

Oltre ai costi individuali, l'abbandono scolastico ostacola lo sviluppo economico e sociale dei giovani e costituisce un serio ostacolo all'obiettivo dell'Unione europea di una crescita intelligente, sostenibile e inclusiva. Ciò è esplicitamente riconosciuto nella strategia Europa 2020, che include l'obiettivo di ridurre il tasso medio di abbandoni scolastici nell'UE al di sotto del 10%.

I problemi di salute mentale sono un costo per la società.

A livello internazionale, si riconosce sempre più l'importanza di un intervento tempestivo e della prevenzione per evitare dei problemi di salute. Come sottolineato dall'Organizzazione Mondiale della Sanità, la promozione e la tutela della salute dei bambini e degli adolescenti non solo apportano benefici alla loro salute, sia a breve che a lungo termine, ma contribuiscono anche all'economia e alla società, con (giovani) adulti sani in grado di dare un maggiore contributo alla forza lavoro, alle loro famiglie, alla comunità e alla società nel suo insieme.

Investire nei giovani è un investimento sociale. Come riconosciuto dall'UE nel programma di investimenti sociali, gli interventi tempestivi possono affrontare alla radice le disuguaglianze socio-economiche, possono spezzare il circolo vizioso degli svantaggi e possono quindi promuovere le pari opportunità.

TRA SOSTEGNO ED EMANCIPAZIONE – IL DILEMMA DEGLI YOUNG CARERS

Prima di procedere, vale la pena di esaminare il dilemma etico riguardante la situazione degli young carers, secondo il quale: "non spetta di fatto ai bambini e ai giovani assumersi responsabilità assistenziali e, di conseguenza, sostenere gli young carers è sostanzialmente dannoso per i loro interessi". Di seguito sono riportate le argomentazioni di coloro che sostengono questi approcci tra loro contraddittori.

La visione del consorzio Me-We

La libera scelta

dourebbe essere la colonna portante di ogni decisione riguardante i familiari curanti. Le persone dovrebbero avere il diritto di scegliere liberamente se vogliono essere - e rimanere – in un ruolo di assistenza e in che misura vogliono esserne coinvolte. Tuttavia, non vi è possibilità di scelta quando non è presente l'alternativa di un'assistenza professionale o informale. La disponibilità universale di servizi di assistenza a lungo termine, a prezzi accessibili e di buona qualità è quindi un prerequisito per l'autodeterminazione dei familiari curanti. Allo stesso tempo, riconosciamo che la disponibilità di alternative - pur essendo essenziale - può talvolta non essere sufficiente a consentire una scelta autentica. Infatti, altri fattori (come il senso di colpa o di dovere familiare) possono giocare un ruolo nell'influenzare la percezione personale delle alternative offerte. Detto ciò, quando le responsabilità assistenziali derivano da una scelta ben informata, e che non ha subito influenze esterne, sia da chi presta assistenza che da chi la riceve, la missione della società dovrebbe essere quella di prevenire e minimizzare l'impatto negativo che le responsabilità assistenziali possono avere sugli young carers, al fine di garantire che essi possano perseguire i loro obiettivi di vita e raggiungere il loro pieno potenziale.

<p>Punto di vista 1: “Gli young carers non dovrebbero esistere e l'attenzione politica dovrebbe essere posta altrove.”</p>	<p>Punto di vista 2: “Gli young carers dovrebbero essere identificati e supportati.”</p>
<p>Sostenendo gli young carers e insegnando loro come affrontare le situazioni difficili, accettiamo di fatto il trasferimento delle responsabilità assistenziali dalla sfera pubblica a quella privata, danneggiando in questo modo sia il principio dell'accesso universale all'assistenza sanitaria che i diritti degli young carers.</p>	<p>Anche se l'idea che i bambini dovrebbero essere esentati dai compiti assistenziali ha senso, non è realistico pensare che i bambini non abbiano nessun ruolo nel processo di assistenza. Quindi, si dovrebbero piuttosto fornire interventi, programmi di sostegno e metodi per prevenire o ridurre l'onere dell'assistenza tra gli young carers.</p> <p>Gli young carers esistono ed esisteranno per molti anni a venire, quindi dovremmo concentrarci su come sostenerli e su come dare seguito alle loro esigenze.</p>
<p>“Se le persone bisognose di assistenza ricevessero servizi adeguati, i bambini e i giovani potrebbero concentrarsi sulle attività volte alla loro crescita. Pertanto, è importante indirizzare le risorse e le strategie in modo da ridurre il ricorso a dei bambini per la cura e l'assistenza (fornendo servizi direttamente alla persona bisognosa di assistenza).”[*]</p>	<p>“Riconosciamo che in un mondo ideale, in cui i servizi di supporto ufficiali e basati sul volontariato siano disposti e capaci di fornire un supporto esteso o illimitato, il ruolo degli young carers sarebbe notevolmente ridotto. Ma riconosciamo anche le attuali realtà politiche ed economiche spiacevoli e che, in un sistema di protezione sociale sempre più sotto pressione e ridotto alla sua forma più semplice, in un contesto di recessione economica, incertezza e oneri per l'assistenza sociale, ci si aspetti che i familiari continuino a fornire il loro sostegno. In questo contesto, è importante che il ruolo dei familiari curanti (adulti e giovani) sia pienamente apprezzato e valorizzato.”^{**}</p> <p>Con l'adozione di una politica a tolleranza zero – ignorando la realtà e fingendo che gli young carers non esistano - non percepiremmo la loro presenza fino a quando non sarà troppo tardi, quando i loro bisogni di sostegno avranno raggiunto un livello troppo elevato.</p>
<p>Da un punto di vista dei diritti umani, i bambini hanno il diritto di essere bambini e di non fornire assistenza. Un sistema di sostegno avrebbe l'effetto di intrappolarli in un ruolo di assistenza da cui dovrebbero essere liberi, violando così i loro diritti.</p>	<p>Il diritto all'autodeterminazione degli young carers comprende il diritto di fornire assistenza, se lo desiderano, a condizione che sia salvaguardato il loro interesse superiore. Le misure dovrebbero pertanto cercare di proteggere gli young carers da un ruolo d'assistenza inadeguato, vale a dire da responsabilità di assistenza che abbiano un impatto negativo sulla loro salute, sul loro benessere o sulla loro istruzione o che possano essere considerate inadatte alle circostanze del bambino o della bambina.</p>

^{*}Richard Olsen & Gillian Parker, Critical Social Policy, numéro 50

^{**} Jo Aldridge and Saul Becker, Critical Social Policy, numéro 16.3

Capitolo 1:

Come ci si sente ad essere adolescenti e young carers?

Figura 1- Il sondaggio online Me-We



Come ci si sente a vivere in un mondo che cambia - il periodo di transizione dall'infanzia all'età adulta - mentre si svolgono compiti di assistenza? Per scoprirlo, il consorzio Me-We ha condotto un sondaggio online in sei paesi europei da aprile a metà novembre 2018.

L'obiettivo era di valutare l'entità dell'assistenza e i suoi effetti (impatto sul benessere generale e sull'istruzione) sugli adolescenti con compiti di assistenza.

In Svizzera, su 2.057 intervistati, 485 erano persone con un ruolo assistenziale di età compresa tra i 13-27 anni (nati tra il 1991 e il 2005). Il numero totale di partecipanti nel nostro **gruppo target (young carers adolescenti di età compresa tra i 15 e i 17 anni)** nel campione svizzero era di **85** persone (che si occupano di un/a familiare, di un amico o di un'amica, compresi quelli che si prendono cura di entrambi). Il 19%

ha riferito di aver fornito assistenza a qualcuno fin da quando riesce a ricordare.

La maggior parte degli adolescenti con un ruolo di assistenza nel campione svizzero (78%) sono donne, il che si differenzia dai precedenti dati rilevati in Svizzera (Leu et al. (2019), ma è in linea con la letteratura esistente sulla natura di genere dell'assistenza e sulle aspettative culturali, sociali e familiari dell'assistenza.

62 adolescenti con compiti di assistenza hanno dichiarato di essere cittadini svizzeri. Il 56% ha riportato di abitare in un piccolo centro abitato.

La maggior parte dei partecipanti (compresi quelli senza compiti di assistenza) ha riferito di vivere con entrambi i genitori (85%). Il 29,5% vive con un fratello e il 24% con una sorella, il che indica che un gran numero di partecipanti può essere l'unico/a figlio/a a carico della famiglia. Le famiglie multigenerazionali sono una realtà molto piccola per i partecipanti a questa indagine: il 5,5% vive con una nonna e il 4,5% vive con un nonno.

DI CHI SI OCCUPANO GLI ADOLESCENTI CON COMPITI D'ASSISTENZA?

Dei 116 partecipanti che hanno indicato di avere qualcuno in famiglia con un problema di salute, 57 (50%*) hanno riferito di fornire cure, assistenza o supporto alla persona in questione. Ciò significa che nel campione svizzero **ci sono 57 young carers adolescenti che si prendono cura di un/a familiare con un problema di salute**. Di questi giovani, 26 (57,8%) si prendono cura di un solo membro della famiglia. Altri assistono più membri della famiglia: 9 di loro (20%) si occupano di 2 persone, 4 di loro (8,9%) forniscono assistenza a 3 persone, 3 di loro (6,7%) assistono 4 persone, 2 giovani (4,4%) forniscono assistenza a 5 persone, e 1 young carer (2,2%) ha riferito di occuparsi di 9 persone.

Il profilo "tipico" degli adolescenti con un ruolo di assistenza in Svizzera è quello di una **ragazza** che si prende cura del-

* Nota: in questo capitolo i valori mancanti non sono stati inclusi nel calcolo delle percentuali.

la **madre con una disabilità fisica**. Le nonne e i nonni sono rispettivamente la seconda e la terza categoria di persone bisognose dell'assistenza da parte dei giovani.

La persona che riceve l'assistenza può anche essere un amico o un'amica. Dei 99 partecipanti che hanno dichiarato di avere un/a amico/a intimo/a con un problema di salute, **46** hanno riferito di **fornire loro assistenza**. Nella maggior parte dei casi il problema di salute è una malattia mentale.

18 young carers forniscono assistenza ad una sola persona nella loro cerchia di amicizie (62%). Pochissimi partecipanti si prendono cura di più amici intimi.

QUANTA ASSISTENZA È FORNITA DAGLI YOUNG CARERS?

Le attività di assistenza possono includere le faccende domestiche, la gestione della casa, la cura della persona, il supporto emotivo, il badare ai fratelli e alle sorelle e l'assistenza finanziaria o di tipo pratico. Rispetto ai loro coetanei senza un ruolo di assistenza, gli young carers svolgono un numero maggiore di attività di assistenza. Di conseguenza, le loro esperienze di vita quotidiana sono molto diverse da quelle dei loro coetanei. Il 24% del totale degli young carers adolescenti nel campione svolge un numero elevato di attività di assistenza (con un punteggio superiore a 14 sulla scala Multi-Dimensional Activities of Caring Checklist (MACA)), rispetto al 20% dei partecipanti senza un ruolo di assistenza. Il 17% degli young carers adolescenti svolge un'attività d'assistenza molto elevata (punteggio MACA superiore a 18), rispetto al 12% dei loro coetanei.

Nel complesso, le ragazze svolgono un numero maggiore di attività di assistenza rispetto ai ragazzi (tuttavia, le differenze non sono statisticamente significative).

L'IMPATTO SUI RISULTATI SCOLASTICI

52 adolescenti con un ruolo di assistenza (64%) hanno riferito di svolgere attualmente un apprendistato nell'ambito della formazione secondaria professionale. Questo risultato rispecchia la strategia di campionamento utilizzata in Svizzera che prevedeva la partecipazione di tre scuole professionali. Ulteriori scuole sono state incluse nella fase di reclutamento successiva per raggiungere l'obiettivo di 200 adolescenti con compiti di assistenza di età compresa tra i 15 e i 17 anni.

Il 15% ha riferito di aver avuto delle difficoltà scolastiche a causa del ruolo d'assistenza. Allo stesso modo, il 14% ha riportato che il rendimento scolastico ne è stato influenzato negativamente. Il 15% ha riferito di essere stato vittima di

bullismo, di essere stato deriso o preso in giro a causa del ruolo di assistenza.

Questi risultati evidenziano la necessità di coinvolgere il settore dell'istruzione nell'identificazione e nel sostegno degli young carers.

BENESSERE GENERALE

Si è riscontrato che i giovani con compiti d'assistenza hanno più probabilità di riportare uno stato di benessere inferiore rispetto ai loro coetanei. Su una scala in cui 50 indica un benessere estremamente elevato e 10 indica un benessere basso, i partecipanti senza compiti d'assistenza hanno riportato un valore medio di 34,9. Gli adolescenti con un ruolo d'assistenza hanno invece riportato un valore medio di 30,5. Questa disparità di 4,4 è molto significativa dal punto di vista statistico ed è un potenziale motivo di preoccupazione.

IMPATTO DEL RUOLO DI ASSISTENZA SULLA SALUTE

Gli adolescenti con compiti di assistenza in Svizzera hanno generalmente segnalato maggiori problemi di salute a causa del loro ruolo rispetto agli altri paesi europei (eccetto il Regno Unito): il 40% degli young carers ha riportato problemi di salute fisica dovuti al loro ruolo di assistenza, mentre il 33% ha segnalato problemi di salute mentale.

Sono necessarie ulteriori ricerche per spiegare le ragioni di questo risultato particolarmente significativo.

GRAVI EFFETTI SULLA SALUTE MENTALE DOVUTI ALL'ASSISTENZA: AUTOLESIONISMO E FAR MALE AD ALTRE PERSONE

A causa del loro ruolo di assistenza, il 21% degli young carers ha pensato di farsi del male e il 5% ha pensato di fare del male ad altre persone (di questi, il 50% ha pensato di fare del male alla persona assistita).

La percentuale degli adolescenti con un ruolo d'assistenza che hanno pensato di farsi del male è superiore a quella degli altri paesi esaminati (8-11%), ad eccezione del Regno Unito. Anche in questo caso, sono necessarie ulteriori ricerche per analizzare le ragioni di questa differenza.

Questo risultato indica che gli adolescenti con compiti di cura e assistenza sono a rischio di disturbi a livello psico-

logico ed evidenzia la necessità di coinvolgere gli operatori sanitari, in particolare i professionisti in ambito della salute mentale, per identificare e sostenere gli young carers.

ACCESSO A FORME DI SUPPORTO FORMALI E INFORMALI

In Svizzera, il 15% dei giovani con un ruolo di assistenza riceve personalmente un sostegno di tipo ufficiale. Rispetto agli altri paesi presi in esame per questo studio, in Svizzera un minor numero di famiglie riceve un sostegno finanziario. Si potrebbe quindi supporre che la situazione socioeconomica delle famiglie degli young carers in Svizzera possa essere migliore di quella di altri paesi, ma sono necessarie ulteriori ricerche per esaminare la vera causa di questa differenza.

Mentre diversi adolescenti con compiti d'assistenza potrebbero non avere la possibilità di accedere a servizi di sostegno formale a loro dedicati, molti di loro (61%) hanno segnalato la presenza di un'amica o di un amico che è a conoscenza della loro situazione e offre loro supporto. È importante considerare questo dato alla luce dei fattori di resilienza e di protezione associati all'essere un young carer: in assenza di servizi ufficiali a loro dedicati, gli adolescenti con compiti di assistenza possono trovare un sostegno informale prezioso.

Alla domanda se le persone nella loro cerchia di conoscenze siano consapevoli del loro ruolo assistenziale, gli young carers hanno indicato che è più probabile che essi abbiano un amico o un'amica a conoscenza del loro ruolo, piuttosto che qualcuno a scuola o un datore di lavoro. Questo è in linea con i risultati di altri paesi partecipanti allo studio.

Chapitolo 2:

Riconoscimento, protezione, sostegno: cosa dice la legge a proposito degli young carers?

L'obiettivo del presente capitolo è quello di esaminare la legislazione e i quadri politici e relativi ai servizi esistenti per sostenere gli adolescenti con compiti di assistenza in sei paesi europei, con particolare attenzione al modo in cui vengono applicati nella pratica, ai loro punti di forza, ai loro limiti e a ciò che ha portato al loro sviluppo. A tal fine sono state condotte una revisione della letteratura e una serie di interviste con esperti (in ambito giuridico, accademico o governativo) sul tema degli young carers (in Svizzera sono state realizzate quattro interviste).

LEGISLAZIONE E QUADRI POLITICI E RELATIVI AI SERVIZI

In Svizzera non esiste una legislazione specifica che protegga e sostenga gli young carers e le loro famiglie. Gli young carers non sono definiti nella legislazione. Il sistema attuale si limita a fornire un sostegno indiretto agli young carers, principalmente attraverso la legislazione relativa alla protezione dell'infanzia e alla sicurezza sociale:

- ▶ [Costituzione federale della Confederazione Svizzera](#), in cui si afferma che i bambini e i giovani hanno diritto ad una speciale protezione della loro integrità e all'incoraggiamento del loro sviluppo. Essi possono anche esercitare autonomamente i loro diritti nei limiti delle loro capacità;
- ▶ [Codice civile svizzero](#), legge sulla protezione dei minori e degli adulti;
- ▶ Convenzione concernente la competenza, la legge applicabile, il riconoscimento, l'esecuzione e la cooperazione in materia di responsabilità genitoriale e di misure di protezione dei minori ([Convenzione dell'Aia sulla protezione dei minori](#));
- ▶ [Legge sulla sicurezza sociale](#), in particolare Art. 29septies della legge federale su l'assicurazione per la vecchiaia e per i superstiti: fornisce finanziamenti finanziari per le famiglie (accreditati per compiti assistenziali), sgravando così indirettamente anche gli young carers.

Per quanto riguarda i cambiamenti nella legislazione, si è verificato un **cambiamento di paradigma** da un approccio di tipo assistenziale ad un approccio basato sui diritti. Ciò permette ai bambini di essere maggiormente informati sui loro diritti.

Esistono quadri politici e relativi ai servizi rivolti in particolare agli young carers:

- ▶ [Piano d'azione per chi presta cure ai congiunti](#)

Il 5 dicembre 2014 il Consiglio federale ha pubblicato il "Rapporto sul sostegno alle persone che si occupano e si prendono cura dei familiari". Questo è stato il risultato di un'azione politica del Parlamento svizzero e del Consiglio federale in relazione all'[agenda Sanità2020](#) e mostra un crescente interesse attorno al tema dei familiari con un ruolo assistenziale nel panorama politico svizzero. Le misure indicate nel piano d'azione, che comprendono una migliore informazione, lo sgravio, la conciliazione tra lavoro e assistenza familiare - devono essere implementate in collaborazione con i Cantoni, i Comuni e le organizzazioni private.

Nel 2014 gli young carers non erano inclusi nel piano d'azione. Tuttavia, una petizione del Parlamento ha messo in discussione la loro esclusione e ora gli young carers sono esplicitamente menzionati.

- ▶ Programma federale di ricerca "[Offerte di sostegno e di sgravio per le persone con attività lucrativa che assistono e curano i propri familiari 2017-2020](#)". La ricerca si rivolge alle persone con compiti assistenziali di qualsiasi età. Gli young carers sono esplicitamente inclusi. Il programma metterà a disposizione basi di conoscenza e modelli di buone pratiche basati su dati concreti per le parti interessate nei Cantoni, nei Comuni, nelle imprese e in altre organizzazioni, affinché possano sviluppare o promuovere i propri programmi o introdurre nuove offerte adeguate.

Gli esperti hanno anche menzionato dei quadri politici e relativi ai servizi non specifici per gli young carers, ma che possono supportare indirettamente sia i giovani che le loro famiglie:

- ▶ [Politica dell'infanzia e della gioventù](#)

- ▶ [Promozione Salute Svizzera](#), la quale è una fondazione sostenuta dai Cantoni e dalle assicurazioni. Con un mandato legale, essa avvia, coordina e valuta le misure attuate dai Cantoni nel campo della prevenzione e della promozione della salute. Quattro moduli e otto principi possono essere utilizzati dai Cantoni come base per i loro programmi d'azione cantonali.
- ▶ Nel Canton Vaud, l'organizzazione [Espace Proches](#) offre servizi di sgravio e di consulenza alle persone con compiti assistenziali.
- ▶ In quasi tutti i Cantoni sono previsti servizi pubblici per i giovani e per le loro famiglie.

PUNTI DI FORZA E LIMITI DELLA LEGISLAZIONE E DEI QUADRI POLITICI E RELATIVI AI SERVIZI

Agli esperti è stato chiesto di valutare i punti di forza e i limiti principali della legislazione e dei quadri politici e relativi ai servizi.

Principali punti di forza

- ▶ La legislazione è molto chiara.
- ▶ C'è un sistema giuridico solido che protegge i bambini.
- ▶ Il sistema di protezione dell'infanzia in Svizzera è ben consolidato e applica efficacemente un approccio interdisciplinare.
- ▶ La legislazione e i servizi sono flessibili a livello regionale, consentendo soluzioni che si adattano ai contesti regionali (flessibilità). La pluralità di soluzioni facilita inoltre l'innovazione.
- ▶ Il sistema federalista permette un effetto "Me-too": se un Cantone ha delle buone pratiche, prima o poi anche altri Cantoni le adotteranno.
- ▶ La terminologia del Codice civile svizzero, come ad esempio l'"interesse superiore del bambino", è molto aperta all'interpretazione. Questo può essere sia un limite che un'opportunità, perché permette di agire e reagire alle singole situazioni e alle circostanze individuali.

Principali limiti

- ▶ Gli young carers non esistono come un gruppo sociale specifico in Svizzera e pertanto non sono beneficiari di programmi di sostegno.
- ▶ Le leggi, i quadri politici e persino alcune associazioni

che lavorano con i familiari con compiti assistenziali non utilizzano un linguaggio adatto ai giovani, per cui l'informazione potrebbe non essere accessibile agli young carers che non hanno ancora raggiunto un livello di alfabetizzazione adeguato.

- ▶ C'è una mancanza di coordinamento tra i diversi sistemi giuridici (ad esempio, sistema di sicurezza sociale, diritto di famiglia, diritto sanitario, protezione dell'infanzia, etc.).
- ▶ Le disposizioni politiche per i familiari con compiti assistenziali non sono sempre pertinenti per gli young carers, in particolare quando mirano a conciliare lavoro e assistenza informale, senza tener conto della situazione degli young carers che studiano o svolgono un apprendistato.
- ▶ Vi sono differenze tra i Cantoni nell'attuazione della Convenzione ONU sui diritti dell'infanzia, nonostante le raccomandazioni a livello federale sulle modalità di implementazione.

Riguardo ai servizi di protezione dell'infanzia, sono stati individuati i seguenti limiti:

▶ **Identificare gli young carers è una sfida**

L'autorità per la protezione dell'infanzia viene coinvolta solo se i problemi di un bambino o una bambina con compiti di assistenza sono evidenti. Dato che gli young carers non si mettono in contatto con le autorità (ad esempio con i servizi di protezione dell'infanzia), queste dovrebbero essere informate dai professionisti (in ambito dell'istruzione, sociale e sanitario). Tuttavia, poiché i professionisti non sono sempre consapevoli dell'esistenza degli young carers, questi ultimi rimangono invisibili.

▶ **Concentrazione sulla protezione anziché sulla prevenzione o sulla responsabilizzazione (empowerment)**

Le autorità di protezione dell'infanzia possono intervenire solo se **l'interesse superiore del bambino è minacciato**. Non è sufficiente che l'interesse superiore del bambino **non venga pienamente raggiunto**. È necessario superare un certo limite prima che i servizi di protezione dell'infanzia possano intervenire. Pertanto, l'attenzione si concentra sulla protezione dei bambini una volta che i problemi si sono già aggravati, piuttosto che sull'adozione di misure per prevenirli prima che essi si verifichino.

Analogamente, secondo alcuni esperti, il concentrarsi sulla protezione è in contrasto con la necessità di responsabilizzare gli young carers e con il riconoscere che il ruolo di assistenza può anche portare a risultati positivi (non è solo qualcosa da cui devono essere protetti).

▶ **Le famiglie non chiedono aiuto ai servizi di protezione dell'infanzia**

I servizi di protezione dell'infanzia possono spaventare le famiglie perché il loro ruolo è quello di intervenire per salvaguardare i bambini. È come se non ci fosse una via di mezzo tra l'"invisibilità" degli young carers e i "maltrattamenti" (e di conseguenza l'intervento dei servizi di protezione dell'infanzia).

La lunga e travagliata storia della protezione dell'infanzia in Svizzera (si veda il focus sulla determinazione dell'interesse superiore del bambino) ha creato una situazione in cui gli young carers e le loro famiglie non chiedono aiuto ai servizi sociali per paura di essere separati.

► **Nessuna valutazione dei risultati degli interventi di protezione dell'infanzia**

Gli esiti degli interventi delle autorità per la protezione dell'infanzia non vengono valutati. Non è quindi chiaro se questi interventi siano appropriati per gli young carers e per le loro famiglie.

BISOGNI FUTURI

Dopo aver individuato i punti di forza e i limiti del sistema attuale, agli esperti è stato chiesto cosa sia necessario modificare nella legislazione e nei quadri politici e relativi ai servizi.

Un primo dilemma da risolvere era la questione se adottare una legislazione specifica sugli young carers, seguendo l'esempio del Regno Unito (si veda il focus sul modello inglese).

Gli esperti sono concordi sul fatto che il modello inglese non sia adatto al contesto svizzero, per diverse ragioni:

- Una legislazione specifica sarebbe un progetto lungo e complicato a causa della struttura federale. Gli young carers non hanno il tempo di aspettare. È quindi più appropriato includere gli young carers nelle strategie e nei programmi già esistenti o in fase di sviluppo.
- Non è necessario disporre di una legislazione specifica per gli young carers perché non esistono leggi specifiche per ogni gruppo di persone in difficoltà.
- In Svizzera esistono già numerose disposizioni giuridiche che possono costituire la base per nuovi quadri politici o servizi rivolti agli young carers, come la legislazione sulla protezione dell'infanzia e la Convenzione delle Nazioni Unite sui diritti dell'infanzia. L'introduzione di una legislazione specifica per gli young carers risulterebbe in un'eccessiva regolamentazione.
- L'esistenza di una legislazione specifica non è sufficiente a garantire che gli young carers siano sostenuti nella pratica (nel Regno Unito, ad esempio, il sostegno e la protezione che gli young carers ricevono non riflettono necessariamente gli obiettivi della legislazione).

FOCUS : COME DETERMINARE L'“INTERESSE SUPERIORE DEL BAMBINO”?

La Convenzione ONU sui diritti dell'infanzia stabilisce che l'interesse superiore del bambino deve essere una considerazione primaria in tutte le azioni che riguardano i bambini.

Il termine “interesse superiore” descrive in generale il benessere di un bambino. Tale benessere è determinato da una varietà di circostanze individuali, come l'età, il livello di maturità del bambino, la presenza o assenza dei genitori, l'ambiente e le esperienze del bambino.

In Svizzera c'è un dibattito sulle autorità preposte alla protezione dell'infanzia: alcuni pensano che i bambini non siano “proprietà” dei genitori e che lo Stato abbia l'obbligo di intervenire, mentre altri pensano che le autorità per la protezione dell'infanzia abbiano troppo potere. Ciò è dovuto a diverse interpretazioni del principio dell'“interesse superiore del bambino”.

Il concetto è stato spesso applicato per giustificare l'allontanamento dei bambini dalla propria famiglia da parte dei servizi di protezione dell'infanzia, considerandola l'opzione più sicura. Le autorità hanno obbligato i bambini a lasciare le loro famiglie in nome della protezione dell'infanzia in circostanze che oggi sarebbero viste come gravi violazioni dei diritti di questi bambini e delle loro famiglie.

È importante che l'interpretazione e l'applicazione del principio siano conformi alla Convenzione ONU e ad altre norme giuridiche internazionali. Inoltre, è necessario trovare soluzioni su misura per la situazione, affrontando la questione caso per caso, poiché l'interesse superiore può essere diverso per ogni bambino! Pertanto, è necessaria una maggiore partecipazione degli stessi young carers (e delle loro famiglie) per quanto concerne le decisioni che li riguardano.

Alla luce di queste considerazioni, gli esperti hanno convenuto che, piuttosto che introdurre una legislazione specifica per gli young carers, sia più opportuno integrare questi giovani nella legislazione e nella politica esistente. Queste devono essere estese e modificate, in modo che gli young carers possano essere riconosciuti e adeguatamente supportati.

Gli esperti hanno inoltre fornito le seguenti raccomandazioni:

- ▶ La questione degli young carers deve essere affrontata in maniera sistematica. Sono necessari più dati e più informazioni in modo da trovare soluzioni che rendano visibili questi bambini, capire come funzionano le misure di protezione dell'infanzia e informare i processi decisionali e la legislazione in merito al sostegno che potrà essere offerto in futuro agli young carers.
- ▶ Sono necessari un forte impegno politico e un forte sostegno, ad esempio da parte di organizzazioni senza scopo di lucro o non governative.
- ▶ Modificare la legge per quanto riguarda i doveri legali per la protezione dei minori, per garantire che un approccio preventivo funzioni nella pratica.
- ▶ Integrare il tema degli young carers (adolescenti) nella politica nazionale di assistenza dell'Ufficio federale della sanità pubblica. Oltre ai cambiamenti nel programma federale, sono necessari anche cambiamenti a livello cantonale.
- ▶ Sono necessari ulteriori legislazioni e quadri politici che siano indirizzati alle strutture e alle condizioni necessarie per permettere una buona cooperazione tra i professionisti (tenendo conto del diritto alla privacy).
- ▶ Includere una definizione degli young carers.



DILEMMA

Abbiamo bisogno di una legislazione e di una politica specifiche per gli young carers? Oppure un approccio migliore sarebbe mantenere una legislazione e politiche non specifiche?

La risposta dipende da aspetti che riguardano i singoli paesi, come ad esempio: "Quanto è efficace l'attuale legislazione/politica non specifica nel riconoscere, identificare, proteggere e sostenere gli young carers?" La risposta dovrebbe basarsi sulla comprensione della realtà locale. Infatti, il nostro studio dimostra che il sostegno e la protezione che gli young carers ricevono nella pratica non sempre riflettono gli obiettivi della legislazione e della politica in vigore. Senza un'accurata comprensione delle realtà locali, l'ipotetica natura delle analisi sull'efficacia dei quadri legislativi e politici esistenti rischia di lasciare involontariamente i giovani senza supporto, non riconoscendone nemmeno l'esistenza.

Abbiamo bisogno di una legislazione o le "soft laws" e l'impegno delle diverse parti interessate sono sufficienti?

Affinché vi sia impegno, è necessario che le diverse parti interessate (professionisti, famiglie, persone con un ruolo assistenziale, organizzazioni, lo Stato) **siano consapevoli** e riconoscano che i bambini e i giovani si assumono ruoli di assistenza e che ciò può avere degli effetti negativi.

Affinché il loro impegno sia efficace, le parti interessate devono sapere **come sostenere efficacemente questi giovani**.

Affinché l'impegno sia messo in atto, le parti interessate devono disporre di capacità adeguate e delle risorse necessarie.

In assenza di uno o più di questi fattori, è possibile che la legislazione o la politica debbano intervenire.

FOCUS SUL MODELLO INGLESE

Solo il Regno Unito ha una **legislazione specifica** che riconosce esplicitamente e definisce i giovani con responsabilità di assistenza. Pertanto, è utile esaminare questo sistema più da vicino.

In Inghilterra, le disposizioni per gli young carers rientrano nel Care Act 2014 e nel Children Act 1989 (modificato dal Children and Families Act, 2014) che lavorano insieme per conseguire un approccio **preventivo e comprendente l'intera famiglia** all'identificazione, alla valutazione e al supporto.

Diritto alla valutazione dei bisogni e al sostegno. Il nuovo quadro legislativo definisce gli young carers, impone alle autorità locali **l'obbligo universale di valutare i loro bisogni**, nonché l'obbligo di adottare **misure ragionevoli per identificare** gli young carers che hanno bisogno di sostegno nella loro area geografica (vale a dire, che li cerchino attivamente). Il Children and Families Act 2014 dà ai giovani e ai giovani adulti con compiti assistenziali in Inghilterra il diritto alla valutazione e il diritto che le loro esigenze siano soddisfatte (nel caso in cui la valutazione dimostri che ciò sia necessario). La valutazione dei bisogni di un o di una young carer deve considerare se sia appropriato che il/la giovane fornisca o continui a prestare assistenza alla persona in questione. Possono essere considerate come **responsabilità di assistenza inadeguate** tutto ciò che può avere un impatto sulla salute, sul benessere o sull'istruzione del bambino, o che può essere considerato inadatto alla luce delle sue circostanze.

Entrambi gli atti menzionano specificamente gli young carers per la prima volta. Nella legislazione precedente gli young carers erano menzionati come un gruppo vulnerabile, ma il diritto alla valutazione dipendeva da due presupposti: l'assistenza fornita doveva essere considerevole e regolare. Ciò che equivaleva ad un'assistenza regolare e considerevole era aperto all'interpretazione delle autorità locali, il che significava che qualcuno poteva avere diritto ad una valutazione in una zona, ma non in un'altra.

Con la nuova legislazione vi è una chiara responsabilità nell'identificare gli young carers e nel fornire sostegno a tutta la famiglia attraverso un lavoro congiunto tra i servizi destinati sia agli adulti che all'infanzia, la sanità e l'assistenza sociale.

La logica dietro alla nuova legislazione: Investire nel benessere e nella prevenzione dei familiari con compiti assistenziali è un investimento proficuo!

Il motivo principale per cui è stato deciso di modificare la legislazione - per i familiari con compiti assistenziali in generale - è la consapevolezza che **investire nel benessere delle persone con responsabilità assistenziali e nel lavoro di prevenzione è un investimento utile** al fine di ridurre i costi per lo Stato. Un rapporto del 2015 di Carers UK e dell'Università di Sheffield ha rivelato che i familiari con compiti assistenziali permettono al Regno Unito un risparmio pari a £132 miliardi all'anno. Il fallimento nell'identificazione precoce e nel sostegno ha portato a un'escalation dei bisogni, con conseguenze negative non solo per i familiari con un ruolo assistenziale (effetti negativi e costosi sulla salute e il benessere di queste persone, sui loro risultati nell'ambito dell'istruzione e dell'occupazione), ma anche sulle finanze dello Stato. Nel caso degli young carers, vi sono prove che dimostrano la percentuale molto bassa di giovani che ricevono una valutazione dei loro bisogni. Come dichiarato dalla National Young Carers Coalition in un briefing del 2013: "Crediamo fermamente che la riforma della legge per gli young carers non solo migliorerebbe l'identificazione e il sostegno degli young carers, il che avrebbe un impatto positivo a lungo termine, ma la riforma legislativa ridurrebbe anche gli oneri per le autorità locali, prevenendo il rischio di un'assistenza inadeguata e fornendo un chiaro quadro per il sostegno all'intera famiglia, con un costo finale inferiore per lo Stato."

Cambiamento di paradigma: un approccio per tutta la famiglia

Oltre a ciò, il governo ha avuto la prova di una mancata coordinazione tra la legge per gli adulti con quella per i bambini, impedendo il lavoro su tutta la famiglia. Gli young carers erano sostenuti separatamente, senza che le loro famiglie ricevessero il giusto supporto. Pochissimi young carers sono stati identificati e indirizzati ad un sostegno da parte dei servizi sociali e sanitari per gli adulti, solo il 4-10% dei rinvii ai servizi per gli young carers provenivano dai servizi di assistenza per gli adulti*. Questo sistema non era efficace. Si è quindi verificato un cambiamento di paradigma: l'approccio al sostegno degli young carers si è spostato dal sostegno separato dalla famiglia al sostegno attraverso un "approccio per l'intera famiglia".

I fattori alla base del cambiamento nella legislazione

Le **organizzazioni non governative** hanno svolto un ruolo chiave nella **sensibilizzazione e nella campagna per il cambiamento**. Hanno anche avuto un ruolo strategico nel guidare e plasmare il discorso pubblico e gli sviluppi politici attraverso il coinvolgimento dei responsabili politici e degli stessi young carers. Affinché potessero svolgere questo ruolo, le organizzazioni non governative hanno attinto a **risultati di ricerca** specifici per i loro paesi.

*https://www.childrensociety.org.uk/sites/default/files/tcs/nycc_key_points_briefing_on_young_carers_the_care_bill.pdf

Chapitolo 3:

Strategie di successo per migliorare la salute mentale e il benessere degli young carers

FOCUS SULLA SVIZZERA

I partner partecipanti al progetto hanno intervistato 10 esperti ed esperte in Svizzera provenienti dal mondo accademico, della politica, della sanità e/o dell'assistenza sociale sul tema degli adolescenti con un ruolo assistenziale e su temi correlati. Le interviste si sono concentrate sulla visibilità degli young carers in Svizzera e sul sostegno che ricevono.

Visibilità e consapevolezza degli young carers

Secondo gli esperti, in Svizzera la visibilità, la consapevolezza e la comprensione degli young carers sono basse o inesistenti, a livello sia locale, che regionale e nazionale. Pertanto, è necessario aumentare il riconoscimento e la consapevolezza dei professionisti e delle famiglie sul tema degli young carers e sulle loro esigenze.

Il termine "young carers" non è generalmente noto. Solo le persone del settore lo usano (è interessante notare che si tende ad usare il termine inglese).

Non viene praticamente ammesso che un bambino o una bambina possa prendersi cura dei propri genitori, fratelli e sorelle, nonni, etc. Poche persone ne parlano e lo stigma rimane.

Gli young carers spesso non si identificano come tali o, quando lo fanno, non ne parlano, lo tengono riservato, per paura di essere stigmatizzati e per paura che le autorità lo scoprano e li allontanino dalla famiglia.

Alcuni esperti hanno affermato che i bambini provenienti da un contesto migratorio sono più aperti a parlare della loro esperienza di assistenza, poiché nella loro cultura l'assistenza ai membri della famiglia è un fenomeno comune. Un esperto si è trovato in parziale disaccordo e ha sottolineato che, se il termine "young carer" viene visto sotto una luce negativa nella società, anche i bambini provenienti da famiglie di migranti non sono disposti a parlare dei loro compiti di assistenza.

Gli esperti intervistati si sono trovati d'accordo sulla **manca di consapevolezza tra professionisti** di diversa provenienza (sanità, istruzione, servizi sociali). L'unica eccezione riguarda i bambini che si prendono cura di una persona con una malattia mentale, perché in questo caso c'è un po' più di visibilità.

La copertura mediatica degli young carers è scarsa. Dove questa è presente, l'attenzione si concentra su bambini più piccoli.

Le cose probabilmente cambieranno. Infatti, il gruppo di ricerca sugli Young Carers sta sviluppando un insieme di evidenze scientifiche che, si spera, si tradurrà in una maggiore visibilità degli young carers. Grazie a questi sviluppi, è probabile che la Svizzera risulti più in alto nella prossima iterazione della classificazione proposta da Leu e Becker sulla consapevolezza e sulle risposte politiche agli young carers a livello nazionale (attualmente è al livello 5 - emergente).

Supporto disponibile

In Svizzera, gli young carers non rappresentano un gruppo sociale specifico, per cui non ci sono interventi a loro dedicati. Il sostegno agli young carers viene fornito dalla protezione dell'infanzia e da alcuni interventi più generali (per bambini e giovani in generale).

Esistono molte piattaforme per i giovani, come ad esempio [Pro Juventute](#), una fondazione che si occupa di sostenere i diritti e le esigenze dei bambini e dei giovani in Svizzera.

Alcuni nuovi programmi, principalmente a livello locale, sono volti specificamente a sostenere gli young carers, come le attività di sensibilizzazione nelle scuole, in cui i professionisti discutono la questione degli young carers con gli studenti.

Esistono programmi speciali e ben avviati per gli young carers che si prendono cura dei genitori con problemi di salute mentale. Ad esempio, la fondazione [Kinderseele Schweiz](#) si impegna affinché i figli di genitori con una malattia mentale possano avere uno sviluppo simile a quello dei loro coetanei.

nei. Offrono consulenza alle persone in questa situazione, a chi è loro vicino e ai professionisti e forniscono loro aiuto.

Nell'ambito della salute mentale, l'approccio del dialogo aperto (Open Dialogue Approach) - in cui i professionisti lavorano direttamente con l'intera famiglia (approccio familiare) - potrebbe avere il vantaggio di identificare gli young carers e sgravare il "peso" del loro ruolo d'assistenza. Tuttavia, questo approccio non è ancora sufficientemente sviluppato né accettato in Svizzera.

Valutazione delle misure di supporto disponibili e dei bisogni futuri

Gli esperti hanno valutato l'attuale sistema di supporto agli young carers e, sulla base di questa analisi, hanno individuato delle esigenze chiave.

► Il ruolo assistenziale come fenomeno quotidiano

Una delle maggiori sfide è la percezione che il **ruolo assistenziale sia qualcosa da tenere privato**, nascosto, per paura di essere stigmatizzati o separati dalla famiglia.

Dunque, è importante rendere visibile la questione e rimuovere qualsiasi stigma legato all'essere un o una young carer. L'attenzione dovrebbe essere focalizzata sul fatto che **l'assistenza fa parte dell'esperienza umana** e che ci sono aspetti positivi ad essa associati (fornire assistenza aiuta a sviluppare competenze, a migliorare la capacità di affrontare diverse situazioni e conflitti e a costruire relazioni con gli altri).

► Responsabilizzare i professionisti

È importante **sostenere i professionisti** di tutti i settori (istruzione, assistenza sociale e sanitaria), in modo che siano in grado di identificare e sostenere meglio gli young carers. Devono essere forniti loro strumenti pratici (ad esempio, linee guida, checklist).

► Lavoro integrato

Attualmente, ci sono dei divari tra il sistema sanitario, le scuole, il sistema educativo e il sistema sociale, tutte entità molto diverse tra loro e con poche interconnessioni.

Gli esperti vorrebbero un lavoro meglio integrato, invitando tutte le parti interessate di una regione a incontrarsi e a discutere dell'argomento e a trovare insieme delle soluzioni (in linea con quanto è stato fatto per i figli di genitori con problemi di salute mentale).

► Un approccio per l'intera famiglia

I servizi che lavorano con gli adulti bisognosi di assistenza si concentrano solo sulla persona adulta stessa, non sulla rete che c'è intorno. Di conseguenza, gli young carers restano invisibili.

Gli esperti vorrebbero un approccio rivolto all'intera famiglia, che potrebbe ridurre l'onere degli young carers.

► Supporto personalizzato

Gli esperti hanno posto l'accento sulla necessità di accettare la diversità delle famiglie. Gli young carers non sono un gruppo omogeneo. Ogni bambino ha la sua storia. Pertanto, invece di sviluppare un concetto adatto a tutti, è preferibile fornire un sostegno personalizzato, basato sui bisogni individuali.

"Ma bisogna dire che ci sono sempre più bambini con una grande diversità e non si può soddisfare questa diversità standardizzando i programmi. Ed è altrettanto impossibile organizzare una campagna di sensibilizzazione per ogni situazione personale, ma si può dire alle persone interessate che probabilmente ci sono 4, 5, 6 bambini in ogni classe, uno dei quali vive in condizioni di povertà, l'altro ha un passato migratorio, un terzo deve occuparsi di qualcuno a casa, un quarto ha un fratello o una sorella con disabilità, e invitarli a rispondere alle loro esigenze individuali."

► Includere gli young carers negli interventi e nei programmi già esistenti

Anziché creare programmi specifici per gli young carers, gli esperti raccomandano di includerli nell'offerta generale di servizi. C'è stato tuttavia disaccordo riguardo al livello di sostegno attualmente fornito: per un esperto, gli adolescenti non sono ben sostenuti dalla società svizzera. Al contrario, un altro esperto ha evidenziato che "la varietà dei servizi che offrono aiuto agli adolescenti è abbastanza rispettabile e anche il numero di servizi lo è".

► Migliorare la comunicazione, la promozione e l'accesso ai programmi di supporto

Gli esperti hanno espresso preoccupazione in merito alla visibilità dei programmi di sostegno tra la popolazione in generale.

"Penso che in generale ci troviamo in una situazione molto buona, molto favorevole in Svizzera o in Europa centrale. Ci sono molte offerte, ma quello che noto, o quello che sento, è che la comunicazione o talvolta l'accessibilità per gli young carers è spesso il problema maggiore, per cui non va molto bene se abbiamo programmi incredibilmente buoni, ma non li rendiamo accessibili al gruppo target. Penso che l'obiettivo principale debba essere un lavoro di comunicazione".

► Fare uno sforzo particolare per identificare e sostenere gli adolescenti con compiti assistenziali

Gli esperti hanno riconosciuto che la difficoltà nell'identificare gli young carers è ancora più grande quando si tratta di adolescenti, perché sono in una fase di transizione dai servizi per bambini a quelli per adulti. Di solito, non consultano più i pediatri e non comunicano la loro situazione ai loro medici di base. Hanno terminato i nove anni scolastici di base e in seguito iniziano tipicamente un apprendistato o un'ulteriore formazione.

► Più finanziamenti per i servizi di prevenzione

Le fondazioni e le organizzazioni che potrebbero fornire sostegno agli young carers sono in parte private e in parte finanziate dallo Stato, ma sono piccole e sottofinanziate. Secondo gli esperti, si potrebbe migliorare la situazione se

La legge fosse modificata per consentire maggiori finanziamenti per i servizi di prevenzione. Gli interventi dovrebbero essere finanziati da diverse fonti (fondazioni, governo, donatori, assicurazioni sanitarie,...) in modo da mantenerli indipendenti. Potrebbero essere finanziati dal bilancio della protezione sociale, ma come parte di un finanziamento generale e non come misura una tantum.

► **Co-progettare le misure di sostegno con gli young carers**

Le misure di sostegno devono essere co-progettate con gli young carers per garantire che siano adatte alle loro esigenze. Per poter partecipare attivamente, gli young carers devono essere informati adeguatamente.

L'ESPERIENZA DI ALTRI PAESI

Il progetto di ricerca Me-We, con il suo confronto transnazionale, ci permette di fornire una panoramica delle possibili strategie per identificare e sostenere gli young carers. L'esperienza di altri paesi può essere una grande fonte di ispirazione per i responsabili politici e i fornitori di servizi in Svizzera (con il dovuto riconoscimento delle specificità del contesto svizzero, come sottolineato nella sezione precedente).

Strategie di successo per identificare gli young carers

È preferibile che gli young carers siano identificati da qualcuno di esterno, piuttosto che dover attirare l'attenzione. Perciò, possono essere applicate le seguenti misure:

Screening nelle scuole e nei contesti socio-sanitari

- Le scuole svolgono un ruolo vitale nell'identificazione degli young carers. Per facilitare l'identificazione, potrebbero essere utilizzati strumenti come MACA-YC18.
- Gli operatori sanitari e sociali – quando entrano in contatto con una persona adulta bisognosa di assistenza – dovrebbero chiedere regolarmente se la cerchia intorno a questa persona include dei bambini e se hanno qualche tipo di bisogno. Dovrebbero fare questo tipo di controllo con regolarità (con l'evolversi della malattia, anche il tipo di assistenza cambia).

Formazione per i professionisti

- I professionisti (del settore educativo, sanitario e sociale) potrebbero ricevere una formazione sugli young carers (sulle sfide che devono affrontare, sulle misure per identificarli e per offrire loro supporto, così come sui modi efficaci per ascoltarli). Tale formazione potrebbe essere inclusa nei loro programmi di formazione di base.

Sensibilizzare i professionisti e l'opinione pubblica

- I temi dell'assistenza non retribuita, della resilienza e della salute mentale o della dipendenza potrebbero essere discussi a scuola, in modo che non siano più un tabù.
- Gli effetti positivi delle attività di assistenza dovrebbero essere comunicati maggiormente (fornire assistenza è un elemento che porta a sviluppare delle competenze e la capacità di affrontare diverse situazioni e conflitti, e a costruire relazioni con gli altri).
- Settimane di sensibilizzazione nelle scuole, condivisione di storie personali durante le lezioni, programmi televisivi e campagne sui social network sono tutti dei buoni metodi per aumentare la consapevolezza sul tema e ridurre lo stigma.

Strategie di successo per sostenere gli young carers nella loro formazione

Per garantire che gli young carers possano completare i loro studi e ottenere buoni risultati, la principale misura di sostegno è la **flessibilità**, la quale può avere forme diverse:

- comprensione da parte degli insegnanti in caso di ritardi, assenze, compiti a casa non fatti
- piani educativi e attività di apprendimento più focalizzate sui bisogni degli young carers

Oltre alla flessibilità, le scuole possono mettere in atto un **sostegno supplementare e su misura** per evitare l'abbandono scolastico e garantire una transizione senza intoppi verso una formazione superiore o verso il lavoro.

Ad esempio:

- Avere dei consulenti a cui gli young carers possano parlare individualmente.
- Indirizzare gli studenti a dei servizi di supporto (ad esempio, club sportivi, club giovanili) e metterli a conoscenza di questi servizi.
- Applicare agli young carers delle misure speciali già esistenti per altri gruppi (ad esempio, in alcune scuole i bambini che praticano sport di alto livello hanno uno status speciale, che consiste nell'avere più tempo durante gli esami o altri trattamenti di favore). Queste misure potrebbero essere estese ai bambini e ai giovani con delle responsabilità assistenziali.
- Prevedere una supervisione psicologica a scuola in modo da supportare gli young carers nel gestire la frustrazione, la rabbia e altre emozioni derivanti dalle attività di assistenza.
- Rilasciare una tessera per gli young carers, così che non debbano spiegare ogni volta la loro situazione.
- Offrire del tutoraggio.
- Sostenere gli young carers in modo da permettere loro di fare scelte informate sul tipo di scuola che desiderano

frequentare. Creare un sistema di valutazione (e certificazione) per valorizzare le competenze trasversali acquisite dagli young carers, le quali possono rivelarsi molto utili sul mercato del lavoro.

- Prevedere condizioni di lavoro flessibili per gli young carers, ad esempio incentivando i datori di lavoro che assumono a tempo parziale delle persone con un ruolo d'assistenza, permettendo loro anche il lavoro da casa.

Strategie di successo per sostenere la salute mentale degli young carers

Alcune misure che possono essere implementate per sostenere la salute mentale degli young carers sono illustrate di seguito:

Supporto di gruppo/da parte di pari e informazione

- Creare dei gruppi di young carers, dei gruppi di sostegno tra pari, in modo che questi ragazzi siano consapevoli di non essere soli (anche questo può aiutarli).
- Offrire agli young carers la possibilità di trarre vantaggio dall'esperienza di altri giovani che sono stati young carers (come mentori o attraverso programmi di coaching).
- Migliorare l'accesso alle informazioni sulle possibilità di sostegno esistenti (ad esempio, informare gli insegnanti, i medici generici e gli assistenti sociali sulle attività locali a sostegno degli young carers).
- Dare agli young carers lo spazio necessario per condividere le loro emozioni e frustrazioni, anche quando non cercano necessariamente un supporto pratico per "sistemare" la loro situazione. Tale spazio e riconoscimento può essere importante in un contesto professionale, ad esempio all'interno della propria scuola, ma lo è ancor di più nel proprio ambiente personale.

Fornire delle pause agli young carers

- Organizzare campi estivi, gite scolastiche, cinema, attività sportive per allontanare il giovane dalla "pentola a pressione".
- Dare agli young carers la possibilità di una pausa dall'attività di assistenza, farli divertire e metterli in contatto con i loro coetanei.
- Assisterli con i costi finanziari affinché possano partecipare a queste attività.

Migliorare la resilienza

- Consentire agli young carers di accedere agli strumenti e al sostegno per trovare strategie utili ad affrontare la situazione. Aumentare la resilienza degli young carers

ha anche il vantaggio di ridurre la loro dipendenza dai servizi di sostegno formali, in particolare in tempi di tagli di bilancio e di riduzione dei servizi disponibili.

- La psicoeducazione può essere uno strumento utile per migliorare la resilienza.

Strategie di successo per coinvolgere gli young carers

Gli young carers devono essere coinvolti in tutte le decisioni che li riguardano. Per partecipare attivamente ai processi decisionali, essi devono essere informati. I loro diritti devono essere presi sul serio e le loro opinioni devono essere ascoltate.

Possono essere attuate le seguenti strategie:

- Fornire agli adolescenti con responsabilità assistenziali le informazioni necessarie, ad esempio riguardo alla malattia della persona bisognosa di assistenza, nonché riguardo al sostegno che possono ricevere e a come possano accedervi.
- Garantire che il personale che si occupa dell'assistenza, il personale sanitario, gli assistenti sociali, gli insegnanti e i genitori sappiano come comunicare con i giovani in modo rispettoso e con un linguaggio appropriato.
- Progettare il sostegno assieme agli young carers, in modo da garantire che esso sia adatto alle loro esigenze. Un sostegno personalizzato può migliorare la situazione dei bambini e delle famiglie nel momento presente - ed evitare di trasmettere i problemi alla prossima generazione.



NIENTE SU DI NOI SENZA DI NOI!

Il progetto Me-We applica un approccio di co-design, incoraggiando la partecipazione diretta degli utenti finali (adolescenti con ruoli assistenziali, professionisti in ambito educativo o assistenziale, e responsabili politici) e favorendo la collaborazione tra le parti interessate.

In linea con l'approccio di co-design, tutti i partner nel progetto hanno creato dei "Blended Learning Networks", ovvero delle "comunità di pratica" eterogenee che coinvolgono giovani con responsabilità assistenziali e altre persone interessate. A queste persone, sedute assieme ad un unico tavolo, viene chiesto di trovare le soluzioni più adatte (ad esempio, esse sono coinvolte attivamente in tutte le attività del progetto, in particolare nella pianificazione degli interventi e nello sviluppo di un'app per gli young carers adolescenti).

Un altro canale che ha garantito il coinvolgimento attivo degli young carers nelle attività del progetto Me-We è stato la creazione di un legame con il gruppo di lavoro "Young Carers" di Eurocarers.

Il gruppo di lavoro "Young Carers" di Eurocarers è una piattaforma che riunisce young carers ed ex young carers di diversi paesi. È stato fondato nel 2017 sulla base delle incredibili esperienze condivise durante la Conferenza Internazionale sugli Young Carers (Maggio 2017, Malmö, Svezia). Attualmente ci sono 27 membri provenienti da 10 Stati europei e un membro dall'Australia. L'obiettivo è quello di unire sforzi e risorse, in modo che le voci degli young carers siano ascoltate e che in tutta Europa siano messe in atto politiche e pratiche per rafforzarli e sostenerli.

Quattro membri del gruppo di lavoro "Young Carers" fanno parte del Comitato Etico e Consultivo Internazionale (International Advisory and Ethics Board), sullo stesso piano di altri esperti. Inoltre, i membri del gruppo di lavoro "Young Carers" hanno avuto regolarmente l'opportunità di dare la loro opinione sulle attività del progetto.

Chapitolo 4:

Tradurre i risultati della ricerca in azioni politiche

RACCOMANDAZIONI ADATTATE AL CONTESTO SVIZZERO

Molti degli esperti intervistati durante il nostro studio hanno sottolineato che l'assistenza è vista come una questione privata dalle famiglie in Svizzera. È importante rompere questo tabù: l'assistenza, piuttosto che essere **una questione nascosta e "privata", deve essere al centro delle politiche e degli interventi pubblici (la sfera personale è anche politica)**.

In Svizzera c'è un crescente interesse politico nei confronti dei familiari che prestano assistenza ai loro congiunti. Il "Rapporto sul sostegno alle persone che si occupano e si prendono cura dei familiari", pubblicato dal Consiglio federale nel 2014, conferma questa tendenza. Il Consiglio federale riconosce l'importante ruolo svolto nella società dalle persone che prestano assistenza informale (e non retribuita). Con l'invecchiamento della popolazione e la mancanza di risorse, si tratta di un ruolo che sarà ancora più importante in futuro, in modo da soddisfare la crescente domanda di assistenza a lungo termine. Sono stati compiuti i primi e importanti passi verso il riconoscimento e il sostegno delle persone con una responsabilità assistenziale.

- ▶ Esortiamo i responsabili politici ad essere innovativi e ad attuare una **strategia a sostegno delle persone con un ruolo assistenziale di qualsiasi età**. Tale strategia dovrebbe **adottare una prospettiva basata sull'intero arco della vita**, perché in ogni fase della vita ci si può ritrovare in questo ruolo.
- ▶ Raccomandiamo di **estendere e di modificare la legislazione e la politica esistente** in modo che gli young carers possano essere identificati, riconosciuti e sostenuti. In particolare, raccomandiamo di concentrare maggiormente l'attenzione sulla prevenzione, che viene attualmente trascurata.
- ▶ **Chiediamo che i fornitori di servizi includano gli young carers nel target delle loro attività**. Come sottolineato dagli esperti, per far sì che il sostegno sia efficace, devono essere soddisfatti i seguenti requisiti:
 - È necessario un approccio integrato, con la cooperazione delle diverse parti interessate (del settore dell'educazione, sociale, sanitario, delle ONG, del

mondo politico).

- Dovrebbe essere adottato un approccio che tenga conto dell'intera famiglia.
- Il supporto dovrebbe essere adattato alle esigenze specifiche di ciascun individuo.
- Gli young carers devono essere attivamente coinvolti nella progettazione e nell'implementazione del sostegno a loro dedicato.
- Tutte le decisioni prese dai fornitori di servizi (compresa la determinazione dell'interesse superiore del bambino) dovrebbero basarsi su un approccio fondato sui diritti.

L'esperienza di altri paesi europei conferma che la ricerca specifica per ogni paese e la presenza di ONG che sostengano la tematica sono fattori chiave per indurre un cambiamento nelle politiche e nelle pratiche riguardanti gli young carers (Becker & Leu, 2016). Pertanto,

- ▶ Chiediamo **ulteriori ricerche sugli young carers**, che consentiranno di prendere decisioni migliori sul tipo di sostegno necessario per loro e, in questo modo, di apportare modifiche alla legislazione e alla politica basate sull'evidenza scientifica.
- ▶ Poniamo l'accento sull'urgente necessità di attività di **sensibilizzazione su larga scala** tra gli operatori sanitari, in ambito educativo, tra gli assistenti sociali, tra i responsabili politici e nella società nel suo complesso. Le ONG potrebbero svolgere un ruolo chiave, se adeguatamente sostenute da finanziamenti statali.

Uno sforzo congiunto da parte di ciascun membro della nostra società ci permetterà di **progredire** nella nostra visione: una in cui gli young carers possano godere appieno dei loro diritti.

RACCOMANDAZIONI A LIVELLO EUROPEO

A livello europeo, si riconosce sempre di più la necessità di agire per sostenere e rafforzare gli young carers.

L'European Network of Ombudspersons for Children – nella loro [dichiarazione sulla salute mentale nell'infanzia adottata](#) il 21 settembre 2018 – ha sottolineato l'importanza di programmi di sostegno per migliorare e proteggere la salute mentale degli young carers.

Il Parlamento europeo, nella [Relazione sui servizi di assistenza nell'UE per una migliore parità di genere](#) - approvata il 15 novembre 2018 – invita la Commissione e gli Stati membri a **intraprendere una ricerca sul numero di young carers e sull'impatto che il loro ruolo ha sul loro benessere e sui mezzi di sostentamento** e, sulla base di tale ricerca, a **fornire sostegno** e rispondere alle esigenze specifiche degli young carers, in collaborazione con le ONG e gli istituti scolastici.

Le azioni raccomandate ai responsabili politici in Svizzera possono essere integrate da azioni prese a livello europeo.

- ▶ Sostenere **degli studi approfonditi** sul profilo e sui bisogni dei ragazzi e dei giovani adulti con responsabilità assistenziali; raccogliere informazioni sui numeri reali.
- ▶ Garantire che le **buone pratiche esistenti siano diffuse** e rese visibili in tutta Europa; fare confronti con quanto sta accadendo in altri paesi per sostenere le pratiche e la legislazione in via di sviluppo.
- ▶ **Includere gli young carers** nella Strategia dell'UE per la gioventù o nell'agenda dell'UE sull'istruzione superiore e in altri dossier politici pertinenti.
- ▶ **Ascoltare gli young carers.** Sulla falsariga di "Europe Kids Want" (L'Europa che i bambini vogliono), prevedere piattaforme e opportunità di partecipazione per gli young carers.
- ▶ **Utilizzare gli strumenti disponibili** – vale a dire il Semestre Europeo, il Pilastro Europeo dei Diritti Sociali, i Fondi Strutturali e di Investimento Europei, la Strategia dell'UE per la Gioventù, l'Agenda dell'EU sull'istruzione superiore, la Piattaforma Europea per Investire nell'Infanzia, la Garanzia per i Giovani, e il Metodo Aperto di Coordinamento – per promuovere lo sviluppo di approcci integrati per l'identificazione, il supporto e l'integrazione sociale dei giovani (adulti) che prestano assistenza in tutta Europa.

Figura 1 - Il Pilastro Europeo dei Diritti Sociali e la sua rilevanza per gli young carers

I principi	La rilevanza per gli young carers
Principio 1 Istruzione, formazione e apprendimento permanente	Le responsabilità assistenziali possono avere un impatto negativo sulla formazione degli young carers (insuccessi, assenze e abbandoni scolastici)
Principio 4 Sostegno attivo all'occupazione	Gli young carers hanno un maggiore rischio di diventare NEET (persone né occupate professionalmente, né inserite in un percorso di istruzione o di formazione) rispetto ai loro coetanei.
Principio 11 Assistenza all'infanzia e sostegno ai minori	Gli young carers dovrebbero essere considerati come bambini provenienti da ambienti svantaggiati che hanno quindi diritto a un sostegno complementare e personalizzato per poter beneficiare delle pari opportunità e per poter esercitare i loro diritti sociali.
Principio 18 Assistenza a lungo termine	Fornendo servizi formali di assistenza di lunga durata e di buona qualità alle persone assistite, è possibile evitare che gli young carers si facciano carico di un'assistenza inadeguata.

Il ruolo dei responsabili politici è quello di prevenire e minimizzare i (potenziali) impatti negativi che possono derivare dall'avere un ruolo assistenziale durante la fase di crescita (restrizioni nell'educazione, prospettive di vita ridotte, influenze sul benessere, isolamento) e di consentire agli young carers di crescere e di realizzarsi come essere umani.

Sono in gioco le prospettive di vita di migliaia di bambini in tutta Europa

NON C'È TEMPO DA PERDERE.



#youngcarers

Maggiori informazioni:
www.me-we.eu



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Psychosocial support for promoting mental health and wellbeing among adolescent young carers in Europe



Enabling young carers to pursue their goals in life and reach their full potential – Converting research findings into policy actions

Country Focus: Switzerland

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Summary

Childhood is commonly seen as a protected and responsibility-free stage of life where adults are “in charge” and provide care, while children are primarily beneficiaries of care. Yet, for a number of children and adolescents across Europe, this is far from being true as they find themselves providing – sometimes very intensive levels of – care to a family member/friend in need of support (because of illness, disability, addiction, etc.) and have to assume responsibilities that would be more fitting for an adult. We call them young carers*.

Number of young carers across Europe

Although there is currently very limited data regarding the number of young (adult) carers across Europe, some national statistics and pilot projects have helped to unveil a substantial - and yet largely unknown – population group.

The [2011 census for the UK \(England and Wales\)](#) revealed that there are 177.918 young carers under the age of 18. The number of young carers is increasing over time: 27.976 more than in 2001 (an increase of 19% over 10 years).

In Italy, according to the most recent national statistics, there are 391.000 young and young adult carers (15-24 years), corresponding to 6,6 % of the whole population.*

In Switzerland, 7,9% of children aged 10-15 years are young carers (Leu et al. (2019); Leu & Becker, 2019).

In the Netherlands, research projects give us the following estimated numbers: young carers form the 6% of the population aged 13-17.

In Sweden, according to a survey, 7% of children aged 14-16 years carry out substantial amounts of caring.

In Ireland, the 2016 Census showed that 3.800 children under 15 years engaged in providing care to others, accounting for 1,9 % of all carers. Half of these children (1.901) providing unpaid care were aged 10 and under.

Census and official statistics are very important. Yet, they often overlook young carers or underestimate their number (the adult who fills in the census may not be aware/want to reveal that in his family there is a young carer). As confirmation of this, an unofficial data from a [2018 BBC survey](#) revealed there are 800.000 young carers in England (opposed to the 166.000 identified via the Census).

*Istat, Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea, dati 2015.

* Please refer to page 4 for the exact definition.

While the phenomenon of informal care – the provision of care, usually unpaid, by a family member/friend outside of a professional framework – is gaining momentum across Europe, little is known on the situation

of those carers who are under 18. Young carers are indeed still largely invisible to public authorities and service providers and this failure to identify and support them can negatively affect their (mental) health, educational experience, employability and social inclusion. The negative impact at individual level can entail long-lasting negative consequences for society as a whole.

Oftentimes, policy-makers and service providers are unaware of the challenges faced by young carers and the possible measures to prevent or overcome them - rather than unwilling to address the situation.

This brief precisely aims to raise awareness on the topic and fill the knowledge gap, by sharing the findings of a European research and innovation project, funded through the EU's Horizon 2020 Programme and called Me-We - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe. While this document directly draws on research and evidence, its objective is to reflect and ponder on the policy impact of Me-We's findings. As such, it should not be approached as a scientific report.

The Me-We project (2018-2021) brings together prominent universities, research institutes and civil society organisations from six different European countries – including Eurocarers, the European network representing informal carers of any age. The project aims to improve the mental health and wellbeing of adolescent young carers, by strengthening their resilience (the process of positive adaptation within the context of significant adversity).

The first year of the project was dedicated to gain insight into:

- a) the profiles, needs and preferences of adolescent young carers in six European countries (Italy, Netherlands, Slovenia, Sweden, Switzerland and UK);
- b) the legislation, policy and service frameworks that exist to support adolescent young carers in the six countries (with a focus on how they work in practice, the drivers of their development, their strengths and limitations); and
- c) successful strategies to support young carers.

An online survey, literature review and a series of interviews with key experts were carried out to that end. As a result, and for the first time ever, our research has made cross comparisons on the topic of young carers possible between six European countries. It also shed light on the differences in the contexts that exist between these countries.

The collated knowledge is currently being used to co-design an innovative framework of primary prevention interventions, with adolescent young carers themselves as well as with other relevant stakeholders. These interventions will be implemented and evaluated in the six project countries.

The Me-We project is part of a bigger picture and it is framed in the context of ongoing debates regarding the future of European care systems – in the face of ageing societies - and the implementation of the Europe 2020 Strategy's goals in the fields of education and employment. The introduction to the brief builds on pre-existing research and data to shed light on the impact of the caring role of young carers themselves and on urgent need to act.

The Introduction is general, whereas the following sections focus specifically on Switzerland. To have an overview of the main findings across all the project countries, please refer to the European brief (available [here](#)).

Chapters 1, 2 and 3 focus on the initial findings of the Me-We project, arising from the first year of activity, which have consisted in an online survey, an analysis of the legislative/policy frameworks as well as a review of existing support measures.

The complete study results will be published in peer reviewed journals in 2020 and 2021.

Chapter 4 theorises on the basis of the Me-We findings, the knowledge deriving from previous research and the current policy environment, in order to identify policy priorities as well as possible courses of action.

Each of these recommendations is driven by our core vision: young carers should be able to pursue their goals in life and achieve their full potential, without being negatively impacted by their caring responsibilities.

Introduction

The challenges of being a young carer

Who are young carers?

Young carers are children and young people under 18 who provide or intend to provide care, assistance, or support to a family member or a friend, who has a chronic illness, disability, frailty or addiction. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. (Becker, 2000)

What do young carers do?

- Practical tasks (e.g. cooking, housework and shopping);
- Physical care (e.g. helping someone out of bed);
- Emotional support (e.g. talking to someone who is distressed);
- Personal care (e.g. helping someone dress);
- Managing the family budget and collecting prescriptions;
- Helping to give medicine;
- Helping someone communicate;
- Looking after brothers and sisters

Young carers aged 15-17 are called “**adolescent young carers**”. They deserve special attention, as they are in a key, transitional phase of their development: moving from childhood into adulthood. This transitional stage is critical not only for biological and psychosocial considerations; but will also affect the positioning of potentially vulnerable adolescents with regards to the law, policy, as well as health and social care.

The reasons why children become carers are manifold and include (among others) the cultural background, a sense of duty, the lack of alternative options, love and empathy for the care recipient, lack of financial and practical resources within families (Leu & Becker, 2019).

There is a continuum of children providing care, which starts with caring about (low levels of care responsibility, routine levels of caregiving and little evidence of negative outcomes) moving to taking care of (increasing care tasks and responsibilities) to caring for (high levels of care responsibility, substantial regular and significant caregiving, evidence of significant negative outcomes) (Joseph et al. (2019).

The impact of caring

Mental health and wellbeing

There are some positive impacts related to caring, for example young carers can gain satisfaction from caring and experience self-esteem, empathy, maturity (Banks et al., 2001; Cass et al., 2009; Cassidy et al., 2014; Heyman & Heyman, 2013; Joseph et al., 2009; Robson et al., 2006). Yet, having to reconcile the challenges that life throws at them with caring responsibilities can be overwhelming. The pressure associated with caring is considered as a risk factor for mental ill-health (Aldridge & Becker, 2003; Ali et al, 2015; De Roos et al., 2017; Greene et al., 2016).

Education

Young carers face particular barriers in relation to school and further education: they may have frequent lateness, absences and ultimately, they may be forced to drop out (Becker & Sempik, 2018; Kaiser & Schulze, 2014; Moore et al., 2009). Similarly, it can be challenging to combine paid employment with caring responsibilities.

Social life

Young carers may have less time for personal development and leisure and be isolated. They can also become victims of social stigma and bullying and may be more frequently subject to social exclusion throughout their life course (Barry, 2011).

Despite these negative impacts, young carers are still too often invisible to policy makers and service providers.

Why are young carers invisible?

“We ignore young carers at our peril and at the peril of these children’s future.”*

- Young carers do not recognise themselves as young carers.
- They are afraid of being taken away from their home by social services/child protection.
- They are afraid of being judged or misunderstood by their peers, teachers or service providers.
- There is stigma (especially when cared for person has mental illness or substance dependency).
- They are uncertain about who to talk to.
- They believe that nothing will change if they disclose their caring responsibilities.
- Service providers tend to focus on the cared for person.
- Wider community is not aware of specific services for young carers (if any exists).

→ Young carers remain unidentified and their needs are not met.

* Prof Saul Becker, University of Sussex

Why do we need to address the issue?

Young carers are unable to fully enjoy their human rights

The UN Convention on the Rights of the Child states that **“Every child has the right to...”**- among others- rest and leisure (Article 31), education (Articles 28 & 29), adequate standard of living (Article 27), express their views (Article 12), enjoy the highest attainable standard of health (Article 24).

Young carers, just like all children, should be able to enjoy the rights to which they are entitled. Too often though, the challenges they face directly hinders that process and so the level playing field may no longer be sufficient to guarantee equal opportunities for young carers. Young carers are a particularly vulnerable group of children and should be recognised as such. They should not only benefit from the universal implementation of their rights but be subject to additional and tailored policy and support measures with a scale and intensity that is proportionate to their level of disadvantage. This is in line with the international human rights law which requires States to adopt **affirmative actions** in fulfilling their obligations to respect the equality principle. It can be argued that the lack of positive actions from States to support young carers is a failure to protect and promote their rights.

Supporting young carers makes economic sense

- **Early school leaving creates high individual, social and economic costs.**

Young people with only lower secondary education or less are more often affected by unemployment, are more likely to depend on social benefits and have a higher risk of social exclusion. Their lifetime earnings, well-being and health are negatively impacted, as well as their participation in democratic processes.

In addition to the individual costs, early school leaving hampers economic and social development and is a serious obstacle to the European Union's goal of smart, sustainable and inclusive growth. That is explicitly recognised by the Europe 2020 strategy, which includes the target of reducing the EU average rate of early school leavers to under 10%.

- **Poor mental health is a cost for societies.**

At international level, there is growing recognition of the importance of early intervention and **prevention** to avoid poor health outcomes. As stressed by the World Health Organisation, promoting and protecting children and adolescents' health brings benefits not just to their health, both in the short and the long term, it also contributes to economies and society, with healthy (young) adults able to make greater contributions to the workforce, their families, communities and society as a whole.

Investing in young people is a social investment. As recognised by the EU in the Social investment Package, through early interventions, socio-economic inequalities can be tackled at the roots, the cycle of disadvantages can be broken and equality of opportunity can thus be promoted.

Between support and emancipation - the Young carers' Dilemma

Before proceeding, it is worth to look into the common ethical conundrum regarding the situation of young carers according to which: "it actually does not pertain to children and young people to assume caregiving responsibilities and consequently, supporting young carers is by essence detrimental to their best interests". Here are the various arguments brought about by those endorsing these contradictory approaches.

Vision 1: "Young carers should not exist and policy attention should be put elsewhere"	Vision 2: "Young carers should be identified and supported"
By supporting young carers and teaching them how to cope, we effectively accept the <u>transfer of care responsibilities from the public to the private sphere</u> , thereby harming both the principles of universal access to care and the rights of young carers.	The idea that children should be free from having a caring role makes absolute sense. Yet, it is <u>unrealistic</u> to ensure that children have no caring roles anymore and we should therefore rather provide interventions, support programmes and methods to prevent or lower the care burden among young carers. <u>Young carers exist</u> and they will be there for many years to come, so we should focus on how to support them and follow up on their needs.
"If appropriate services are delivered to the cared for person, the child or young adult could get on with the ordinary business of growing up. Hence, it is important to <u>direct resources and strategies at reducing the need for children to care in the first place (by providing services to the person in need of care)</u> ."*	"We recognize that in an ideal world where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of young carers would be greatly reduced. But we also recognize unpalatable current political and economic realities and that in an increasingly pressurised and residual welfare system, in the context of economic recession, uncertainty and charges for social care, <u>family carers are going to be expected to continue their support</u> . In such a context, it is important that the role of (adult and) young carers is fully appreciated and valued."** If we have zero tolerances – pretending that young carers do not exist – then we will not see them until it is too late, when their needs for support have escalated.
From a human rights perspective, children have the right to be children and not to be carers. A system of support would have the effect of entrapping them into a caring role from which they should be free, in so doing violating their rights.	<u>Young carers' right to self-determination includes the right to care</u> , if they wish to do so, provided that their best interests is safeguarded. Measures should therefore seek to preserve young carers from <u>inappropriate caring</u> , i.e. caring responsibilities which have a negative impact on the child's health, wellbeing or education, or which can be considered unsuitable in light of the child's circumstances.
The vision of the Me-We consortium:	

Choice should be the backbone of every decision about carers. People should have the right to choose freely whether they want to be – and remain – a carer, and to what extent they want to be involved in caring. However, choice is unlikely when no professional or informal care alternative is available. The universal provision of affordable and good quality long-term care services is therefore a prerequisite for the self-determination of carers. At the same time, we recognize that the availability of alternative options – while being imperative – may sometimes not be sufficient to allow for a genuine choice. Indeed, other factors (such as the feeling of guilt or of familial duty) may play a role and influence personal perception on offered alternative options. Having said that, when caring responsibilities result from a well-informed and unaffected choice by both the carer and care recipient, society's mission should be to prevent and minimise the negative impact that caring responsibilities can have on young carers, in order to ensure that they can pursue their life goals and reach their full potential.

*Richard Olsen & Gillian Parker, Critical Social Policy, Issue 50

** Jo Aldridge and Saul Becker, Critical Social Policy, issue 16.3

Chapter 1: What is it like being an adolescent and a carer?



What is it like to navigate a changing world – the transitional period from childhood to adulthood – while implementing caring tasks? To gain insight into this, the Me-We consortium ran an online survey in six European countries from April to mid-November 2018.

The aim was to assess the extent of caring and its effects (impact on general wellbeing and education) for adolescent young carers.

In Switzerland, out of the 2.057 respondents to the survey, 485 were carers aged 13-27 years (born between 1991 and 2005). The total number of **our target group (adolescent young carers aged 15-17 years)** in the Swiss sample was **85** (caring for either a family member or a friend, including those who care for both, i.e. overlaps). 19% report that they have been providing care to someone for as long as they can remember.

Figure 1- The Me-We online survey

The majority of adolescent young carers in the Swiss sample (78%) are women, which is different from previous Swiss data so far (Leu et al. (2019), but is in line with the existing literature on the gendered nature of care, and the cultural, social and familial expectations of care.

62 adolescent young carers indicated that they are Swiss citizens. 56% reported that they reside in villages.

The majority of respondents (non-carers included) reported that they live in dual parent households (85%). 29.5% live with a brother and 24% live with a sister, indicating that a large number of respondents may be the only dependent living with a family. Multigenerational households are a very small feature of family life for the respondents in this survey: 5.5% live with a grandmother and 4.5% live with a grandfather.

Who do adolescent young carers care for?

Of the 116 respondents who indicated that they have a family member with a health condition, 57 (50%*) reported that they provide care, look after, or help their family member with a health condition. Thus, in the Swiss sample, **there are 57 adolescent young carers looking after a family member with a health condition**. Of these adolescent young carers, 26 (57,8%) provide care for only one family member. There are a number of AYCs who care for multiple family members: 9 AYCs (20%) provide care for 2 people, 4 AYCs (8.9%) provide care for three people, 3 AYCs (6.7%) provide care for 4 people, and 2 AYCs (4.4%) provide care for 5 people, and 1 AYC (2.2%) reported caring for 9 individuals.

* Note, the calculated percentages – in this chapter - exclude missing values.

The “typical” profile of adolescent young carer in Switzerland is a **girl** providing care for her **mother with a physical disability**. Grandmothers and grandfathers are respectively the second and the third type of care recipient.

The care recipient can also be a friend. Of those 99 respondents who indicated that they have a close friend with a health condition, **46 adolescent young carers** reported that they **provide care for their close friend**. In the majority of cases the health condition is mental illness.

18 AYCs provide care for only one friend (62%). There are a very small number of AYCs who provide care for multiple close friends.

How much care do young carers provide?

Caring activities can include domestic tasks, household management, personal care, emotional care, sibling carer and financial/practical care. When compared to their non-caring peers, adolescent young carers perform greater amounts of caring activities. Hence, they have different experiences of daily life than their non-caring peers. 24% of the total adolescent young carers in the sample perform high amounts of caring activity (on a Multi-Dimensional Activities of Caring Checklist (MACA) score above 14), compared to 20% non-carers. 17% adolescent young carers perform very high amounts of caring activity (MACA score above 18), compared to 12% non-carers.

Overall, girls perform greater amounts of care activities compared to boys (however, the differences are not statistically significant).

Impact on educational attainment

52 AYCs (64%) reported that they were currently enrolled in an apprenticeship within vocational secondary school. This reflects the Swiss sampling strategy that featured three vocational schools. Further schools were included later on in the next recruitment phase in order to achieve the target number of 200 adolescent young carers aged 15-17.

15% reported that they experience difficulties in school because of caring for someone. Similarly, 14% reported that their school performance has been negatively impacted due to caring. 15% reported that they have been bullied, teased, or made fun of due to their caring role.

These findings underline the need to engage the educational sector in identifying and supporting young carers.

Overall wellbeing

Adolescent young carers were found to be more likely to report a lower state of wellbeing in comparison to their non-caring peers. On a scale where 50 indicates extremely high wellbeing and 10 indicates low wellbeing, non-carers have a mean value of 34.9. Adolescent young carers have a mean value of 30.5. This disparity of 4.4 is highly statistically significant and can also be considered as a potential for concern.

Health impact of the caring role

Adolescent young carers in Switzerland generally reported higher amounts of health difficulties because of caring in comparison to the other European countries (except the UK): 40% of adolescent young carers reported physical health problems due to their caring role. 33% reported mental health problems.

Further research is needed to explain the reasons for this particularly significant finding.

Severe mental health impacts due to caring: self-harm and harm to others

Due to their caring role, 21% of adolescent young carers have thought about hurting themselves and 5% have thought about hurting others (of these, 50% have thought of hurting their care recipient).

The proportion of adolescent young carers who have thought of hurting themselves is higher than that found in the other surveyed countries, except the UK (8-11%). Again, further research is needed to investigate the reasons behind this difference.

This finding indicates that adolescent young carers are at significant risk of mental distress and underlines the need to engage health professionals, particularly mental health practitioners, to identify and support young carers.

Access to formal and informal support

In Switzerland, 15% of adolescent young carers personally receive formal support. Fewer families of AYCs receive monetary assistance in Switzerland in comparison to the other countries sampled in this research study. One might surmise therefore that the socioeconomic position of AYC families in Switzerland may be higher than those in other countries, however additional research is needed to examine the true cause of this difference.

Whereas adolescent young carers may not have the opportunity to access dedicated formal support services for their caring role, many (61%) reported the presence of a friend who is aware of their caring role and offers them support. This finding is important to consider in light of the resilience and protective factors associated with being a young carer: adolescent young carers may find informal support valuable in the absence of formal dedicated services.

When considering external awareness of their caring role, the AYCs in this survey indicated that it is more likely that they have a friend aware of their caring role, rather than someone at school or an employer. This follows the findings of other countries in this research study.

Chapter 2: Recognition, protection, support: what does the law say on young carers?

The aim here was to examine the legislation, policy and service frameworks that exist to support adolescent young carers in six European countries, with a focus on how they work in practice, their strengths and limitations and the drivers in their development. To this end, a literature review was conducted as well as a series of interviews with experts (working either in a legal, academic or government position) on the topic of young carers (four interviews were carried out in Switzerland).

Legislation, policy and service frameworks

In Switzerland, no specific legislation protecting and supporting young carers and their families exists. Young carers are not specifically defined in the law.

The current system delivers (only) indirect support to young carers, mainly from legislation related to child protection and social care::

- ✓ [Federal Constitution of the Swiss Confederation](#), which states that children and young people have the right to the special protection of their integrity and to the encouragement of their development. They may also personally exercise their rights to the extent that their power of judgement allows;
- ✓ [Swiss Civil Code](#), Child and adult protection law;
- ✓ Convention on jurisdiction, applicable law, recognition, enforcement and cooperation in respect of parental responsibility and measures for the protection of children ([Hague Convention on the Protection of Children](#));

- ✓ [Social Security Law](#), in particular Art. 29 septies Federal Law on Old Age and Survivors' Insurance: it provides financial funding for families (care credits), thus indirectly relieves the burden on young carers as well.

Regarding the changes in legislation, there has been **paradigm shift** from a welfare approach to a rights-based approach. This has also led to children now being better informed about their rights.

There are policy and service frameworks, specifically addressing young carers:

- ✓ [Action plan for support and respite of relatives providing care](#)

On December 5th 2014, the Federal Council published the "Report on supporting people looking after and caring for relatives". This has emerged from a political push from the Swiss Parliament and of the Federal Council as part of the [agenda Health 2020](#) and it shows a growing momentum around carers in the Swiss political landscape. The measures indicated in the plan which include better information, respite, reconciliation of work and family care – are to be implemented in cooperation with the cantons, communes and private organisations.

In 2014, young carers were not included in the action plan. However, a petition from the Parliament addressed their exclusion and they are now explicitly mentioned.

- ✓ Federal Research Programme "[Support and Relief Offers for Carers 2017-2020](#)". The Research targets carers of any age. Young carers are explicitly included. The programme will provide stakeholders in the cantons, communities, companies and other organisations with evidence-based knowledge bases and models of good practice, so that they can develop or promote their own programmes or introduce appropriate new offers themselves.

The experts also mentioned non-specific policy or service frameworks that can indirectly support young carers and their families:

- ✓ [Children and youth policy](#).
- ✓ [Health Promotion Switzerland](#) is a foundation supported by cantons and insurers. With a legal mandate it initiates, coordinates and evaluates measures implemented by the cantons in the field of health prevention and promotion. Four modules and eight principles can be used by the cantons as a basis for their cantonal action programmes.
- ✓ In the Canton of Vaud, the organisation [Espace Proches](#) offers respite and counselling services to carers.
- ✓ In almost every canton, there are likely to be public services for young people and their families.

[Strengths and limitations of legislation, policy and service frameworks](#)

The experts were asked to assess any key strengths or limitations in legislation, policy and service frameworks.

Key strengths

- Legislation is very clear.
- There is a solid legal system with a lot of protection for children.
- The child protection system is very well established and working well in an interdisciplinary manner in Switzerland.
- Legislation and services are regionally flexible, enabling solutions that fit with the regional contexts (flexibility). The plurality of solutions makes innovations easier.
- The Federalist system allows a "Me-too-effect": where one canton has good practice, then other cantons will adopt this sooner or later.
- Terminology within the Swiss Civil Code such as "best interests of the child" is very open to interpretation. This can be a limit, but it also is an opportunity, because it allows acting and reacting to individual situations and individual circumstances.

Key limitations

- Young carers do not exist as a specific social group in Switzerland and therefore they are not addressed by support programmes.
- Laws, policy frameworks, and even some associations working with carers do not use an age-appropriate language for young people, so the information may not be accessible to young carers, who do not have an adequate level of literacy.
- Lack of coordination between the different legal systems (e.g. social security system, family law, medical law, child protection, etc.).
- The policy provisions for carers are not as relevant for young carers, since they relate to supporting a balance between work and informal care, without taking into account young carers who are studying or who are doing an apprenticeship.
- There are differences between how cantons implement the UN Convention on the Rights of the Child, despite the recommendations made by the Federation about how to enact it.

In relation to child protection services, the following limitations were identified:

- **Identifying young carers is challenging**

The child protection authority only becomes involved if a young carer's problems are evident. As young carers do not reach out themselves, professionals (from education, social and healthcare) should notify the authorities (e.g. child protection services). However, since professionals are not aware of young carer, they remain invisible.

- **Focusing on protection rather than prevention or empowerment.**

Child protection measures can only be taken if the child's best interest is threatened. It is not sufficient that the child's best interests are not being fully achieved. A threshold needs to be reached before child protection services can intervene. Hence, the focus is on protecting children once problems have already escalated, rather than on preventing them from arising in the first place.

Similarly, according to some experts, the focus on protection is in contrast to the need to empower young carers and recognising that caring responsibilities can also bring positive outcomes (not just something to be protected from).

- **Families do not reach out for help from child protection services**

Child protection services can be frightening for families as their role is to intervene to safeguard children. It seems like there is no middle ground between "invisibility" of young carers and "mistreatment" (and consequently the intervention of child protection services).

The marred history with respect to child protection in Switzerland (see focus on determining the best interest of the child) has created a situation where young carers and their families do not ask for help from social services, for fear of being separated.

- **No evaluation of the outcomes of child protection interventions**

The outcomes of the interventions taken by child protection authorities are not actually evaluated. It is therefore unclear whether these interventions are appropriate for young carers and their families.

Focus: Determining the “best interest of the child”

The Convention on the Rights of the Child (CRC) states that the best interest of the child shall be a primary consideration in all actions affecting children.

The term “best interest” broadly describes the well-being of a child. Such well-being is determined by a variety of individual circumstances, such as the age, the level of maturity of the child, the presence or absence of parents, the child’s environment and experiences.

In Switzerland, there is a debate on child protection authorities: some think that children are not “property” of their parents and the State has an obligation to intervene, while others think that child protection authorities have too much power. This is due to different interpretations of the “best interest of the child” principle.

The concept has often been applied to justify intervention from child protection services in removing from their family, considering this a safer option. Child protection services have forced children out of their families in the name of child protection under circumstances that would be seen from today’s perspective as grave violations of the rights of these children and their families.

It is important that the interpretation and application of the principle is in compliance with the CRC and other international legal standards. Moreover, there is a need for solutions tailored to the situation, addressing the issue on a case-by-case basis, as **the best interests of a child can be different for every child!** Hence, a call for increased participation of young carers themselves (and their families) is needed, in regard to decisions that concern them.

Future needs

After the experts had identified the strengths and limitations of the current system, they were asked about changes in legislation, policy and/or service frameworks.

A first dilemma to solve was the opportunity to adopt a specific legislation on young carers, following the example of the UK (see box Focus on the English model).

The experts agreed that the UK model is not likely to suit the Swiss context, for different reasons:

- 1) A specific legislation would be a lengthy and complicated project, because of the federal structure. Young carers do not have time to wait. Hence, it makes more sense to include young carers within strategies and programmes that already exist or are in development.
- 2) It is not necessary to have specific legislation for young carers, because specific laws do not exist for every group of people in need.
- 3) In Switzerland, there are already many existing legal provisions that can form a basis for new frameworks or services addressing young carers, such as child protection legislation and the UN Convention on the Rights of the Child. Introducing legislation that specifically targets young carers would mean over-regulating.
- 4) Having a specific legislation is not sufficient to ensure that young carers are supported in practice (it can be seen in the UK for example that the support and protection that young carers receive in practice does not necessarily reflect the objectives of legislation).

Given the aforementioned considerations, the experts agreed that, rather than introducing a specific legislation for young carers, it is more advisable to integrate young carers into existing legislation/policy.

This needs to be extended and amended, so that young carers can be recognised and adequately supported.

Among others, the experts recommended:

- The issue of young carers must be systematically addressed. More data is needed in order to find solutions to make these children visible, understand how child protection measures are working and to inform decision making and legislation in regard to future support for young carers.
- Strong political commitment and support from for example, non-profit, or non-government organisations
- Changing the law with regard to the legal duties for child protection, to ensure that a preventative approach is working in practice.
- Integrating the topic of (A)YCs into the national care policy of the Federal Office of Public Health in Switzerland. Besides changes in the Federal programme, there should also be changes on cantonal level
- Further legislation and policy frameworks to address the structures and conditions allowing professionals to work well together (taking into consideration the right to privacy).
- Include a definition of young carers.

Dilemma: Do we need specific legislation and policy for young carers? Or would a better approach be maintaining non-specific legislation/policies?

The answer depends on aspects that are specific to individual countries, such as 'how effective is the current non-specific legislation/policy at recognising, identifying, protecting and supporting AYCs?'. The answer should be based on an understanding of the local reality. Indeed, our study shows that the support and protection that AYCs receive in practice does not always reflect the objectives of legislation and policy that is in place. Without an accurate understanding of the local realities, assumptions regarding the efficacy of existing legislative and policy frameworks may be unwittingly leaving AYCs to fend for themselves without even recognising their existence.

Dilemma: Do we need legislation or are soft laws and the commitment of different stakeholders enough?

For there to be commitment, it is necessary for different stakeholders (professionals, families, carers, organisations, the State) to be aware of and recognise that children and young people do take on caring roles and that this can result in negative impacts.

For their commitment to be effective, the stakeholders must know how to effectively support AYCs.

For commitment to be actioned, stakeholders require adequate capacity and the necessary resources.

Where one or more of these factors are missing, then that is perhaps the role that legislation and policy should play.

Focus on the English model.

Only the UK has **specific legislation on the topic** that explicitly recognises or defines young people with caring responsibilities. Hence, it may be worth investigating this system more closely.

In England, provisions for young carers fall within The Care Act 2014 and the Children Act 1989 (amended by the Children and Families Act, 2014) which work together in order to bring about a **preventative** and **whole family approach** to identification, assessment and support.

Right to assessment of needs and support. The new legislative framework defines young carers, places an **universal duty to assess young carers' needs** on local authorities, as well as the duty to take **reasonable steps to identify** the extent to which there are young carers within their area who have need for support (i.e. actively look for them). The Children and Families Act 2014 gives young carers and young adult carers in England a right to a carer's assessment and to have their needs met (if the assessment shows this is necessary). A young carer's needs assessment must include an assessment of whether it is appropriate for the young carer to provide, or continue to provide, care for the person in question. **Inappropriate caring** responsibilities should be considered as anything which is likely to have an impact on the child's health, wellbeing or education, or which can be considered unsuitable in light of the child's circumstances.

Both acts specifically mention young carers for the first time. In the previous legislation young carers were mentioned as a vulnerable group but the right to assessment was dependent on two pre-requisites: the care provided had to be substantial and regular. What equated to regular and substantial care was open to local interpretation, which meant that in one area someone might qualify for an assessment, whereas they wouldn't in another area.

With the new legislation, there is clear accountability and responsibility for identifying young carers and for providing support to the whole family through joined up working across adult and children's services, health and social care.

The rationale of the new legislation: Investing in carers wellbeing and prevention is a worthwhile investment!

The main reason why the English legislator decided to change the legislation – for carers in general – is the understanding that **investing in carers wellbeing and prevention** work was a **worthwhile investment** ultimately reducing the cost to the state. A [2015 report](#) by Carers UK and Sheffield University revealed that carers save the UK £132 billion a year. The failure in early identification and support led to escalation of needs, with negative consequences not only on individual carers: Negative and costly impacts on carers' health and wellbeing, their education and employment outcomes but also on the finances of the State. In the case of young carers, there was evidence showing the very low percentage of young carers who were receiving an assessment of their needs. As stated by the National Young Carers Coalition in a [briefing](#) in 2013: "We strongly believe that reforming the law for young carers would not only improve identification and support for young carers which would have a positive impact on their long-term outcomes, but legislative reform would also reduce burdens on local authorities by preventing the risk of inappropriate caring and providing a clear framework for whole family support, at an ultimately lower cost to the state."

Paradigm shift: a whole family approach

Moreover, the government had received evidence that adult and children's law didn't join up, preventing whole family working. Young carers were supported in isolation, without their families receiving the right support. Very few young carers were identified and referred for support by adult's social care and health services, only 4-10% of referrals to young carers services were from adult social care*. This was not effective. Hence, a paradigm shift occurred: the approach to supporting young carers moved from supporting them separately from their family to supporting them through a 'whole family approach'.

The drivers of the change of legislation

Non-Governmental Organisations have played a key role in **raising awareness and campaigning for change**. They have also played a strategic role in steering and shaping public discourse and policy developments through engaging with policy-makers, politicians and young carers themselves. In order for them to be able to carry out this role, they have drawn upon **research findings** that are specific to their countries.

*https://www.childrenssociety.org.uk/sites/default/files/tcs/nycc_key_points_briefing_on_young_carers_the_care_bill.pdf

Chapter 3: Successful strategies to improve the mental health and well-being of young carers

Focus on Switzerland

The project partners interviewed 10 Swiss experts from the fields of academia, policy, health and/or social care on the topic of adolescent young carers and related topics. Interviews focussed on the visibility of young carers within Switzerland and the support provided to them.

Visibility and awareness of young carers

According to the experts, in Switzerland the visibility, awareness and understanding of young carers is low or invisible, at the local, regional and national level. Therefore, increasing recognition and awareness of young carers and their needs with professionals and families is required.

The term young carer is generally not known. Only people specialized in the field use it (interestingly, they tend to use the English term).

The idea that a child takes over care for their parents, siblings, grandparents etc. is practically not recognised. Few people talk about this topic and stigma remains.

Young carers often do not self-identify as carers, or, even if they do, they do not speak about it, they keep it private, for fear to be stigmatized and for fear that the authorities will find it out and take them away from the family.

Some experts mentioned that children with migrant backgrounds are more open to talk about their caring experience, as in their culture caring for family members is a common phenomenon. One expert was in partial disagreement and pointed out that – if the term young carer is viewed in a negative light in society – even children from migrant families will no longer be open to speak about their caring tasks.

The interviewed experts agreed about **the lack of awareness among professionals** from different backgrounds (healthcare, education, social service). The only exception is for children caring for someone with a mental illness, as for this specific case there is a little bit visibility.

There is little significant media coverage of young carers. Where there is, the focus is on younger children.

Things are likely going to change. Indeed, the Young Carers Research Group is developing a body of research evidence and this will hopefully result in increased visibility of AYCs. Thanks to these developments, it is likely that Switzerland will emerge higher in the next iteration of the classification proposed by Leu and Becker of in-country awareness and policy responses to 'young carers' (currently, it is at level 5 – emerging).

Available support

Young carers do not exist as a specific social group in Switzerland, hence there are no dedicated interventions for them. Support for (A)YCs comes through child protection routes and some more general interventions (for children and young people in general).

There are many platforms for young people, for example, [Pro Juventute](#), which is a charitable foundation dedicated to supporting the rights and needs of Swiss children and youth.

There are a few new, – mainly local – programs, aimed specifically at supporting (A)YCs, such as awareness raising activities in schools, where professionals discuss the issue of young carers with students.

Special programmes are well established for young carers who care for parents with mental health conditions. For instance, the foundation [Kinderseele Schweiz](#) is committed to ensuring that children of mentally ill parents can develop as well as unaffected children. They advise those affected, their social environment and professionals and provide help.

In the mental health field, the Open Dialogue Approach – where professionals work directly with the entire family (Family Approach) – could have the advantage of identifying young carers and reduce the care “burden” on them. Yet, this approach is underdeveloped and not yet accepted enough in Switzerland.

Evaluation of available support and future needs

The experts evaluated the current support system for young carers and, based on this analysis, identified key needs.

✓ **Caring role as an everyday phenomenon**

A huge challenge relates to the perception of **caring as something to be kept private**, hidden, for fear of being stigmatized or separated from the family.

Hence, it's important to make the issue visible and to remove any stigma attached to being a young carer. The focus should be on the fact that **caring is part of the human experience** and that there are positive aspects associated with it (providing care helps to build skills, to develop the ability to face situations and conflicts and to build relationships with others).

✓ **Empower professionals**

It is important to **empower professionals** from all sectors (education, social and health care), so that they can better identify and support young carers. Practical tools (e.g. guidelines, checklists) have to be provided to them.

✓ **Integrated work**

Currently, there are gaps between the healthcare system, the schools, the educational system and the social system, those are all very different entities with little inter-connections.

The experts called for better integrated work, for inviting all the relevant stakeholders from one region to meet and discuss the topic and find solutions together (along the lines of what has been done with the topic of children of parents with a mental health problem).

✓ **Whole family approach**

Services working with adult in need of care focus only on the adult, not on the network gravitating around him/her. As a result, young carers are invisible.

The experts called for a family approach, that could reduce the burden on (A)YCs.

✓ **Personalised support**

The experts stressed the need to accept the diversity of families. Young carers are not an homogenous group. Every child has his/her own story. Therefore, instead of creating one concept that fits all, it is better to provide personalised support, based on individual needs.

“But there are more and more children where one has to say that this is a very great diversity and one cannot meet this diversity by standardizing programs. And also not by doing an awareness raising campaign for every single life situation, but telling the people who work with them for example, hey, if you have a class, there are certainly 4,5,6 children, some are poor, others have a migrant background, the third have a parent at home they have to care for, the fourth have a disabled sibling, the fifth have an escape behind them, look at these children and look at what they need individually.”

✓ **Include young carers in existing interventions and programmes**

Rather than creating programmes specifically targeted at young carers, the experts recommended including them in the general offer of services. There was disagreement on the level of support currently provided: for

one expert, adolescents are not very well supported by Swiss society. On the contrary, another expert stressed that the “the variety of services that offer help for adolescents is quite respectable and the numbers too.”

✓ **Improving communication, promotion and access to support programmes**

The experts expressed concerns about how well known support programmes are within the general population.

“I really do think we are in a very good, very favourable situation in Switzerland or Central Europe in general. There are many offers, but what I notice, or what I feel is that communication or sometimes the accessibility of the one of the stakeholder group is often the biggest problem, so that it doesn't do much good if we have insanely good programs, if you don't bring them to the target group. I really think the big focus must be on communication work.”

✓ **Make special efforts to identify and support adolescent young carers**

The experts recognised that the difficulty in identifying young carers is even bigger in the case of adolescent young carers, because they are in transition from child to adult services. They typically don't see paediatricians anymore and they do not communicate their situation to their GPs. They have finished the regular nine school years and then typically start an apprenticeship or further schooling.

✓ **More funding for preventative services**

Foundations and organisations that could provide support to young carers are partly private and partly state-funded, but they are small and underfunded. According to the experts, more could be done if the law was changed to allow more funding for preventative services. Interventions should be funded by different sources (foundations, government, donors, health insurances...) to keep them independent. They can be financed from the welfare budget, but it should be a general financing, not a case financing.

✓ **Co-design the support with the young carers**

The support needs to be co-designed with young carers, to ensure that it fits their needs. In order to actively participate, young carers have to be properly informed.

The experience of other countries

The Me-We research study – with its cross-national comparison – allows us to provide an overview of possible strategies to identify and support young carers. The experience of other countries can be a great inspiration for Swiss policymakers and service providers (with due recognition of the specificities of the Swiss context underlined in the previous section).

Successful strategies to identify young carers

It's important for young carers to be noticed, rather than having to reach out themselves. Hence, the following measures can be applied:

Screening at schools and social/health settings

- Schools can play a vital role in early identification of young carers. In order to facilitate identification, tools such as MACA-YC18 could be used.
- Health care professionals/social workers – when coming into contact with an adult in need of care – could routinely ask whether the network around the adult includes children and whether they have any needs. They should follow up on a regular basis (as the disease evolves and so does caring).

Training for professionals

- Professionals (from the educational, health and social sectors) could receive training on young carers (on the challenges they face, measures to identify and support them, as well as effective ways to listen to them). Such education for professionals could be included in the professionals' basic education programs.

Raising awareness among professionals and general public

- The topic of unpaid caring, resilience and mental health or addiction could be discussed at school, so that they become less a taboo.
- The positive effects of caring activities could be promoted (providing care is an element leading to build skills, to develop the ability to face situations and conflicts and to build relationships with others).
- Awareness weeks in schools, sharing individual stories in lectures, television programs, social network campaigns are good ways for improving awareness and reducing stigma.

Successful strategies to support young carers with education

To ensure that young carers can complete educational programs and perform well, the main support measure is flexibility, which can have different values:

- understanding from teachers in case of lateness, absences, no homework done
- educational plan and learning activities more focused on (A)YCs needs

In addition to flexibility, schools can put in place extra, tailored support, to prevent drop-outs and to ensure a smooth transition to further education or work.

For example:

- Have counsellors that young carers can talk to one-to-one.
- Refer students to help services (e.g. sport club, youth club) and let them know that these support services exist.
- Apply to young carers special measures already existing for other groups (e.g. in some schools, children performing top sports have a special status, consisting in getting extra time for their exams and other favoured treatments). These measures could be extended to children/young people who have caring responsibilities.
- Envisage a psychological supervision in school, in order to support (adolescent) young carers in managing frustration, anger and the feelings raising from caregiving activities.
- Release a carers card so that young carers don't have to explain their situation every time.
- Offer tutoring
- To support young carers to enable them to make informed choices about which type of school to attend. Create an evaluation (and certification) system in order to enhance the soft skills gained by young carers, which can prove very useful on the labour market.
- Envisage flexible working conditions for young carers, e.g. by providing incentive for employers who hire teleworking carers with part-time working hours.

Successful strategies to support the mental health of young carers

Measures that can be implemented to support the mental health of young carers are exemplified below:

Peer/Group support/Information

- Set up young carers' groups, peer support groups, in order to provide children with the insight that they are not alone (this can also empower them).
- Provide young carers with the opportunities to take advantage from the experience of former young carers (via mentoring or coaching).
- Improve access to information on the available support (e.g. inform teachers, GPs and social workers about local activities to support young carers).

- Give young carers enough space to share their emotions and frustrations, also when they do not necessarily seek practical support to 'fix' their situation. Such space and recognition may be important in a professional context, for example within their school, but even more so within their personal environment.

Provide respite breaks for young carers

- Organise summer camps, school camps, cinema, café, sport activities to remove the young person from the "pressure cooker"
- Give young carers a break from caring, let them have fun and get in contact with peers.
- Assist them with the financial cost so they can participate in these activities

Increase resilience

- Allow young carers access to tools and support to find useful coping strategies. Building young carers' resilience also has the advantage of reducing the dependency of young carers onto formal support services, particularly in times of budget cuts and reduced services available.
- Psychoeducation may be a useful tool to increase resilience.

Successful strategies to engage with young carers

Young carers need to be involved in all decisions that affect them. In order to actively participate in decision processes, they have to be informed. Their rights have to be taken seriously and their opinion listened to.

The following strategies can be implemented:

- Provide adolescent young carers with information, e.g. about the parent's illness, as well as what support they can get and how to access it.
- Ensure that care assistance staff, health care staff, social workers, teachers and parents know how to communicate with children in a child/youth friendly and respectful way.
- Co-design the support with young carers, to ensure that it fits their needs. A tailor made support can make families and children better off here and now – and prevent the problems from being passed on to the next generation.

Nothing about us without us!

The Me-We project applies the **co-design approach** we advocate for, by encouraging direct participation by end users (adolescent young carers, education/care professionals and policy makers) and by fostering collaboration amongst stakeholders.

In line with the co-design approach, all project partners have set up Blended Learning Networks, i.e. heterogeneous 'communities of practice' involving adolescent young carers and relevant stakeholders. These actors, sitting together at one table, have to find the best solutions (e.g. they are actively engaged in all the project activities, in particular in planning the interventions and in the development of an app for adolescent young carers).

Another channel that has ensured the active involvement of young carers in the Me-We project activities has been the establishment of links with the Eurocarers Young Carers Working Group.

The Eurocarers Young Carers Working Group is a platform bringing together young/adult carers and former young carers from different countries. It was established in 2017, building on the incredible energies shared during the International Young Carers Conference (May 2017, Malmö, Sweden). Currently, there are 27 members from 10 European States and one from Australia. The aim is to combine efforts and resources, so that young carers' voices are heard and policies and practice are put in place all across Europe to empower and support them.

Four members of the Young Carers Working Group are part of the International Advisory and Ethics Board, on an equal footing with the other experts. Furthermore, the members of the Eurocarers Young Carers Working Group have regularly had the opportunity to give their perspective and feedback on the project activities.

Chapter 4: Translating research findings into policy

Recommendations tailored to the Swiss context

Many of the experts interviewed in our study stressed that caring is seen as a private issue by Swiss families. It is important to break this taboo: caring, rather than being **a hidden, 'private' issue, has to become the focus for public policy and intervention (the personal is political)**.

In Switzerland, there is a growing political interest towards informal carers. The "Report on supporting people looking after and caring for relatives" – published by the Federal Council in 2014 – is evidence of this trend. The Federal Council recognises the important role in society played by informal (unpaid) carers. With an ageing population and a lack of resources, this is a role that will become even more important in the future in meeting the increasing demand of long-term care. Initial and nonetheless important steps on the path towards recognition and support of unpaid carers have been taken.

- 1) We call on policymakers to be innovative and implement a **strategy to support carers of any age**. Such a strategy will **adopt a life-course perspective** to caring, because in every life-phase one can be a carer.
- 2) We recommend to **extend/amend existing non-specific legislation/policy** so that young carers can be identified, recognized and supported. In particular, we recommend strengthening **the focus on prevention**, which is currently lacking.
- 3) **We call for service providers to include young carers among the target groups of their activities.** As highlighted by the experts, for the support to be effective, the following elements have to be satisfied:
 - A joined-up approach is needed, with different stakeholders (from educational, social, health care, NGOs, policy) working together.
 - A whole family approach should be adopted.

- The support needs to be tailored to the specific needs of each individual.
- Young carers need to be actively engaged in designing and implementing their support.
- A rights-based approach should inform every decisions by service providers (including the determination of the best interest of the child).

The experience of other European countries tells us that country specific research and the presence of championing NGOs are key drivers to bring about change in policies and practice on young carers (Becker & Leu, 2016). Therefore,

- 4) We call for **further research on young carers**, which will allow to make better decisions on the type of support needed by young carers and in this way make evidence-based changes to the legislation/policy.
- 5) We stress the urgent need of a **large-scale awareness-raising** exercise among health, education, social care practitioners, policy makers and society as a whole. NGOs could play a key role, if adequately supported by state funding.

A joint effort by each member of our society will ensure that we **move forward** in our vision: one where young carers can fully enjoy the human rights they are entitled to.

Recommendations at European level

At European level, the need to take action to support and empower young carers is increasingly recognised.

The European Network of Ombudspersons for Children – in their [statement on child mental health](#) adopted on 21 September 2018 – has stressed the importance of support programmes to better enhance and protect the mental health of young carers.

The European Parliament, in the [Report on Care services in the EU for improved gender equality](#) - approved on 15 November 2018 – calls on the Commission and the Member States to **undertake research on the numbers of young carers and on the impact of this role on their well-being and livelihoods** and, on the basis of this research, to **provide support** and address the specific needs of young carers, in cooperation with NGOs and educational establishments.

The actions recommended to the Swiss policy-makers can be complemented by actions taken at European level.

- Support **further research** on the profile and needs of young (adult) carers; Gather an insight into actual numbers.
- Ensure existing **good practice is disseminated** and made visible across Europe; Make comparisons with what is happening in other countries to support developing practice and legislation.
- **Include young carers** in the European Youth Strategy or EU agenda on higher education and other relevant policy dossiers.
- **Listen to young carers.** Along the lines of the Europe kids want, envisage platforms/opportunities to have meaningful participation of young carers.
- **Make use of instruments at hand** – i.e. European Semester, European Pillar of Social Rights, European Structural and Investments Funds, European Youth Strategy, EU agenda on higher education European Platform for Investing in Children, Youth Guarantee and Open Method of Coordination – to promote the development of integrated approaches for the identification, support and social integration of young (adult) carers across Europe.

The Principles	The relevance for young carers
Principle n. 1 – Education, training and life-long learning	Caring responsibilities can have a negative impact on young carers' education (under-achievement, absence and drop-outs)
Principle n. 4 – Active support to employment	Young carers are more likely to be NEET (not in education, employment or training) than their peers.
Principle n 11 – Childcare and support to children	Young carers need to be considered as children from disadvantaged backgrounds —→ have the right to extra, tailored support so that they can have equal opportunities in enjoying social rights.
Principle n. 18 – Long-term care	By providing good quality formal LTC services to the person they care for, inappropriate caring can be avoided.

Figure 2 - The European Pillar of Social Rights and its relevance for young carers

It is the role of policy makers to prevent and minimise the (potential) negative impacts of growing up while being a carer (restricted education, reduced life chances, affected well-being, isolation) and to enable young carers to thrive and flourish as human beings.

The life chances of thousands of children across Europe are at stake. There is no time to lose.



Einblick in die nationalen Forschungsergebnisse / Insight into the national research results

Prof Dr Agnes Leu, Marianne Frech, Sarah Rabhi-Sidler, Fabian Berger

Young Carers in Switzerland

2014

2016

Sub-project 3

"Awareness training for health, education and social services professionals"

...

Awareness training for health and social services professionals"

2017

Sub-project 4

"Survey of school pupils" for
Age 10-15 years

...

Representative survey on the needs of carers for family members"
Age 9-x years

2017-2019

Sub-project 7-9

"Young Carers and Young Adult Carers between school, education and work"

2018

Sub-project 5

"Young Carers and Young Adult Carers and the relatives they care for"

...

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- Ebnet Foundation
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- Federal Office of Public Health
- Ebnet Foundation, Beisheim Foundation, Gesundheitsförderung Schweiz
- Swiss Health Observatory (Obsan)
- Horizon 2020, European Union



Survey with Professionals

Ziele / Study aims

- to examine the awareness of young carers amongst Swiss professional populations
- to examine how often they encounter young carers in their professional context
- to identify their ability to support young carers
- to examine the support needs of young carers and the training needs of professionals

Auswahl & Methode / Sampling & Method

Sample

- Convenient sample among professionals from health care, education & social services, Swiss wide

Data

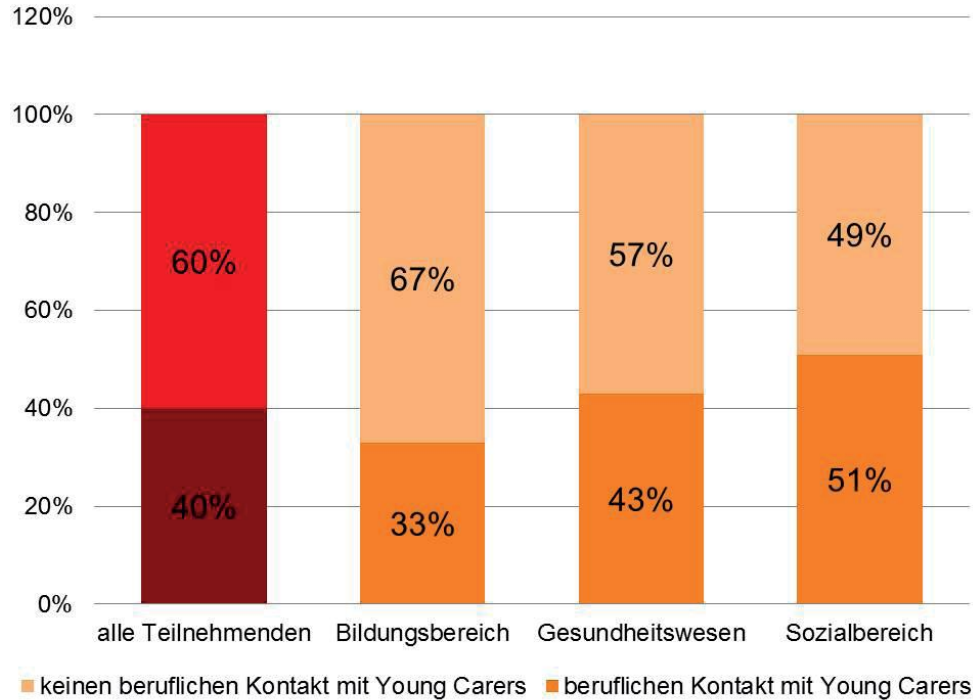
- Cross-sectional online survey

Analysis

- Statistical analyses were conducted with IBM SPSS Statistics 25

Ergebnisse / Results

Beruflicher Kontakt mit Young Carers / Occupational encounter

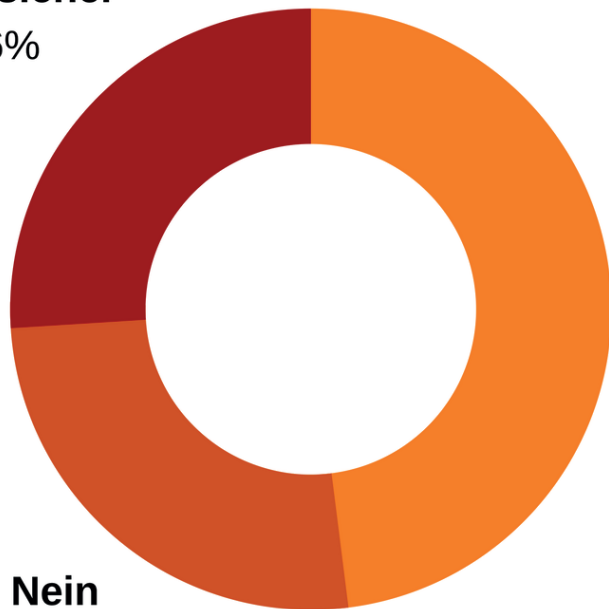


Ergebnisse / Results

Sich fähig fühlen Young Carers zu unterstützen / Ability to support

Nicht sicher

26%

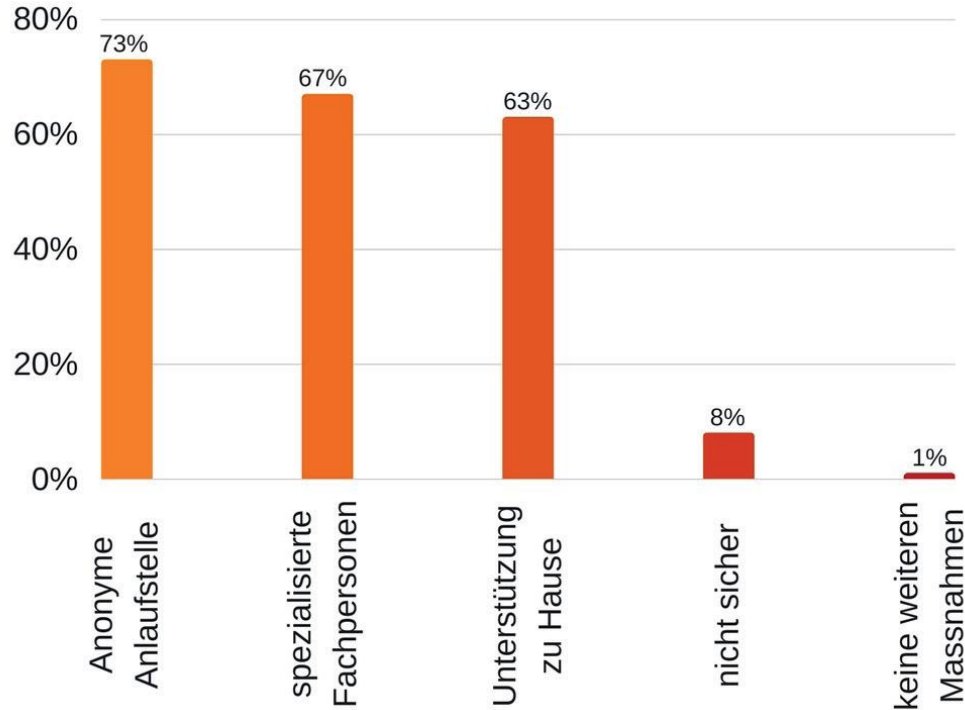


Ja
48%

Nein
26%

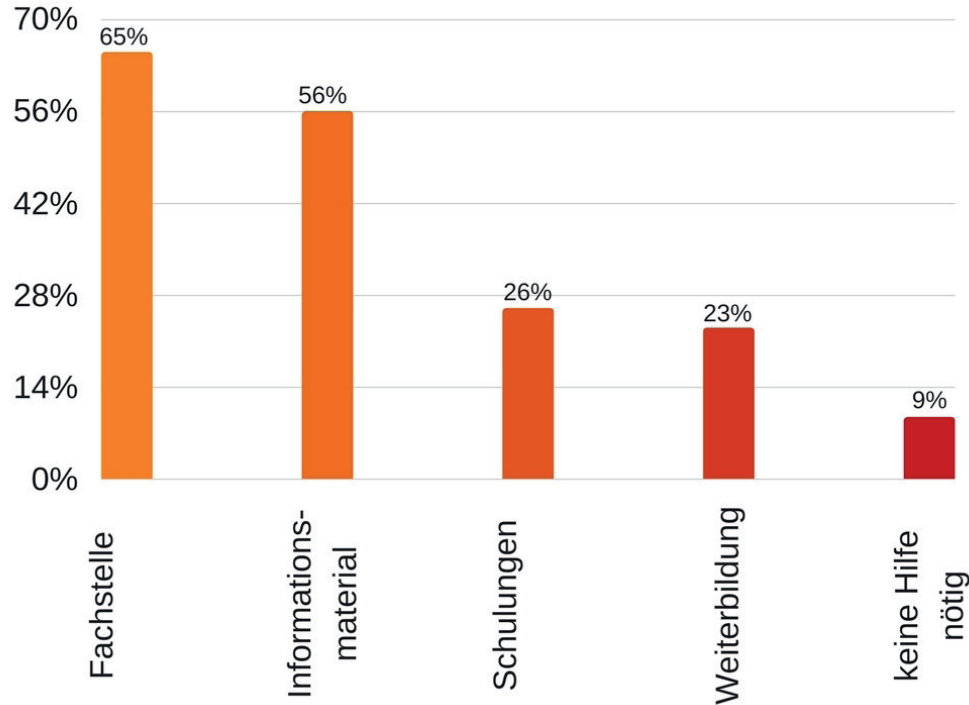
Ergebnisse / Results

Wünschenswerte Unterstützung für Young Carers / Support needs



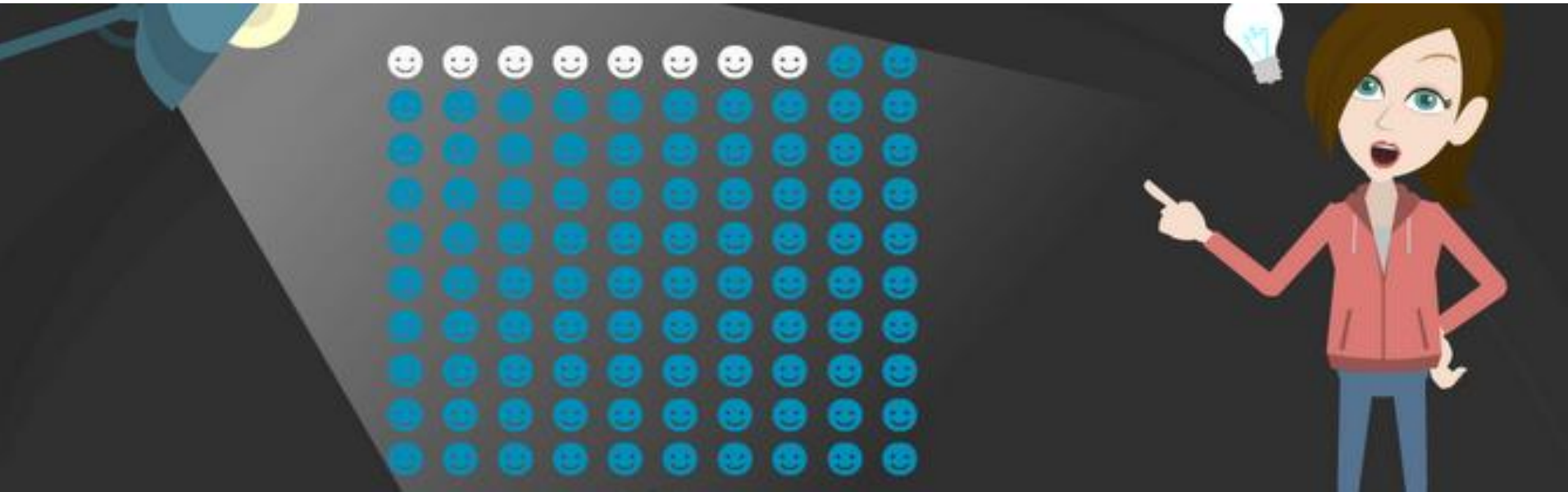
Ergebnisse / Results

Hilfestellungen für Fachpersonen / Training needs of professionals



Schlussfolgerungen / Conclusion

- Young carers are often not recognised and therefore are overlooked by professionals.
- *Familiarity, relevance* and *identification* represent key factors describing the level of awareness of Swiss professionals' on young carers.



Counting Young Carers

Ziele / Study aims

- to estimate the prevalence of young carers (aged 10 to 15) in Switzerland
- to identify the characteristics of those young carers e.g. gender distribution, age, age at which they started caring
- to examine the extent of caring
- to explore any associations between the extent of caring and wellbeing

Auswahl & Methode / Sampling & Method

Sample

- Random Sampling (2-stage process)
- 711 schools grades 4 to 9 were selected

Data

- Multidimensional Assessment of Caring Activities (MACA-YC18)
- KIDSCREEN10 measure of wellbeing

Analysis

- Complex sample analysis to extrapolate to general population – descriptive and inferential statistics

Ergebnisse / Results

Dankesvideo (D, F, I)
/ Video with results



<https://www.kalaidos-fh.ch/de-CH/Forschung/Fachbereich-Gesundheit/Young-Carers/Umfragen/Ergebnisse-Schule>

Schlussfolgerungen / Conclusions

- The prevalence of young carers aged 10 to 15 in Switzerland is 7.9%. This is equivalent to 38,400 children.
- Extrapolating the prevalence to children aged 9 to 16, the data suggests that 51,500 are young carers.
- There is no clear association between extent of caring & wellbeing.
- *Research data provides important data for professionals & policy makers in order to develop specific young carers support services.*
- *Our further research needs to look at outcomes of young carers in more detail.*



Interviews with Young Carers & their Families

Ziele / Study aims

- to consolidate and validate the findings of the other work packages
- to hear directly from care-dependent family members and younger carers about their experiences of the issues identified in the surveys and in previous published research

Auswahl & Methode / Sampling & Method

Sample

- 34 interview with young carers and/or with their care recipient or healthy parents in 20 families

Data

- Semi-structured interview at a place of the participant's choice
- Socio-demographic information and MACA checklist

Analysis

- Content analysis using MaxQDA (Kuckartz, 2014)

Ergebnisse / Results

SOC-Dimension	Young carers	Social network	Professionals
Comprehensibility	Health Literacy	Relationship CR Adults as confidants Peer support	Information
Manageability	Coping strategies Competence Education	Relationship CR Peer support	Trustful relationship Support
Meaningfulness	Seeking Normality Competence	Relationship CR	

Schlussfolgerungen / Conclusion

- Seeking normality: young carers will hardly expose their situation to others.
- The caring tasks of young carers needs to be manageable.
- Both sides of the caring relationship between young carers and care recipient expressed their need for more help for the other person.
- Young carers and their care recipient accentuate the importance of trust to professionals.

International Advisory Group

- **Prof. Luke Clements**, Professor of Law at Cardiff Law School, Director of the Law School's, Cardiff University (UK)
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- **Agnes Lundström**, National Board of Health and Welfare, Stockholm (S)
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- **Prof. Gisela C. Schulze**, Director Graduate School of Social Sciences and Humanities, Universität Oldenburg (D)

Literatur / Selected Publications

- Leu, A., Frech, M., Wepf, H., Sempik, J., Joseph, S., Helbling, L., Moser, U., Becker, S., Jung, C. (2019). Counting Young Carers in Switzerland – A Study of Prevalence. *Children & Society*, 33(1), 53–67. <https://doi.org/10.1111/chso.12296>
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- Leu, A., Frech, M., & Jung, C. (2018). Young carers and young adult carers in Switzerland: Caring roles, ways into care and the meaning of communication. *Health & Social Care in the Community*, 26(6), 925-934. [doi:10.1111/hsc.12622](https://doi.org/10.1111/hsc.12622)
- Leu, A., Jung, C., Frech, M., Sempik, J., Moser, U., Verner, M., & Becker, S. (2018). Study protocol: young carers and young adult carers in Switzerland. *BMC Health Services Research*, 18(1), 183. [doi:10.1186/s12913-018-2981-5](https://doi.org/10.1186/s12913-018-2981-5)

Was kommt als Nächstes? / What's next?

- Get-together/ Blended Learning Networks
- ME-WE Intervention



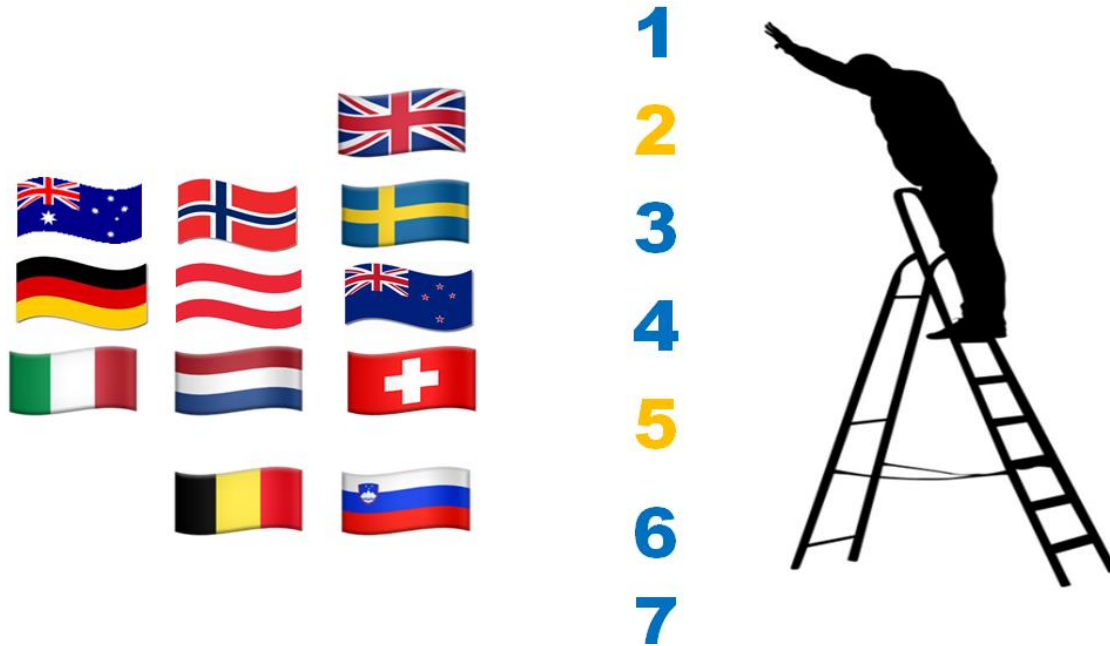
- Prototyp Netzwerkkarte/ Homepage



Young Carers im internationalen Vergleich / Research & policy – an international comparison

Internationale Klassifikation / International classification

Leu A., Becker S. (2016)



LEU, A., BECKER S. (2016). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, 1-13.

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<https://blog.careum.ch/young-cares-end-of-project-conference/>
[https:// www.careum-hochschule.ch/Young-Carers](https://www.careum-hochschule.ch/Young-Carers)

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Literatur / Selected Publications

- Aktuelle Publikationsliste / Full publication list:

<https://www.kalaidos-fh.ch/en-GB/Forschung/Fachbereich-Gesundheit/Young-Carers/Publikationen>

Counting Young Carers in Switzerland – A Study of Prevalence

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An online survey of children in school grades 4–9 (mostly aged 10–15) was conducted in order to determine the prevalence of young carers in Switzerland using a 2-stage stratified sampling approach. 4082 respondents were drawn from 230 schools. A total of 3991 respondents were included in the analysis and of these 307 (7.7%) were identified as young carers. The population estimate of prevalence was 7.9 per cent. This suggests that there are around 38 400 young carers in school grades 4–9 in Switzerland. Extrapolating to the 9–16 age group gives a figure of almost 51 500. © 2018 The Authors. Children & Society published by National Children's Bureau and John Wiley & Sons Ltd.

Keywords: MACA, prevalence, well-being, young carers.

Introduction

Children and adolescents who provide regular support and care for ill or disabled family members are now becoming increasingly recognised in research and subsequent policy responses (Day, 2015; Hamilton and Cass, 2017; Phelps, 2017). Despite a number of definitions in use, most have the following in common: young carers are young people under 18 years old who provide care, assistance or support to another family member, often on a regular basis. They take on significant or substantial caring tasks and levels of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or another relative with a disability who has some chronic illness, mental health problem or condition requiring care, support or supervision (Becker, 2000, p. 378). Recent conceptual research from Switzerland highlights the importance of 'having a common definition' of (young) carers in order to facilitate their identification, as well as to have a common basis in research (Frech et al., unpublished data; Wepf and others, 2017).

Some countries, including Norway, Sweden, Germany and Austria are now actively engaged in identifying and supporting these 'young carers'. At present, however, the UK is the only country to have reached an 'advanced level' of awareness and recognition of the issue among professionals, policy-makers and the public (Leu and Becker, 2016).

The circumstances of younger carers, young adult carers and their families have only recently been the subject of research in Switzerland. The first qualitative data are now available on their caring activities and support needs (Leu and others, 2018). This shows that different definitions and terminologies are being used for children with ill parents or siblings, but very seldom are they referred to as 'young carers'. The research highlights the importance of raising awareness among professionals so that appropriate support can be provided.

At present, there is no national dedicated young carers' support framework in Switzerland that could assist these young people.

Research on these young people is challenging because they often do not recognise themselves as caring relatives or identify themselves as such (Cass and others, 2009; Noble-Carr and Woodman, 2016). This lack of self-identification combined with a low level of awareness among professionals from healthcare, education and social services (Leu and others, 2018) is one of the reasons for a lack of sustainable policies and intervention strategies (Leu and Becker, 2016), and such is the case in Switzerland.

Most existing studies of young carers are qualitative by nature, exploring their lived experiences, the amount and extent of care they provide, their needs and the effects that the caring role can have on their lives (Aldridge and Becker, 1993; Bibby and Becker, 2000; Dearden and Becker, 2000; Devine and Lloyd, 2008; Frank, 1995). They also show, for example the time spent caring and differences in the amount of caring between different age groups (Moore and McArthur, 2007; Nagl-Cupal and others, 2012). The first qualitative study on young carers in Switzerland illustrates the broad variety of their caring roles (Leu and others, 2018). Until now, previous Swiss studies have focused primarily on the circumstances of children with parents with a mental illness, but without exploring in depth the caring responsibilities of those children (Albermann and others, 2012; Gurny and others, 2007). This new research provides a deep insight into the lives of young carers and the challenges they face. For policy-makers, stakeholders and researchers, this is useful in helping them to develop support structures and projects. However, in order to develop appropriate and effective support on a national scale it is necessary to know how many young people have caring responsibilities.

At present, there are few large-scale surveys which provide information on the actual numbers of young carers (Lloyd, 2013; Nagl-Cupal and others, 2014; Stamatopoulos, 2015). Those that have been conducted show, that in industrialised states, on average, at least 2–4, sometimes up to 8 or more per cent of all children and adolescents under 18 years have caring roles; and in the age group of 18- to 25-year-olds the figure is higher. One of the first sources of information on prevalence was the UK Census in 2001 which estimated that approximately 2 per cent of children between 5 and 17 years had a caring role (Becker and Becker, 2008).

These findings should be treated with caution since the census required parents to disclose the caring role of their children. For various reasons, they may have been reluctant to do so and the results, therefore, underestimate the number of young carers (Lloyd, 2013). In a subsequent survey conducted by Becker and the BBC in the UK (Howard, 2010), pupils in ten secondary schools were asked to self-disclose their own caring roles. The findings of that survey suggested that 8 per cent of children had a caring role. However, full details of the methodology used were not published.

In Germany, the first prevalence study was conducted in 2016. It was estimated that 5 per cent of children and young people aged between 12 and 17 years were young carers (Lux and Eggert, 2017). In Austria, Nagl-Cupal and others (2014) reported that 4.5 per cent of children had a caring role. In her study of young carers in Northern Ireland, Lloyd (2013) found a prevalence of 12 per cent among children aged 10 and 11. These and other studies underline, that in all researched countries, a substantial number of children provide care on a regular basis (Table 1). The choice of method will affect the accuracy of the estimate of prevalence.

In a large English interview study of 378 participants, the researchers found 9 per cent of children and adolescents who identified themselves as young carers (Warren and Ruskin, 2008). The first prevalence study in Germany, conducted in 2016, estimated that 5 per cent

Table 1: Prevalence of young carers in Europe

United Kingdom	Switzerland	Netherlands	Sweden	Italy	Austria	Germany
8% 11–18 years	7.9% 10–15 years	6% 13–17 years	7% 14–16 years	7.2% 15–24 years	4.5% 10–14 years	5% 12–17 years

of children and young people between 12 and 17 years were young carers (Lux and Eggert, 2017); and in Austria in 2012, Nagl-Cupal and his co-authors reported that 4.5 per cent of children had a caring role (Nagl-Cupal and others, 2012, 2014). In her study of young carers in Northern Ireland, Lloyd found a prevalence of 12 per cent among children aged 10 and 11 (Lloyd, 2013). These and other studies underline, that in all researched countries, a substantial number of children provide care on a regular basis. Additionally, research from different countries has shown that young women are over-represented as young carers. For example in their survey of children in Austria, Nagl-Cupal and others (2014) showed that around 70 per cent of young carers were female; and Sempik and Becker (2013) found a similar percentage among young adult carers (aged over 14) who were still at school. So the responsibility for care appears to lay more heavily on young women.

The choice of method will affect the accuracy of the estimate of prevalence. For our first large scale study on young carers in Switzerland, we wanted to use a method that was as precise as possible in order to give policy-makers the most accurate estimate of young carers. We conducted an online survey of pupils in primary and secondary schools using a systematic random sample that allows for statistical inference to the underlying population in order to provide an accurate estimate of the number of young carers in Switzerland.

At present, there is no data on the prevalence of young carers in Switzerland, neither (to our knowledge) has there been any other research (qualitative or quantitative) which has explored the lives of young carers in Switzerland. In their analysis of policy responses of different countries to the issue of young carers, Leu and Becker (2016) make the point that policy responses are heavily influenced by national research. However, they were unable to identify any relevant findings from Switzerland.

In this paper, we present the first estimate of the prevalence of young carers in Switzerland and show whom they care for, their age, gender, extent of caring and the link between caring and well-being.

Methods

Questionnaire

A short online questionnaire was created. This was hosted by a commercial provider (Survey Monkey). The questionnaire collected demographic information including age, gender, school grade and school, the household composition, whether they had siblings, their place of birth and the languages spoken. Participants were also asked whether they provided regular support for a friend or relative. ‘Some children and adolescents do have a family member or friend who needs support on a regular basis, e.g. because he/she is ill. Do you support someone on a regular basis?’ and the reason(s) for that support as an open question (‘Why do(es) the person (or these persons) need your support?’). Using a pre-defined coding schedule, the responses were coded into two categories: 1 = young carer; 0 = not a young carer. Those whose responses showed clear evidence of a caring role (e.g. providing regular care for a parent with cancer, addiction, or a mental health problem) were coded as 1 (i.e. a young carer), and those with no evidence of a caring

role or whose responses were too ambiguous or vague to provide clear evidence of care (e.g. 'I like to help') were coded as 0 (i.e. not a young carer). The rating was carried out by two researchers working independently. The interrater-agreement of the two initial ratings was acceptable (Kappa = 0.89). The differences between the two ratings (in 27 cases) were then compared and discussed to find a consensus. The final results of the rating were used to determine young carer status.

The questionnaire included a German, French and Italian version of the Multidimensional Assessment of Caring Activities (MACA-YC18, Joseph and others, 2012) which is an 18-item inventory of caring activities undertaken by children and young people. The MACA provides a total sum score (range 0–36) and domain scores (range 0–6) for domestic, emotional, financial, household, personal and sibling aspects of care. Translation of the MACA was discussed with the authors of the original instrument and the versions used in this study were deemed to be acceptable. The internal consistency reliability of the total scales (Cronbach's Alpha = 0.79) was satisfactory and comparable to the one reported in the validation study by Joseph and others (2009).

The KIDSCREEN-10 index was included as a measure of subjective well-being. This is a health-related Quality of Life Questionnaire (HRQoL) for children and young people (The KIDSCREEN Group Europe, 2006) and is available in all three languages (German, French and Italian). The KIDSCREEN-10 instrument has previously been used in a similar school survey aimed at identifying young carers (Schlarmann and others, 2008). The version of the questionnaire used in this study was a shortened form developed from the 27-item scale that provides a total sum score (range 10–50) with a higher score indicating greater well-being. The authors of the KIDSCREEN-10 index report a good internal consistency reliability (Cronbach's Alpha = 0.82) and test–retest reliability/stability ($r = 0.73$; ICC=0.72). The internal consistency reliability of our data was identical to published values (Cronbach's Alpha = 0.82). The raw scores were transformed using the Rasch model estimates as described by the authors of the instrument (The KIDSCREEN Group Europe, 2006) and T-values were calculated.

The questionnaire also collected demographic information including age, gender, school grade and school, the household composition. It was initially piloted with eleven children in different language regions.

During the pilot phase, we paid special attention to the wording of the questions to ensure they were understood correctly. We then edited the questionnaire according to the pilot results, and discussed any changes with native speakers and the translators in order to produce a correct translation. The changes were also discussed and agreed with the developers of the MACA and with the KIDSCREEN Group. The KIDSCREEN Group now offers Swiss language versions of their instruments.

Sampling

A 2-stage, stratified sample design was used in order to reach children in school grades 4–9. In Switzerland, grades 4–6 are for primary education and grades 7–9 for lower secondary education. These grades cover the population of 10- to 15-year-olds but also include a small number of children aged 9 and 16 years. Students in special-needs schools and classes were excluded, as were those in private schools; these make up only around 3–4 per cent of children in those grades.

The first-stage sampling units consisted of individual schools with students in the required grades. These schools were sampled systematically from a list provided by the Swiss Federal Statistical Office (FSO).

The Schools were divided into eight groups (explicit stratification) using information on grades (primary education vs. lower secondary education) and the school's language (German, French or Italian). The following eight groups of schools were created:

- German speaking (excluding Zurich), primary education
- German speaking (excluding Zurich), lower secondary education
- Canton of Zurich, primary education
- Canton of Zurich, lower secondary education
- French speaking, primary education
- French speaking, lower secondary education
- Italian speaking, primary education
- Italian speaking, lower secondary education

The sample was allocated proportionally to these 8 strata, that is a sub-sample of schools was drawn from each group in proportion to its student population in grades 4–9.

The canton of Zurich forms a separate strata because authorities only allowed for drawing a limited number of schools from this region ($n = 60$). But as the limitations of the authorities only concerned the number of schools and not regions or specific schools within the canton, we believe, this did not affect the overall quality of the sample, only its size. The Italian-speaking region was slightly oversampled due to its relatively small size.

The explicit stratification used in the sampling increases the precision of the estimates of prevalence in the event that language region and student age are related to caregiving. Before drawing a sample of schools from each of the eight groups, the list of schools for each group was also sorted (implicit stratification) by canton, school size and school type (in the case of lower secondary education). This implicit stratification further tended to distribute the sample within the explicit strata across cantons and schools having different sizes and requirements. Then, schools were sampled using probabilities proportional to that school's estimated number of study-eligible students (Probabilities proportional to size; Kish, 1965).

Schools identified by the sampling process were contacted and invited to participate in the study. Of these 711 selected schools, 230 agreed to take part. Since the survey was not compulsory the response rate of schools (32%) was not very high.

Assuming an average classroom size of about 17 pupils and sampling one classroom per school, 711 schools were sampled initially to yield a target student sample of approximately 12 000 students. All participating schools were asked to submit classroom lists for grades 4–6 (primary education) or grades 7–9 (lower secondary education). The second-stage sampling consisted of sampling 1 classroom per participating school using simple random sampling (see, e.g. Lehtonen and Pahkinen, 1995). The teachers of the sampled classrooms were contacted and instructed regarding how to participate in the survey. Short video clips in German, French and Italian were provided for teachers and pupils (<http://www.careum.ch/yc/umfrage-videos>). Pupils received assurance of granted anonymity.

In contrast to high non-response rates at school level, within the participating schools, the non-response rates were very low and almost all students attempted the survey. The overall response rate for students within participating schools was 94 per cent when conducting the survey. The survey was not obligatory either for the schools or for the pupils. Schools that decided to take part in the survey were closely monitored by the research team who contacted the teachers regularly by email and phone. A 'hotline' was available for real-time support. The final sample size was $N = 4082$ students.

Following standard procedures (Lohr, 2010; OECD, 2014), the inverse of selection probabilities, in combination with non-response adjustments at both sampling stages, were used to

calculate sampling weights. Survey weights ensured that each sampled student represented the appropriate number of students in the population and, hence, allowed for the calculation of accurate population estimates (Lohr, 2010).

The weight W_{ji} for student i in school j consisted of 2 base weights, the school base weight and the within-school base weight, and 2 adjustment factors, and it can be expressed as:

$$W_{ji} = w_{1j} \cdot w_{2ji} \cdot f_{1j} \cdot f_{2ji}$$

where w_{1j} , the *school base weight*, is the reciprocal of the probability of including school j in the sample; w_{2ji} , the *within-school base weight*, is the reciprocal of the probability of including student i from within the selected school j in the sample; f_{1j} is an *adjustment factor* to compensate for *non-participation of schools using other schools* that are in the same explicit strata; f_{2ji} is an *adjustment factor* to compensate for *non-participation of students using other students* that are within the same classroom.

Statistical analysis

Responses to the survey were downloaded as a Microsoft Excel spreadsheet and then prepared for analysis. IBM SPSS Statistics (ver. 24.0, Armonk, NY: IBM Corp.) was used to provide descriptive statistics, including frequency, mean and standard deviation. The following inferential tests were used on the sample: Student's t -test; chi-squared (χ^2); and bivariate correlation (Pearson's coefficient) as appropriate. The complex sample analysis functions of SPSS were used with the sample weights described above for population estimates of frequencies and means and measures of their dispersion. The level of statistical significance was set at $P \leq 0.05$.

Ethical approval

Ethical approval for the study was obtained from the Zurich canton ethics committee (No. 85-2015). Information about the study was provided to schools, students and parents before conducting the survey. Parents were asked whether they had any objections.

Informed consent

Prior to conducting the survey, we provided written information about the study to schools, pupils, as well as to parents. Parents were able to refuse their children's participation in the study. Additionally, pupils were informed by their teachers using an introductory video suitable for the age group that participation in the study was voluntary and that they could abandon the questionnaire at any time without facing any negative consequences. Before the survey was conducted, pupils again received information about the study and the handling of the data, that is anonymisation and confidentiality.

Results

Participants

A total of 4082 respondents attempted the questionnaire. Twenty-seven participants with incomplete questionnaires (i.e. too little data for inclusion in any analysis), and 19 participants with 'frivolous' answers (e.g. including jocular responses or incomprehensible character strings in open-response questions) were excluded because these answers were not considered reliable. In addition, 45 participants were excluded because they were outside the defined age range for the study (9–16 years). The final sample for analysis consisted of 3991 respondents.

The gender distribution of the sample was approximately equal with 1926 (48.3%) males and 2025 females (50.7%); 40 respondents (1%) did not give their gender. The mean age was 12.9 (SD = 1.7). Of those completing the survey, 3313 (83%) completed in German; 473 (12%) in French and 205 (5%) in Italian. Analysis by language was not carried out because of the disparity in group sizes and small size of the Italian-speaking group. Ethnicity of the respondents was not collected.

Prevalence of young carers

Using the method described above, 307 respondents were classed as 'young carers' and comprised 7.7 per cent of the sample. When extrapolated to the general population using complex sample analysis (i.e. incorporating the sample weighting as described above) the prevalence was 7.9 per cent. Sample results and population estimates are shown in Table 2, and the process is summarised in Figure 1.

Therefore, a prevalence of 7.9 per cent was estimated for the population of children in school grades 4–9 in Switzerland. These grades largely represent the 10–15 age group but also include some outside this range. Sample participants ranged in age from 9 to 16; with 1.5 per cent aged 9 and 4.9 per cent aged 16.

Our estimates suggest that there are around 38 400 young carers in school grades 4–9. If we apply the same prevalence to the population of children aged 9–16 (approx. 651 459) (Federal Statistical Office, 2017) in Switzerland, we estimate that there are around 51 500 young carers in this age group. Some caution is necessary here since the prevalence of young carers does vary with age. However, when we excluded 9- and 16-year-old respondents from our analysis, we obtained a sample prevalence of 7.7 per cent (no change) and a population estimate of 8.0 per cent (an increase of 0.1 percentage points). Hence, within this limited age range, the change in prevalence with age may be small.

Characteristics of young carers

Age

The mean age of those identified as young carers in the sample was 12.6 (± 1.8) years; for the population, it was estimated at 12.3 years (95% CI = 12.1–12.5). The mean age at which they started their caregiving role was 9.2 (± 2.9) for the sample and 9.0 (95% CI = 8.6–9.3) for the population.

There was no significant difference in age between male and female young carers in the sample (both had a mean age of 12.6 years; $t_{301} = 0.156$; $P = 0.876$); and in the age they started their caring role (9.0 ± 3.0 and 9.3 ± 2.9 , respectively, for males and females; $t_{303} = 1.043$; $P = 0.298$).

Table 2: Prevalence of young carers in the sample and population estimate

	Sample		Population estimate (10- to 15-year-olds, Swiss-wide)							
	Frequency	Per cent	Estimate	Standard error	95% confidence interval		Per cent	Standard error	95% Confidence Interval	
					Lower	Upper			Lower	Upper
No caring role	3684	92.3%	410 868	4330	402 335	419 401	92.1%	0.7%	90.7%	93.3%
Young carer	307	7.7%	35 352	2906	29 625	41 079	7.9%	0.7%	6.7%	9.3%
Total	3991	100.0%	446 220	3264	439 787	452 652	100.0%	0.0%	100.0%	100.0%

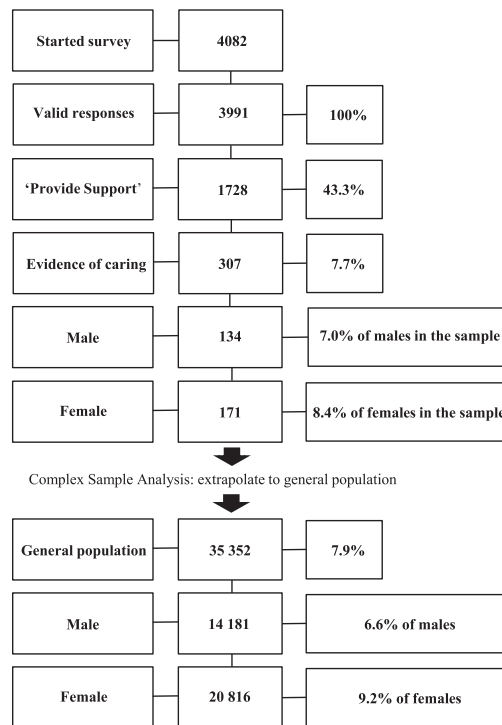


Figure 1. Flow chart of survey results.

Note. The sum of estimates of male and female young carers in the general population are lower than the estimated total since calculation of the total population estimate also included respondents who did not give their gender.

Similarly, for the population estimates, there was no significant difference in mean age between genders (12.4 for males and 12.3 for females; $t_{146} = 0.671$; $P = 0.503$); and in the age at which they started their caring role (8.9 for males and 9.0 for females; $t_{147} = 0.159$; $P = 0.874$).

Gender

Although a slightly higher proportion of females in the sample were identified as young carers (8.4% compared with 7%), the difference was not statistically significant ($\chi^2(1) = 2.859$; $P = 0.091$). For the population, the estimate was 9.2 per cent for females, and 6.6 per cent for males. The odds ratio for the likelihood of being a young carer by gender was 1.44, with 95 per cent confidence intervals of 1.10 (lower) and 1.90 (upper). Since, the confidence intervals do not include the value of '1', the difference in prevalence between genders is statistically significant at the 5 per cent alpha level. Hence, the population estimates but not the sample results suggest a difference in prevalence between genders.

Who they care for

Fifty four per cent of those identified as young carers provided support for their mother, and 41 per cent for their father; 46 per cent cared for their siblings. Over half of respondents (53%) reported that they cared for a grandparent. 18 per cent reported caring for a family friend; and 13 per cent for another relative. 41 per cent cared for one person; 47 per cent cared for between two and four individuals and 12 per cent cared for more than four people.

Caring tasks and extent of caring (MACA)

Those identified as young carers in the sample had significantly higher total MACA score compared with those who showed no evidence of providing care (12.5 ± 5.1 compared with 10.7 ± 5.1). The difference was statistically significant ($t_{3989} = 6.028$; $P < 0.001$).

30 per cent of young carers in the sample carried out a low amount of caring (as defined by the MACA score; Joseph and others, 2009; 32 per cent carried out a moderate amount of caring; 22 per cent and 17 per cent carried out a high amount and a very high amount of caring respectively. Population estimates of caring levels were similar to sample findings that is 32 per cent, 31 per cent; 22 per cent and 15 per cent respectively (see Table 3).

MACA domain scores showed that those identified as young carers in the sample had significantly higher scores for emotional ($P < 0.001$), financial ($P = <0.05$) and personal care ($P < 0.001$) compared with those who did not have a caring role. There was no significant difference for domestic or sibling care domains ($P > 0.05$). These are shown in Table 4.

Females in the sample who were identified as young carers had a significantly higher mean total MACA score than the males ($P = 0.008$). They also had significantly higher MACA domain scores for domestic care ($P < 0.001$); emotional care ($P < 0.001$) and personal care ($P = 0.001$). There was no significant difference for financial, household or sibling care domains ($P > 0.05$). These results (including population estimates) are summarised in Table 5.

Caring and well-being

The mean KIDSCREEN-10 score for the total sample was $56.3 (\pm 12.7)$. Those children identified as young carers had a slightly lower, but statistically significant, KIDSCREEN-10 score than those without caring responsibilities (54.5 ± 13.2 compared with 56.5 ± 12.7 ; $t_{3984} = 2.605$; $P = 0.009$). This suggests that the level of well-being is slightly lower among young carers compared with children who had no caring responsibilities.

The correlation between the mean total MACA score and the mean KIDSCREEN-10 score was very weak for the complete sample (Pearson's $r_{3991} = -0.035$; $P = 0.028$); and there was

Table 3: Extent of caring by young carers

Extent of caring	Sample		Population estimate (10- to 15-year-olds, Swiss-wide)							
	Frequency	Per cent	Estimate	Standard error	95% confidence interval		Per cent	Standard error	95% confidence interval	
					Lower	Upper			Lower	Upper
Low amount of caring	93	30.3%	11 312	1376	8593	14 031	32.0%	3.2%	26.0%	38.7%
Moderate amount of caring	97	31.6%	11 017	1376	8299	13 736	31.2%	3.6%	24.5%	38.8%
High amount of caring	66	21.5%	7721	1101	5544	9898	21.8%	2.6%	17.1%	27.5%
Very high amount of caring	51	16.6%	5302	821	3679	6924	15.0%	2.1%	11.3%	19.7%
Total	307	100.0%	35 352	2221	30 963	39 740	100.0%	0.0%	100.0%	100.0%

Table 4: MACA domain scores for young carers and those without caring responsibilities

MACA domain scores	Young carers			No caring responsibilities			Sig
	<i>N</i>	Mean	Std. deviation	<i>N</i>	Mean	Std. deviation	
Domestic	307	3.19	1.26	3684	3.04	1.3	0.054
Emotional	307	3.51	1.68	3683	2.78	1.76	<0.001
Financial	307	0.83	1.1	3684	0.7	1.07	0.046
Household	307	2.6	1.26	3684	2.23	1.26	<0.001
Personal	307	0.93	1.37	3684	0.6	1.14	<0.001
Sibling	271	1.64	1.73	3398	1.45	1.68	0.072
MACA total score	307	12.51	5.11	3684	10.69	5.06	<0.001

Table 5: Young carers' MACA domain scores and gender

MACA domain scores	Male			Female			Sig
	<i>N</i>	Mean	Std. deviation	<i>N</i>	Mean	Std. deviation	
Domestic	134	2.88	1.3	171	3.44	1.18	<0.001
Emotional	134	3.14	1.66	171	3.81	1.64	<0.001
Financial	134	0.87	1.2	171	0.78	0.96	0.441
Household	134	2.74	1.29	171	2.5	1.22	0.104
Personal	134	0.63	1.09	171	1.16	1.52	0.001
Sibling	122	1.52	1.66	147	1.75	1.79	0.272
MACA total score	134	11.64	5.17	171	13.20	4.97	0.008

no association between MACA and KIDSCREEN-10 scores for those identified as young carers (Pearson's $r_{305} = 0.003$; $P = 0.963$). Hence, among young carers, increased intensity and broader ranges of caring activities (as shown by the MACA score) did not relate directly to differential well-being.

Discussion

In this study, we have estimated the prevalence of young carers in the Swiss population of children in grades 4–9, which largely covers the population of 10- to 15-year-olds, to be 7.9 per cent. Within this age group, this is equivalent to around 38 400 Swiss children. Applying this figure to a slightly wider age group of 9- to 16-year-old children, we estimate that there are around 51 500 young carers in Switzerland.

Whilst there is some variation in estimates of prevalence across countries and studies, overall figures suggest that between 2 and 8 per cent of all children in advanced industrialised capitalist societies are carers, depending on the method which is used to identify and count them (Becker and Becker, 2008; Cass and others, 2011; Hill and others, 2009; Howard, 2010; Hunt and others, 2005; Warren, 2007). Our estimate of prevalence is therefore towards the higher end of the estimated range. However, we have only classed respondents as young carers if they showed clear evidence of providing regular support for a person with an illness, addiction, or disability, for an older person, or if they assumed caring responsibilities in the circumstances of a family crisis (e.g. in the event of a family breakup or following the death of a family member). Hence, we believe we have accurately counted those who have caring responsibilities.

In this study, we first identified young carers using an open question and a pre-defined coding schedule, secondly we assessed the extent of their caring activities using the MACA — the Multidimensional Assessment of Caring Activities. Whilst the first question estimated the prevalence of all carers, the MACA showed that of these, whilst a third provided a 'low' level of care, 38 per cent provided a 'high' or 'very high' level of caring. Since these young people provide different levels of care, they will have different levels of need for support. Also, the type of support that they need will depend on the type of caring activities in which they engage. Those whose caring role, for example includes personal care may need specialist support. Additionally, various social and economic factors such as family income, housing quality and household composition may influence the support that needs to be provided and may exacerbate or mitigate the negative effects of having a caring role (De Roos and others, 2017). Therefore, support needs to be tailored to the type and extent of caring and the context in which it occurs.

This study also showed, not surprisingly, that those who were identified as young carers had significantly higher MACA scores than those without caring responsibilities; and that the MACA domain scores of young carers were significantly higher for all domains apart from sibling care. This was higher for young carers but not significantly so. It thus appears that those young people who do provide care for sick or impaired relatives or persons close do so across a wide range of different activities. Interestingly, there were some young people in our study who were not classed as young carers but who did have high MACA scores including for personal care. We do not know the circumstances of these young people and the context in which they provided care but this does raise the possibility of false negatives as identified in our opening question and predefined coding system. Alternatively, these are young people who do provide care but not on the regular basis which was the focus of the present study. It may be helpful for future studies to also ask questions about whether help is ever provided less regularly to provide more nuanced prevalence data.

Although 56 per cent of carers in our sample were female compared to 44 per cent male, there was no statistically significant difference in prevalence between males and females in the sample. However, the population estimate which was weighted to compensate for sampling error did in fact show a significant difference. This is in line with previous research which has shown differences in prevalence between genders. For example in their study of young carers in Austria, Nagl-Cupal and others (2014) showed that 70 per cent were female. The size of the difference (Austria compared with Switzerland) may reflect different national or cultural characteristics or may be due to differences in sampling methodology. Whilst Nagl-Cupal and others (2014) and Sempik and Becker (2013) have shown a greater proportion of females as young carers, more research is needed to show how the activities of male and female young carers differ in their detail, and how the role has developed (and continues to develop) over time. We saw differences in the type of caring activities carried out by male and female young carers. Young women provided more domestic, emotional and personal care (as measured by MACA domain scores). More research is needed to explore the role that gender plays in constructing the caring role. The provision of support for young carers needs to take into account not only the total extent of caring but also the type of activities that are carried out, and this appears to be linked to gender.

Researchers have previously reported poor mental well-being among young carers, for example Nagl-Cupal and others (2014) reported a greater level of worry, sadness and physical pain among young carers compared with those without caring role. In this study, we showed that children with a caring role had a significantly lower KIDSCREEN-10 score than those without caring responsibilities although the absolute difference in well-being was small. In addition, we saw no association between the extent of caring, as measured by the

total MACA score and well-being, as measured by the KIDSCREEN-10 score. Hence, this study has found no obvious direct effect of the amount of caring on well-being. Whilst there may be no simple correlation between the extent of caring and mental well-being, the context of caring may be important. For example those who have a low income, poor housing and little family or social support are likely to be at greatest risk of adverse effects. Caring for a person with a stable disability will be different to caring for someone whose condition fluctuates and who can make random and unpredictable demands on their carer (WHO, 2011). Similarly stress and coping variables could have an impact on the association between caring and well-being. Therefore, further research is needed to address the role of mediator and moderator variables in the context of young carers' well-being, for example using a method such as structural equation modelling.

The KIDSCREEN-10 index is a validated measure that has been found to be useful in the context of young carers (Schlarmann and others, 2008). However, unlike the longer version of the instrument, it only provides an overall score for well-being. It is possible that the caring role affects different aspects of well-being. Therefore, it would be useful in future research to apply the long version in order to explore the impact of a young person's caring role on different dimensions of well-being, including, for example on its emotional, social and personal aspects.

Limitations and Strengths

Survey participation was not compulsory for schools and only 230 of the schools selected by the sampling process agreed to participate — a response rate of 32 per cent. A non-response bias could be present if the schools which refused to participate had numbers of young carers which were very different to those in participating schools. Hence, some caution may be needed regarding the prevalence estimates reported in this study. Since schools which refused to participate were spread over different regions, were of different sizes and the reasons for refusal were mainly due to overload with other surveys and educational assessments, we believe that non-response bias is small. In addition, among the participating schools nearly all children from the sampled classrooms sampled took part in the survey — the response rate at this level was 94 per cent. Hence, there was no refusal at the level of pupils that could be associated with their caring situation.

In our introduction we mention that the identification of young carers is challenging due to self-identification barriers (Cass and others, 2009; Noble-Carr and Woodman, 2016). In this study, we have used an approach that we believe overcomes this barrier. Firstly, data collection was conducted during regular classes within the classroom setting; the survey was conceptualised so that it could be completed by young people regardless of whether they were young carers or not. Secondly, the questions used to identify young carers were formulated in a way that explored the circumstances of support needs and care provision rather than asking young people to identify themselves as young carers.

Conclusion

Our survey has estimated that around 38 400 children in grades 4–9 (i.e. aged 10–15) in Switzerland have caring responsibilities. However, young carers are not confined to this age group, research has shown that children as young as five can play a caring role; and that adolescents and young adults aged 14–25 can also be involved in providing care. Hence, many tens of thousands of children, adolescents and young adults are caring for ill and disabled family members in Switzerland, and all will need some support at some time.

As Leu and Becker (2016) reported, one of the key factors that influence policy responses is the presence of a reliable country-specific research base. A robust country-specific

research evidence base provides an important foundation for policy developments and service responses. Policy-makers often prefer to have a national research evidence base to inform their local and national decisions rather than drawing or relying on research from other countries. The data from this study as well as the findings from ongoing projects undertaken by the Swiss research group will underpin the development of a national support framework for young carers. The Swiss Federal Council (2014) launched an Action Plan that consists of different areas of action to improve the situation for all carers. Findings from earlier studies (Leu and others, 2018, under review) have led to amendments in the action plan to include young carers in the national carers strategy.

The challenge now is to develop an appropriate policy response and effective services in order to support all of these young people and their families. The development of such services and policy must include schools and the education sector. Previous research in the UK has shown that caring responsibilities lead to absence from school, lateness and disruption to a substantial number of school days (Sempik and Becker, 2013). Some young people did not inform their teachers that they were carers because they could see 'no point' in it, that is they did not believe that telling anyone would have any effect. Teachers and other school staff are in regular contact with young carers but may often not recognise them as such. However, recent research from Switzerland indicates a lack of awareness and a rather meagre commitment among professionals in education towards young carers (Leu and others, in preparation). Hence, one arm of policy needs to address this issue by raising awareness of young carers among teachers and school staff and developing processes and procedures that will support young carers throughout their education and into their working lives.

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Young Carers im internationalen Vergleich / Research & policy – an international comparison

Internationale Klassifikation / International classification

Leu A., Becker S. (2016)



LEU, A., BECKER S. (2016). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, 1-13.



UK

Laura Bennett, Carers Trust, Zurich, 12 November 2019



SWISS NATIONAL SCIENCE FOUNDATION



International YC Classification (Leu & Becker, 2016)

Research questions

1. Does country recognize or do anything *specifically* about YCs?
2. Does country *define* them as YCs (or anything else, i.e., “children as next of kin”)?
3. What does country *do* in terms of policy and services?
4. Does country have any *legislation* that is *specific* for YCs or could be used to support YCs?
5. What factors have been particularly influential in moving policy and practice forward for YCs in your country?

Leu, A. & Becker, S. (2016): A cross-national and comparative classification of in-country awareness and policy responses to ‘young carers’, *Journal of Youth Studies*, DOI: [10.1080/13676261.2016.1260698](https://doi.org/10.1080/13676261.2016.1260698)

1. Recognition and specific Support for Young Carers

- Legislation in all nations covers young carers and their families, giving rights to assessment and support
- Practice-based and sector improvement resources
- Young carer services
- Schools and health support
- Young Carers Awareness Day



2. Definition of Young Carers

- Carers Trust:
 - A young carer is someone under 18 who helps look after someone in their family, or a friend, unpaid, who is ill, disabled or misuses drugs or alcohol.
 - Young adult carers are young people aged 16-25 with unpaid caring responsibilities who are transitioning into adulthood.
- Children and Families Act: *“young carer” means a person under 18 who provides or intends to provide care for another person*
- NHS England: *You're a young carer if you're under 18 and help to look after a relative with a disability, illness, mental health condition, or drug or alcohol problem.*



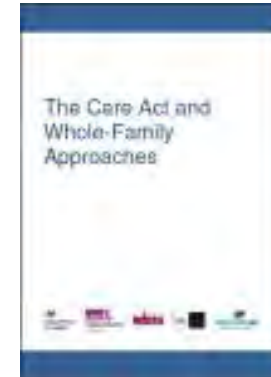
3. Current policy and services in UK

- Young carers' services, provided by voluntary sector and statutory sector
- Some schools, colleges and universities are making meaningful offers of support
- Some health services are supporting young carers
- 'Flu vaccination
- Carers Action Plan
- Understanding of other groups: e.g. LGBT young carers, military young carers, BAME young carers



4. Specific legislation for YC

- Legislation in all nations covers young carers and their families:
 - Children and Families Act
 - Care Act
 - Carers (Scotland) Act
 - Social Services and Well-being (Wales) Act
- All giving rights to assessment and support
- Sector-led improvement resources



5. Key factors for promoting policy & practice for YC

- Having the evidence base (research, qualitative and quantitative)
- Politicians coming together, changing the law
- Working in partnership with Government, NHS, local services
- Local services
- Young carers voices
- Social media, videos



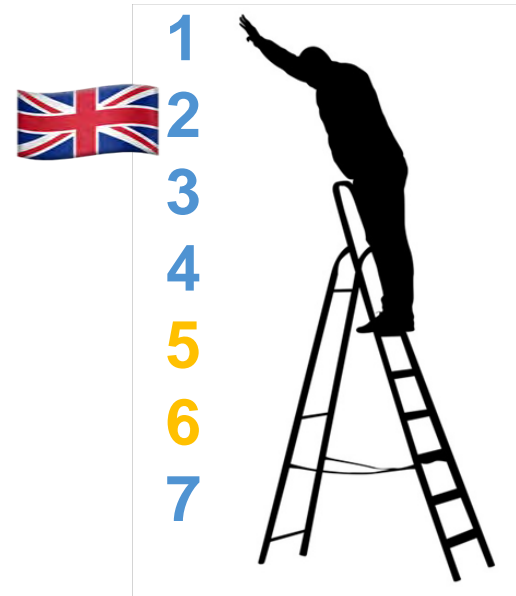
Young Carers Classification

achievements within the last 3 years

2016



2019



Where have we got to, where are we going?

Young carers have rights in law

Young carer services

All young carers should be supported in school

Funding for services

Wider measures for children and young people, e.g. mental health need to support young carers as a specific group



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ITALY

Licia Boccaletti, Zurich, November 12th 2019



SWISS NATIONAL SCIENCE FOUNDATION



1. Recognition and specific Support for Young Carers

- In spite of Italy being one of the European countries with a high proportion of informal carers there is still little awareness and attention from policymakers and practitioners to the needs of young carers.
- There is no distinction between younger and older carers and hence a lack of attention to the specific group and needs of Italian young carers.
- Some level of attention on young siblings of people with disabilities and COPMI
- Some level of attention by the press and in conferences
- Memorandum of understanding signed by ANS – Eurocarers and COMIP in 2018 with the Ministry of Education to support young carers in education

2. Definition of Young Carers

- No official / legal definition
- Most common definition: Becker's
- Limited awareness of the expression «young carers» – need to use circumlocutions such as «children of ..» or «siblings of...»
- In the national law proposal, the definition of informal carer doesn't refer to age but to the kinship (including children and siblings)
- Existing regional laws do not refer to age or kinship but only to the “emotional bond” but in the operational guidelines of Emilia Romagna regional law, young carers are explicitly mentioned (although not defined)

3. Current policy and services in Italy

- No policies or services explicitly dedicated to young carers, with the exception of those offered by ANS in the area of Modena
- Some experiences of targeting young carers in the framework of existing policies / services for vulnerable young persons, for ex.
 - Some schools including young carers in the policies for students with «special educational needs»
 - Some public services working in the field of mental health for youth are «marketing» their services to young carers
 - Some school counsellors / psychologists have been trained on young carers needs

4. Specific legislation for YC

- There is still no national legislation on adult carers
- 4 Italian regions and the Province of Trento have approved laws to recognize informal carers which do not refer to specific ages (so potentially applicable to YCs as well)
- Legislation protecting children from abuse and neglect also applies to YCs



5. Key factors for promoting policy & practice for YC

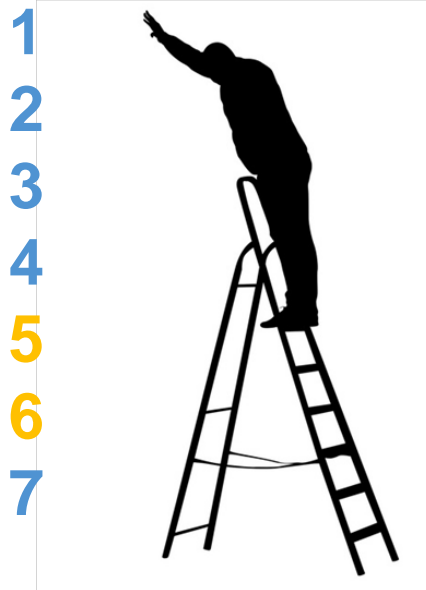
- Awareness raising and advocacy initiatives of NGOs
- Political attention on informal carers (included in the political programme of the current national government)
- Leverage of existing policies and services targeting youth and informal carers



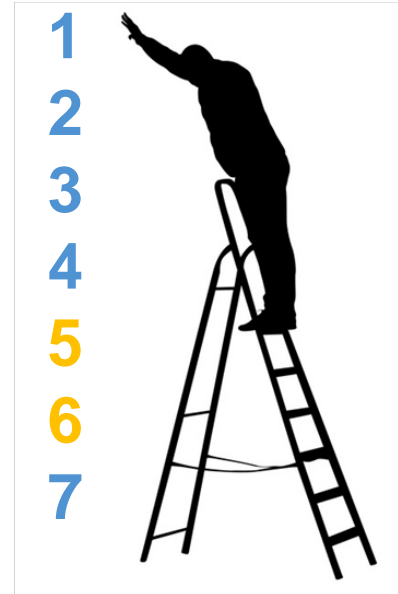
Young Carers Classification

achievements within the last 3 years

2016



2019



To sum it all up

*“We ourselves feel that what we are doing is just a **drop** in the **ocean**.
But the **ocean** would be less because of that missing **drop**.”*

Mother Teresa

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The Netherlands

Presenter, Careum, Zurich, November 12th 2019



SWISS NATIONAL SCIENCE FOUNDATION



1. Recognition and specific Support for Young Carers

- Visibility and awareness is increasing, in particular at local/regional levels
- Lack of recognition and knowledge among professionals
- Young carers often do not self-identify as carers
- 19% of adolescent young carers personally receive any form of formal support -> it is not known what type of support this is.
- Differences in support between schools, welfare organizations, municipalities & regions
- Many support projects & actions, among which SIZ Twente & Vanzelfsprekend projects in The Netherlands



2. Definition of Young Carers

- Young carers are young persons (<18 years of age) that help, support or care for a family or friend with a chronic disease, disability, addiction or problems related to ageing. This varies between caring *about*, caring *that*, and caring *for* (Summary Report Netherlands, ME-WE).
- Young carers are children and young people until 24 years of age that grow up with a family member that is chronically ill or handicapped or who has a mental disorder. This situation can have a large impact on their lives (mantelzorg.nl)
- Young carers are those who grow up with a sick parent, brother, sister or grandparent who live in the direct surroundings of the family and who need intensive care. There can be a physical disease or handicap, a mental disease or addiction problems. The definition is broad, because it cannot be stated that a young person must have a care responsibility (Markant, 2016).



3. Current policy and services in The Netherlands

In the Netherlands, no specific legislation protecting and supporting young carers and their families exists, however legislation exists that supports YCs, in particular via municipalities (next slide more on this).

Non-specific protocols and guidelines:

- The Dutch Ministry of Health, Welfare and Sports launched the program Volwaardig Leven ('A fulfilling life') in 2018
- Guidelines Children of Parents with Mental Problems (KOPP): guidelines for professionals in the field of for youth care and youth protection.
- Toolkit Mantelzorg: an advice of the Association for Dutch General Practitioners for general practitioners to pay attention to informal carers, including young carers.

4. Specific legislation for YC

No formal legislation, however Youth Act and Social Support Act via municipalities

- The Social Support Act (Wet maatschappelijke ondersteuning, Wmo 2015)
- The Child and Youth Act (Jeugdwet 2015), Article 2.1
- Compulsory Education Act 1969 (Leerplichtwet 1969) and The Compulsory Education Act 2007, Article 4a and 4b
- Dutch Civil Code (Burgerlijk Wetboek): Book 1 Law of Persons and Family Law, Section 1.14.4 Custodial control remedies for minors, Article 1:254 Grounds for ordering custodial control over minors to Article 1:278 Request for a restoration of parental authority; probationary period.
- The UN Convention on the Rights of the Child (Het Verdrag inzake de rechten van het kind; UNCRC)

5. Key factors for promoting policy & practice for YC

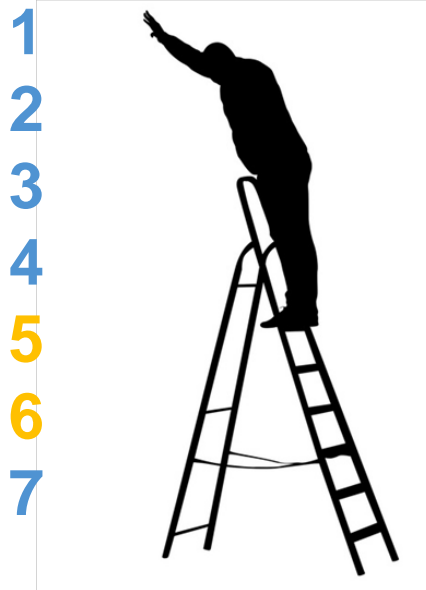
- Media echo
- Communication & Dissemination (independent) organizations
- Expertiselab Young Carers
- European insights/mirror (e.g., ME-WE)
- Validated interventions
- Policy agenda in municipalities
- Integrated care and cooperation between sectors
- Whole Family Approach
- Compatibility needs & wishes & current/future support
- Focus on strengths, no problemization



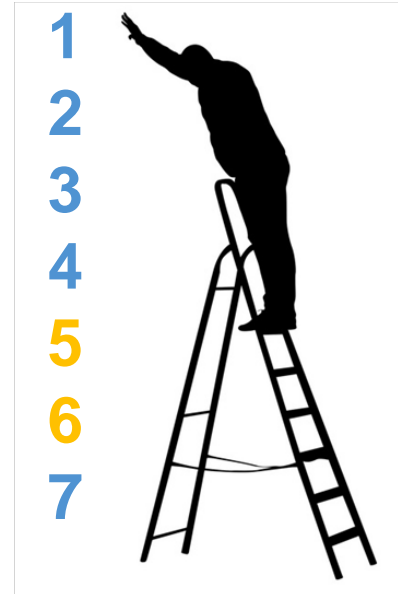
Young Carers Classification

achievements within the last 3 years

2016



2019



1. Awareness & visibility is increasing
2. No specific legislation, however...
3. Multiple local interventions
4. No validated interventions
5. Future is promising!



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Finland

Malla Heino, Careum, Zurich, November 12th 2019



SWISS NATIONAL SCIENCE FOUNDATION



1. Recognition and specific Support for Young Carers

- Still poorly recognized, identified and supported, but encouraging signals of advancement
- The Effective Child&Family Work with Mental Health Finland: Lets talk about Children -method (2001-); preventive interventions and approaches on child wellbeing and parenting; similarities to Sweden and Norway
- Emerging prevalence data on national level in **School Health Promotion Study 9/2019** by the Finnish Institute of Health and Welfare (based on ngo initiative): 3 % of 8.- 9.graders help or care for a family member daily or almost daily
- Key role rests with ngos
 - Young carers - network of 6 ngos established 2017
 - Active work on awareness raising nationally and locally
 - Surveys on care situations conducted among confirmation candidates 2018 and 2019
 - Growing number of young carer projects and initiatives in ngos (chats, online peer support, week-end camps)
 - Issue presented and discussed in Youth Studies- ,Family Research and Social Politics Conferences
- Active policy-maker lobbying by ngos
 - Joint appeal to political parties prior to Parliament elections 2019
 - 2 written questions on young carers to Minister of Family Affairs and Social Services at the Parliament
- Growing public awareness through media attention (national tv, radio, newspapers, internet, social media)
- **2 %** of all municipalities' decisions on support for informal care made for minors

2. Definition of Young Carers

- No established legal or other definition; ongoing discussion; prof. Becker's definition (Becker, S. 2000: 378) often referred to
- Ngos working with issues of mental health use "children as next of kin"
- Among other ngos in social and health care sector, young carer (in Finnish *nuori hoivaaja*) is being introduced; Swedish-speaking Finns use "ung omsorgsgivare" (YC)
- Adult carers are referred to as (informal) carers (*omaishoitaja*), i.e. "carer for a relative"
- Finnish equivalent to 'young carer' somewhat gentler and more relatable with more emotional latitude than the concept for adult carers?
- Lack of social scientific research of children in care situation

3. Current policy and services in (Finland)

- Families with special care needs get support, services and benefits based on a number of laws but a consistent approach for support of young carers is still lacking
- MP's question to the Minister of Family Affairs and Social Services on young carers (September 2019):
“What does the Government intend to do in order to recognize and reach young carers and to develop targeted and affective support for them?”
“Persons under 18 years are children. If the parent or other relative of the child has e.g. become disabled, suffers from a chronic illness or has problems of mental health, the family should be getting help and support that meets their needs in a manner that safeguards the child's rights. It is crucial that the needs of children are recognized also in adult services and care responsibilities that are in conflict with childrens' rights, should not arise.”
- Social Welfare Act: carers are not identified as a group in need of special support, no right to e.g. assessment of own situation and needs
- “Let's Talk About Children” is an evidence-based method for supporting parenting in families with mental illness or substance abuse problems; in use in early childhood education, schools and service providers; Government aims at disseminating the tool
- Measure proposals to diminish risks caused by parent's physical illness in adult health services

4. Specific legislation for YC

- No specific legislation on young carers, but several laws take notice of childrens' situation when a family member is incapacitated
- References to children possibly affected by family member's illness in the following laws (not comprehensive):
 - Child Welfare Act
 - Social Welfare Act
 - Health Care Act
 - Disability Services Act
 - Law on Intellectual Disabilities
 - Act on Welfare for Substance Abusers
- *Act on Support for Informal Care (2005)*: social welfare service that municipalities may grant to carers at their discretion; no reference to the **age** of the carer in the law
- In 2017, **2 %** of receivers of informal care support (total 46 000) were under 18
- Legal and welfare stuctures exist but young carers still inadequately identified

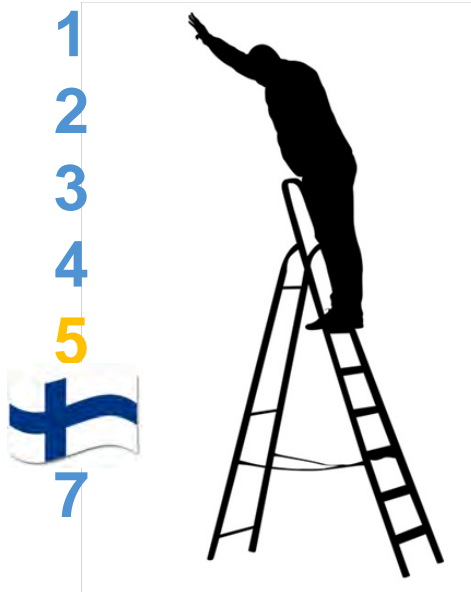
5. Key factors for promoting policy & practice for YC

- International collaboration, concrete help and advice: reliable evidence base from other countries, experiences, good practises, inspiration
- Ngos' work crucial in awareness raising, new insights and evidence
- With the results of the **School Health Promotion Study 2019**, growing national evidence base (some 250 000 respondents)
- Media interest and attention (tv, internet, print media), active advocates (experts by experience, politicians)
- Young carers' issue at the Parliament
- Local service pilot in Eastern Finland; new knowledge and competences about young carers needs and ways of supporting them

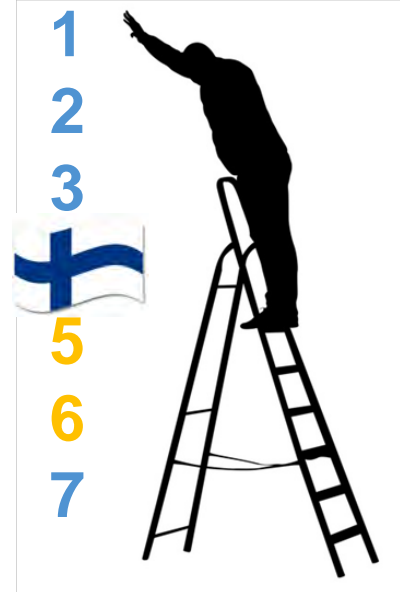
Young Carers Classification

achievements within the last 3 years

2016



2019



To summ it all up:

In the beginning, there was disbelief and sceptisim about young carers in Finland in the first place. Now there seems to be at least an initial will to take a closer look at things. Ngos and experts by experience have a crucial role in passing on the message to researchers and policy makers.

Finnish service system has the prerequisites to support young carers, as long as they are recognized and identified as a distinct group in need of special support.

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SWISS NATIONAL SCIENCE FOUNDATION

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The University of Sussex
(<http://www.sussex.ac.uk>) is a higher education institution established in August 1961 for the advancement of learning and knowledge by teaching and research.

In the 2019-20 Times Higher World University Rankings, Sussex was ranked 19th in the UK and 146th in the world.

It currently has over 14,000 students and 2,100 staff from all over the world. It has had 3 Nobel Prize winners.



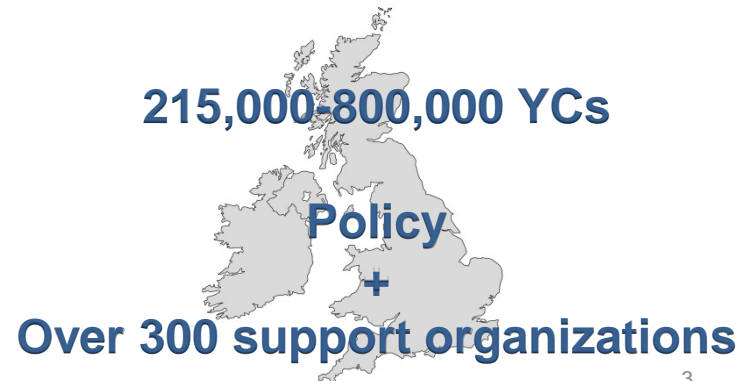
1. Recognition and Specific Support for Young Carers

United States of America: An Emerging Country

- There is a lack of widespread recognition of young carers in the USA
- Currently a greater focus on Millennial caregivers (born between 1981-1996), Sandwich Generation caregivers, and Kinship caregivers
- There is one major NGO for young carers: *The American Association of Caregiving Youth (AACY)*.
- Facebook groups for young caregivers are gaining traction



Switzerland



Why is the USA so different from the UK?



UN Convention of the Rights of the Child



Acceptance of welfare state



Commitment from national non-profit organizations



THE MEDIA!



Size & Federal system

2. Definition of Young Carers

A Language Deficit

- There is no accepted definition or terminology of young carers in the USA.
- **Caregiving youth** has been encouraged by AACY to highlight that young carers are indeed children, not yet of legal age.
- **Young caregivers** is also a term used by researchers and the media



3. Current policy and services in the USA

- There are no specific policies or services for young carers on either a state or a federal level.
- State legislation on child protection or neglect may be relevant in a small minority of cases
- State social services would generally only be involved if there were reports of parental neglect, or severe impacts to a child's welfare, e.g., food insecurity or homelessness
- Formal support is given on an individual & local basis, e.g., a YC may see a school counsellor but only if identified and available to access
- Support groups by disease organisations or hospitals remain focused on adults.
- The care recipient may have a variety of governmental sponsored support available, such as Social Security Disability Benefits—**but only if eligible**

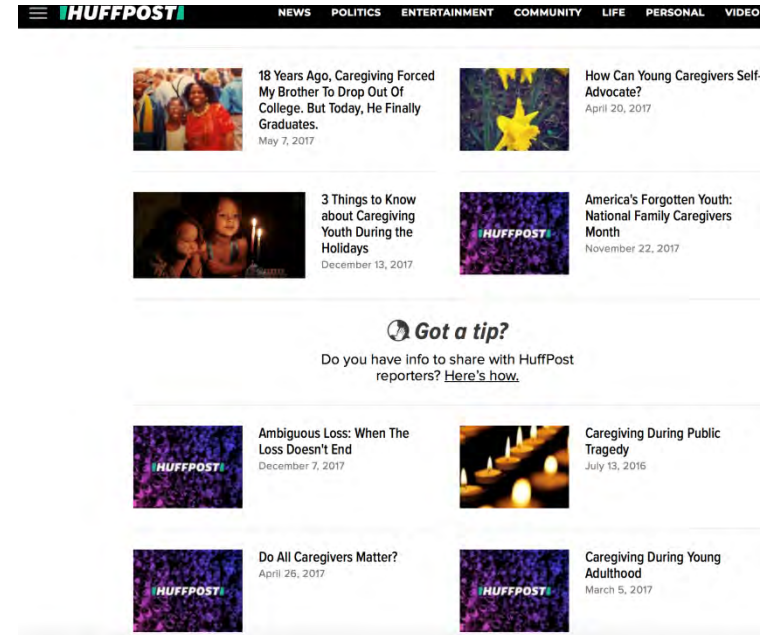
4. Specific legislation for YC

Child Labor & Child Welfare Laws

- Whilst «care as labor» remains a contested subject, US federal child labor laws may help form arguments for more specific legal protection
 - *The Fair Labor Standard's Act's minimum age requirements do not apply to minors employed by their parents.* A clear signal that legal rights weigh heavily in favor of parents!
- Impact of opioid crisis: 36% of children entering foster care in 2017 due to parental substance abuse
- Family First Prevention Services Act (2018) dedicates significant federal funding to states for increased mental health and substance abuses services to decrease entry to foster care system
 - Aim: To allow for more children to stay with parents or kinship carers

5. Key factors for promoting policy & practice for YC

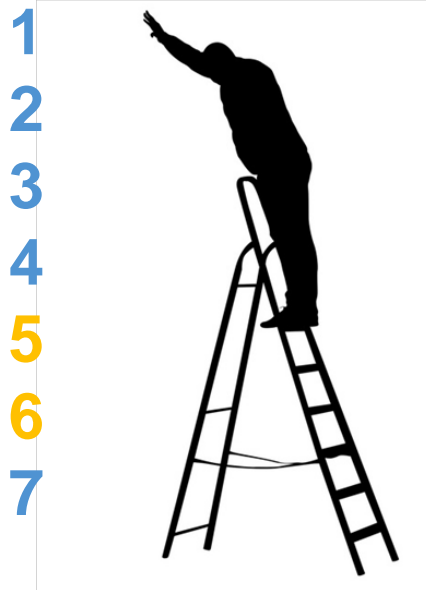
- National research involving young carers is over 15 years old; updated national statistics are needed
- Increased prioritization on media/press opportunities by AACY; see Vice News 2017 feature:
<https://www.youtube.com/watch?v=puwl1tROvkQ>
- Public interest blogging and articles in Huffington Post
- Increased collaboration between invested researchers: see Bookend Caregiving Project by Professor Elizabeth Olsen:
<http://bookendcaregivers.web.unc.edu>
- Involvement of National Alliance for Caregiving in Caregiving in the US 2020 national research study & questions on young carers



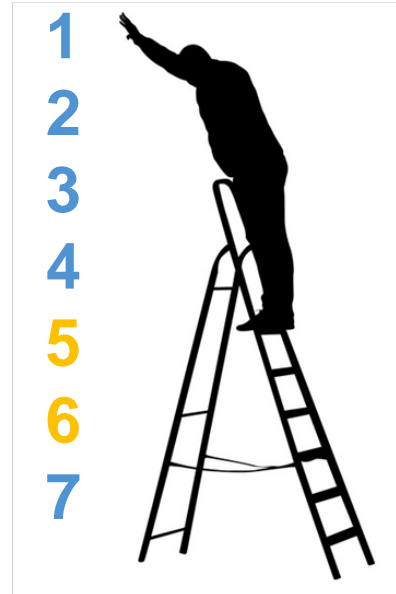
Young Carers Classification

The USA: *An Emerging Country*

2016



2019



Concluding Reflections:

- A watershed moment needed in the USA!

- Opioid crisis could provide this attention onto young carers

- More closer scrutiny needed onto kinship care relationships for the presence of young caring

- Potential to harness the power of social media

- Role of traditional media/press

- Need for national research studies to inform policy creation

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France

Aur lie Untas, Careum, Zurich, November 12th 2019



SWISS NATIONAL SCIENCE FOUNDATION



1. Recognition and Specific Support for Young Carers



- 2014: Artistic respite care for YC created by Françoise Ellien
- 2017:
 - Research project on French YC «JAID»
 - Collaboration between University and French National Association for YC (JADE)
 - Results of a 1st survey on 501 YC or former YC (IPSOS/Novartis)

Research in progress



- 17% YC (N=1448)
- 72.2% girls
- 51.9% help a parent and 28.6% a sibling



- 88% did «not know YC»
- Report few actions to help YC, many barriers and need help from specialists



- 76 YC
- Many benefits reported by YC, parents and professionals



2. Definition of Young Carers

Definition used by the “JAID team” and the French National Association for YC (JADE) :

- A YC is someone under 18 years old who provides significant care, assistance or support to another family member or significant relative. The person receiving care has a physical or mental illness, or a disability.
- Between 18 and 25 years old, we label them Young Adult Carers

3. Current policy and services in France

- **Policy**

23rd of October 2019:

French Prime Minister announced a **strategy for carers' mobilisation and support** «AGIR pour les aidants»

It includes a **specific part for YC !**

- Increase awareness of school professionals to identify and support YC
- Specific arrangements for YAC students
- Complementary measures to screen YC, increase respite and health monitoring

- **Services**

- **Since 2014, only one service for YC** through an artistic respite care
 - ➔ Spread from the region of Paris to 2 others in 2019
- *Work in progress*



4. Specific legislation for YC

- No specific legislation for YC
- According to a law published in may 2008:
YC can be considered as included in a global definition of family caregivers, but they are not explicitly named
- In may 2019: a new law was enacted but only for adult family caregivers

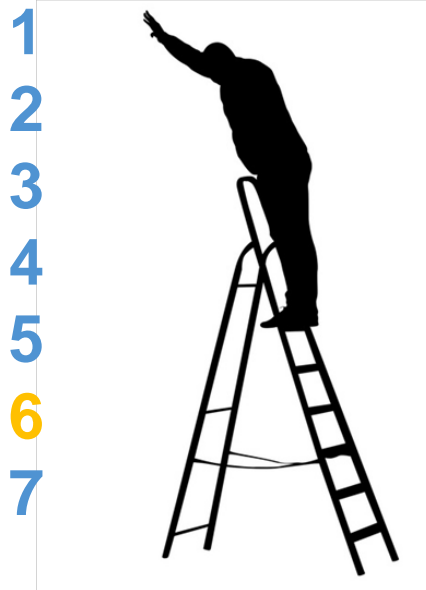
5. Key factors for promoting policy & practice for YC

- Since 2014: Artistic respite care for YC
- 2016: Creation of the French National Association for YC (JADE)
- 2017:
 - Results of a first survey on YC in France (IPSOS/Novartis)
 - 1st funding for a scientific research on YC in France and JAID project
 - Collaboration between JADE and Université de Paris
- 2019: 1st French Conference on YC
- The huge energy of Françoise Ellien and her knowledge of oncology

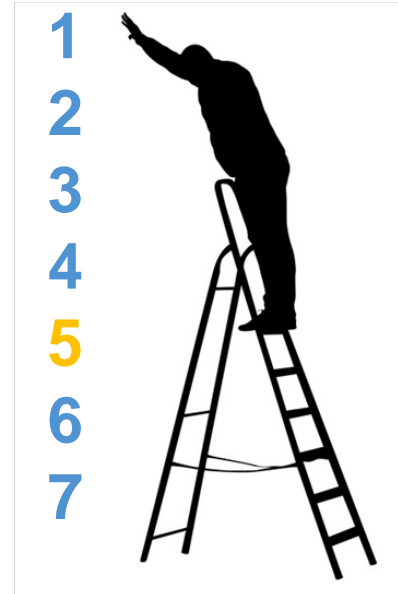
Young Carers Classification

achievements within the last 3 years

2016



2019



To sum it all up

A lot of energy

A growing dynamic

But there still is a long way...

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