



European Parliament Informal Carers Interest Group

Enabling young carers to pursue their life goals – Converting research findings into policy actions

Date: 25 September 2019, from 10:00 to 12:00.

Venue: European Parliament – Room A5E-3

Sirpa Pietikäinen MEP welcomed participants to this first meeting of the Informal Carers Interest Group in the new Parliament and stated her intention to continue its important work. She informed the meeting of the involvement of **Luke Flanagan MEP** as a co-chair; unfortunately he could not attend due to illness. However, he had brought over a group of Irish young carers to participate in the meeting.

Underlining the importance of the topic of the meeting, Sirpa Pietikäinen MEP gave the floor to **Amy Dickinson (Eurocarers Young Carers Working Group)** to present the Group's plans for a European -wide campaign to raise awareness of the situation and needs of young carers. This campaign will be based on three main themes, i.e. 'identify', 'support' and 'listen to'.

In relation to the first theme - 'identify' - Ms Dickinson referred to the cycle of care that was a standard part of the life of her family for generations. Ms Dickinson herself was not identified as a young carer until she had left for university and there are various reasons for this. One of these relates to the fact that her mother's health condition was never properly diagnosed (and still has not been) – not being recognised formally as patient reduces the chances of relatives being identified as carers.

Another reason is that professionals – health professionals, school staff, youth leaders – often make false assumptions about the lives and care needs of their patients; their day to day situation needs to be properly assessed before decisions are taken about care needs and care provision.

Not being identified and recognised as a carer means that access to services is problematic. If you are not identified as a carers, there is no choice with respect to support, let alone to the kind of support you specifically need. As Ms Dickinson's mother preferred to be independent, formal support was not made use of. Warning signs from Ms Dickinson in relation to the care burden and its implications were not picked up.

There is no 'one size fits all' approach; every individual has his or her proper response. However, many young carers put the needs to others before seeing to their own. Carers need to be helped to identify their own needs, both in as well as outside the care situation.

Identification really is the first step. Care in the community, with health care professionals' home visits to assess the situation, can make a real difference. Services also need to communicate better amongst themselves and not work in silos.

In terms of 'support', information on the health condition of the person cared for and how to best provide care is invaluable. Counselling, emotional support and validation of the care provided and person providing it is crucial.

There is a lack of support for the 'normal' issues faced by teenagers. Where does advice and guidance come from at that important stage in life when you are caring for the persons that would normally provide this?

More awareness about informal care in general would help, with friends and peers having a better understanding of what it means to be a carer. Teachers could be more supporting – training curricula should contain information on young carers and the impact of caring.

The focus of support should be on prevention rather than crisis intervention, based on a whole family approach, with consistency over time. Last but not least, appropriate, tailored formal services would have helped Ms Dickinson cope better and would have lightened the load.

As far as 'listen to' is concerned, Ms Dickinson underlined the need to have the choice to be able to say no a request for help. This is about managing personal boundaries; but it is also about people asking the right questions at the right time and digging a little deeper to find out what is really going on in the life of the young carer.

In addition, after the actual caring situation come to an end the need for support continues. Good practice needs to be disseminated; what matters is securing space for young carers. Ms Dickinson concluded by underlining the importance of creating opportunities to contribute for young carers. This could include roles in research, politics and education.

Sirpa Pietikäinen MEP then gave the floor to the **Richard Illett (Linnaeus University, SWE)** who introduced the general objectives of the Me-We project. Me-We, – 'Promoting mental health among adolescent young carers in Europe' – is an EU-funded project which runs from January 2018 to March 2021, looking at the potential negative impacts of caring in a number of areas:

- In terms of mental health and well-being of young carers, caring can have some positive impacts related to self-esteem, empathy and maturity. However, having to reconcile the challenges of adolescent life with caring responsibilities can be overwhelming. The pressure associated with caring is considered as a risk factor for mental ill-health.
- In terms of education, caring can have a negative impact on young carers' education (under-achievement, absence and drop-outs), which can affect employability and future career.
- With respect to social life, young carers may have less time for personal development and leisure. They can also become victims of social stigma and bullying; this can lead to social exclusion.

Me-We has an ambitious overall goal, i.e. *to 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 is defined as the process of positive adaptation within the context of significant adversity

It is also innovative, as it aims to develop an innovative framework of primary prevention interventions to be tested and adapted in 6 European countries at different stages of awareness and development of services. Moreover, it is the first large scale programme to demonstrate the impact of a comprehensive primary prevention intervention for improving resilience of adolescent young carers. Interestingly, the project is based on the principle of co-design, with researchers engaging directly with adolescent young carers, together with carers organisations and major stakeholders at all stages of the project.

The next speaker, **Dr Feylyn Lewis (Sussex University, UK)** talked about the first Work Package of the Me-We project, i.e. the mapping the profiles, needs, and preferences of adolescent young carers. An online survey was carried out involving adolescent young Carers (between the ages of 15-17) with the aim to assess the extent of caring and its effects (impact on general wellbeing, work and education); a total 1,684 adolescent young carers across 6 EU countries were identified. It was found that the “typical” profile of a European adolescent young carer is a girl providing care for her mother with a physical disability. The exception was Italy, where care is mostly provided to grandparents and specifically grandmothers. In Sweden and UK, a significant amount of care is provided by siblings. Of those providing care to a non-family member, the majority of respondents indicated that they provide care for a close friend with a mental illness (with the exception of Italy).

Adolescent young carers engage in many different caring activities, e.g. domestic activity, household management, financial and practical management, personal care, emotional care and sibling care.

When compared to their non-caring peers, adolescent young carers perform greater amounts of caring activities in the home, and the differences are highly significant in statistical terms. Overall, girls perform a greater amount of care activities compared to boys; however, the statistical significance varies between countries.

- In relation to difficulties in school, between 8 and 22 % young carers report a negative school performance; Between 6 and 37% report bullying.
- In terms of health difficulties due to caring, between 12 and 40% report physical health problems; between 11 and 60% report mental health problems
- In relation to severe mental health problems (self-harm and harm to others) between 8 and 30% reported self-harming thoughts; between 4 and 12 % reported thoughts of harm to others (see attached slides for more details with regard to these statistics).

Dr Lewis also proposed a set of EU and national-level policy recommendations, e.g. the need to combat the myth that young carers do not exist or only exist in small numbers: young carers DO exist and contribute significantly to their surroundings and to society as a whole. The -often overlooked -unpaid care provided predominately by girls and young women should be recognised and opportunities should be created for their inclusion into education and employment. Also, the rights of particularly marginalized adolescent young carers (e.g. migrant and refugee AYC) and those caring for individuals with stigmatized conditions should be protected.

In terms of education and employment, it should be recognised that AYC) are at a higher risk of being ‘Not in Employment, Education or Training (NEET)’; new opportunities for apprenticeships should be created and existing ones strengthened, taking into account flexible working possibilities and financial assistance to enable access to college and university.

The EU's values of tolerance and respect should be promoted, encouraging member states to adopt stronger anti-bullying policies and legislations with specific mention of young carers as a protected group.

In terms of health policy recommendations, Dr Lewis emphasised the need to champion the role of connected health services to identify and support adolescent young carers. In addition, general Practitioners, emergency room doctors, nurses and pharmacists can play a very useful role as front-line contacts. Member states should be encouraged to adopt 'whole-family approach' policies to health care. Medical staff must assess adolescent young carers for impact of caring on their mental and physical health. In addition, barriers (e.g. waiting times) to accessing dedicated mental health support must be removed.

Last but not least, member states must recognise the detrimental impact of the lack of long-term care systems and the austerity period on the mental health of its most vulnerable citizens: good quality formal long-term care needs to be in place and easily accessible.

In conclusion, Dr Lewis stated that adolescent young carers have a right to self-determination, including the right to care if they desire to do so. The positive impact of caring, both for the individual as well as for society, should not be overlooked. She stressed that inappropriate amounts and activities of care provided by young carers, combined with a lack of state/societal recognition and support, rather than care provided by young carers as such. This is an important distinction.

Me-We's vision is to move European young carers from vulnerability and exclusion, to full inclusion and participation, to hope for the future and opportunities to thrive.

The next speaker, **Prof Dr Agnes Leu (Careum, CH)** talked about the findings of Me-We's Work Package 2, focusing on the legislation, policy and service frameworks supporting adolescent young carers. Interviews with experts, case study analysis and feedback and input from adolescent young carers themselves supported the identification of the key legislative and policy initiatives that are currently in place. It was found that only the UK has specific legislation recognising children's caring roles in place and provides a specific definition of young carers. This means that currently, recognition of adolescent young carers relies upon 'non-specific legislation' such as legislation in the areas of education, health and social care. Some policy and services frameworks specifically targeting (adolescent) young carers are in place in Sweden and the UK.

But what about the actual translation into practice of this legislation? This relates to existence of implementation guidelines and regulations, collaboration between services, culture of local authorities, type of support offered by legislation and sufficient financial support. The findings indicate that in reality, adolescent young carers are falling through the gaps (e.g. between children's services and adolescent services.)

Changes in legislation and policy were achieved by means of stakeholder involvement, relevant Ministries, family associations, private and state organisations and young people and carers. The key drivers behind policy change consist of academics conducting research and partnerships with voluntary sector, key champions in government, consultation with young people, EU promotion of young people as target group (EU Youth Strategy) and the high workload of Social Workers, combined with analysis of other European legislation and policy.

In summary, Dr Leu stated that currently, some laws not working well in practice, that adolescent young carers are not offered any kind of support and that their roles are not considered by health professionals, that there is a lack of information about their rights and support opportunities and that the school environment should be more supportive.

There should also be support for the role of parents and families of adolescent young carers; they should be involved with decision-making processes that concern them. The importance of awareness raising cannot be stressed enough. There should be strategies to adapt existing legislation; this could be helped by an agreed definition of what is meant when we speak about 'young carers'.

The final speakers presenting the findings of the Me-We project, **Renske Hoefman (The Netherlands Institute for Social research (SCP))** and **Nynke de Jong (National Centre of Expertise for Long-term Care (Vilans), NL)** talked about successful and promising strategies to support young carers, from the point of view of experts.

This work consisted of two strands: a Delphi study with experts from academia, policy and health and social care from 10 EU countries: and a 'rating and ranking' study among experts and young carers.

The Delphi study found that there is a lack of visibility and awareness of young carers and their issues in all countries under study; it is highest in the UK and Sweden. However, visibility and awareness are increasing, in particular at local/regional levels.

Current interventions mainly consist of efforts related to identification (self-tests/assessment, social contacts, mentors and experts), information (on health conditions, legislation, respite, education...), contacts and connections (constant dialogue, social support, whole family perspective, access to mentors (school, social care, per support) and respite and fun (breaks, online forums, specific events). Promising ways to improve awareness are television programmes and social network campaigns.

A number of the good practice examples identified were briefly presented, such as the Bernardo's Action With Young Carers (UK), 2 Dutch projects run by SIZ Twente and Vanzelfsprekend, the Australian-developed Resourceful Adolescent Program (RAP-A), the DNA-V Model and the Me-We model (which is currently being evaluated).

A shared common definition of young carers, early identification and insight in actual number of young carers will be crucial if awareness of young carers and their issues is to be raised. Support should be on offer, based on a whole family approach and integration in care and social system. Needless to say, services and support should be developed in close cooperation with young carers themselves.

More details about the Me-We research findings as well as policy recommendations - at European and country-specific level- are available at <https://me-we.eu/blog/>

Response

Marta Kuljon (European Commission, DG JUST) briefly introduced herself and the work of the Rights of the Child team, which is placed in DG Justice and Consumers and coordinated by Valeria Setti. Marta Kuljon warmly thanked the young carers present in the meeting and those that are participating in the project; their work and involvement is a clear example of the implementation of the basic principle of not talking about children without their involvement. This is a welcome development.

In preparing for the meeting Ms Kuljon looked into how young carers and their issues feature in the Commission's activities – and the result of her search was poor – there has not been any significant study on the situation of young carers, nor any specific project funded under the Rights, Equality and Citizenship programme, that would address the needs of this group. This underlines the need for projects such as Me-We to advocate for the right of young carers

She mentioned that during the last year Forum on the rights of the child, the situation of young carers was discussed in one of the plenary sessions, especially when it came to the assessment of best interests of the child. During the same event, young people themselves called for more focus, more support, funding, psychosocial assistance and more attention to be paid to children and young people.

In the context of mental health, the situation of young carers was discussed during ENOC's (European Network of Ombudspersons for children) general assembly and resulted in a recommendation being issued: Develop support programmes for young carers to enable them to better enhance and protect their mental health.

Obviously, the UN Convention on the rights of the child (UNCRC) has a direct bearing on children and therefore on young carers – but young carers and their needs and rights are not specifically addressed. Nevertheless, art 24 and its interpretation provided by the Committee in the General Comment no 15 clearly talks about the various factors that affect children's mental health, the need to address them and collect more data.

On missing data, Ms Kuljon informed about the European quality of life survey that will be launched again in 2022 and that she contacted Eurofound to check if it is planned to include questions on young carers below 18. The last edition included a question on young carers above 18.

It would be important to ensure that care services are more integrated, while safeguarding a case by case approach. In some situations social services remove children from their family – which is not always in the best interest of the child.

Ms Kuljon stated that she would report back on this meeting to her colleagues in order to create a better awareness, with a view to have a stronger focus on this topic in the future.

Sirpa Pietikäinen MEP then gave the floor to **Amy Dickinson** for a short response to what she had heard in the meeting. She stated that, given the choice, she would have done the same and cared for her mother – but more recognition of her support need would have been extremely welcome.

She also underlined the fundamental importance of peer support and of making services and support fun services rather than as yet another obligation. Care should be integrated, and good practice should be shared and more widely implemented.

Sirpa Pietikäinen MEP thanked participants and speakers. She again underlined the importance of the topic and the need for the Commission to put in place an overall Carers Strategy, as proposed by Eurocarers.

This meeting led to new insights and recommendations for action and all these need to be built into a strong message for the Commission. The European Parliament will help to spread the word and will support this activity.