



European Parliament Informal Carers Interest Group

Young carers – challenges and solutions

Date: 6 March 2018, 11.00 – 13.00
Venue: European Parliament – Room A5E3
Topic: Young carers – challenges and solutions

Hosted by Sirpa Pietikainen MEP

Marian Harkin MEP welcomed participants and briefly introduced the Informal Carers Interest Group, which was launched in the European Parliament in 2007. The Group has been very active over the years, has addressed many issues and policy initiatives and has had an impact on policy development. This meeting was the first time for the Group to address young carers – a highly relevant theme which will be one of the priority topics for the Group as well as for Eurocarers in the coming period.

Marian Harkin MEP then read out two statements by the Interest Group co-chairs that could not attend today, i.e.

- **Jean Lambert MEP** reminded the audience that in 2013, the European Parliament voted for an own initiative report calling on the Commission to develop a framework for all types of care leave (Impact of the crisis on access to care for vulnerable groups 2013/2044). With the momentum of the Commission's Pillar of Social Rights and its proclamation last November, the opportunity should be taken to think about EU level research and action to improve the lives and protect the children's' rights of young carers. Although young people and children performing care duties are not explicitly mentioned among the principles of the pillar, those on "Education", "Equal opportunities", "Childcare and support to children" and "Long-term care" do together encompass a wide range of issues associated with the situation of young carers and the support they need. Jean Lambert expressed her desire for the Social Pillar (as it did for the work-life balance directive) to present a framework within which the EU institutions will undertake action for young carers. In order to push the topic onto national and European policy agendas more awareness and data is necessary. EU-wide surveys and research should fill the information gap and enable policy makers to improve the situation for young carers in the EU.
- **Julie Ward MEP** stated that, as a feminist and a children's rights champion, the issue of care is very relevant to her. Often, women are expected to provide care for their relatives without any form of recognition, financial or otherwise. This is highly problematic as care is dismissed as unimportant and

undeserving, when in fact it should be acknowledged as an activity that truly holds our communities together and contributes to the wellbeing of our society.

When care is provided by children and young people, the problem goes further. Children miss out on fully experiencing their childhoods, they fall behind with their education, are deprived of time to play, and often develop mental health issues.

Policy makers should ensure that children grow up in a positive environment that does not require them to take on responsibilities that the adults in their lives should take. This means investing in our social services in order to avoid situations which result in adults needing to rely on children for care. So, we must also support young carers' rights, in particular when it comes to access to education. Our schools' staff must be aware of the situation of young carers and be able to provide support, including on mental health.

Speakers

Marian Harkin MEP then introduced **Professor Saul Becker (University of Sussex)** as the first speaker, to set the scene and outline the key issues to inform the discussions. He started by defining young carers as 'children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. 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. Young adult carers are as above but aged 18-24'. Commonly, however, young adult carers in transition include 16 and 17-year olds too. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision."

There are 11 million children living in the UK. Three million of these live in households where there is chronic physical or mental health problem, illness or disability; 2,5 million are affected by their parent's mental health problems and 1,3 million are affected by their parent's alcohol problems. Over 360.000 have parents who are drug users.

The 2011 census for the UK (England and Wales) revealed that there are some 215.000 young carers under the age of 18 – an increase of 19% compared with the numbers ten years ago. These carers spend some 178.000 hours per week caring. A BBC survey, carried out in 2010, showed that, from a sample of 4029 pupils, 8 % are involved in personal and intimate caring activities (dressing, washing, showering) and 29% are involved in emotional care (keeping company, keeping an eye on the person they care for). Estimated numbers of carers in other countries: 170.000 in Australia (3-4%), 1.4 million in the US (3 %), 25.000 in Sweden (7%), 230.000 in Germany (5%) and 42.700 in Austria (4,5 %).

Mainstream research in this area was started in 1992; at that time there were no reliable figures, there were few projects or services addressing young carers; there were no policies for young carers, they had no rights or entitlements and there was little public or professional awareness or recognition.

The situation has changed: in the UK, there are statistics, there is research, there are rights and projects, there is recognition.

There are positive as well as negative outcomes when it comes to caring. On the negative side, there are restricted friendships; fear, silence and secrets, emotional problems and health problems. On the more positive side, young carers acquire a number of life skills including resilience, responsibility, maturity, caring skills, control and inclusion.

The transition from being a young carer to a young adult carer (between 18 and 24 years of age -) the process whereby young people move away from dependence for primary, emotional and financial support from their childhood family carers, and their needs for income, shelter and social life are met from a wider range of sources – can be problematic as caring can lead to educational problems, issues finding appropriate work, problematic home leaving and limited career and job choices. Schools are generally not supportive and little career advice is on offer. Many of these carers will continue to care into their adulthood, and their lives are affected by this.

Professor Becker underlined that there had been a 28% increase in this age group between 2001 and 2011 – there are currently some 230.000 of these young adult carers in the UK. They started caring at the age of 10 on average, with 52 % caring for their mother, 14% for their father, 14% for a brother, 8 % for a sister and 4% for a grandparent. In 1 in 5 cases these carers care for more than one person.

Young adult carers report a number of disabilities and difficulties:

- 45 % report mental health problems
- 25 % report dyslexia
- 21 % report physical disabilities
- 8% report learning disabilities
- 8 % report sensory disabilities and 4 v % report autism or Asperger's.

A quarter of the schooldays of young adult carers are affected and 5 % of school days are missed as a result of caring. Half of the days at college or University are affected with 3 days per month missed. And at work, caring impacts on 79 days per year with on average 17 days per year lost.

Reasons why children become carers include a mixture of culture, duty, not having alternatives, love, poverty, socialisation and others. Saul Becker outlined the continuum of children providing care, which starts with caring about (low levels of care responsibility, routine levels of caregiving, 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).

Her emphasised that it is the role of policymakers to move these young carers from a position of vulnerability – due to inappropriate care, excessive care, restricted education, reduced life chances, affected well-being, isolation – to a situation of growth where they learn, thrive, achieve, are protected and supported, enjoy life, are assessed and flourish as human beings.

Countries vary greatly in their awareness and action in relation to carers and much needs to be done in many cases to make a positive change. Strikingly, in some countries, the language does not even include words to describe and discuss young carers issues.

In conclusion, Saul Becker put forward some evidence-based recommendations:

- There is a need for greater awareness of young carers by governments, professionals and policy makers;
- Young carers face similar tasks and outcomes as older adult carers;
- Services can improve the health, education, wellbeing and future about market participation;
- Early interventions are important to prevent caring roles from becoming institutionalised within families;
- Caring roles can be reduced when families receive adequate support and when young carers have personalised interventions especially in the transition years;
- The aim is to reduce inappropriate and excessive caring and move young carers from a position of vulnerability to growth.
- And last but not least research and evaluation of projects and interventions are required: what works and why.

Sirpa Pietikainen MEP then gave the floor to two ex-young carers to provide an insight in what young carers face. The first, **Stefania Buoni (President & Founder of COMIP – Children of Mentally Ill Parents¹)** presented her association as the first association in Italy created by adult children of parents with mental ill health to advocate for young carers, who are often invisible and not listened to or heard and build support strategies and extensive networks to enhance the wellbeing of children and their families. In addition, the organisation develops partnerships with organisations, schools, sport centres, cultural/recreational centres, mental health services, family services and institutions to develop support for young carers who have (a) parent(s) with a mental disorder. Fighting stigma is another priority. As a former young carer Stefania Buoni spoke about her experience, in addition, she provided some strong statements from young carers, providing a real insight in their daily situation and the barriers and challenges they face.

Stefania Buoni made the case for the importance of giving young carers a voice.

More research into the facts and figures relating to young carers is needed as well as training of professionals, working in multi-disciplinary teams. Media campaigns and media guidelines to fight stigma are also needed, promoting resilience and providing relevant information on mental health.

When developing services, the whole family needs to be taken into account, as well as all social actors. Government should invest more into mental health prevention, as the protecting of mental health is a basic human right. Lastly, the motto should be ‘nothing about us without us’ – the voices of families and young carers should always be included in decisions that affect them.

¹ <http://www.comip-italia.org>

The second, **Kirsi Hokkila (Project manager ALISA-project, Finland)** told the audience her personal story. This powerful and moving testimonial underlined the invisibility and feelings of loneliness of young carers and their need for health and social services to take an interest in them. She stated that, during all the years when caring for her parents, nobody ever asked her if and how she was coping – which is shocking in a country such as Finland, with such well-developed health and social care systems in place.

Kirsi Hokkila is now involved with the ALISA project, which helps to develop services for families and raise awareness on the situation and needs of young carers.

More research is needed so that evidence-based interventions, taking a family perspective, can be put in place.

The next speaker was **Margaret Tuite (Coordinator for the rights of the child, European Commission, DG JUST)** who spoke of an Irish radio documentary (1999)² on the topic of a 13-year-old main carer, who had been taking care of her mother for the last six years, last to bed, first to rise, etc., which she heard several years ago and which made a strong impression; this documentary illustrated very well the absence of support for families and young carers, and highlighted the resilience of young carers very clearly. This level of burden on children cannot be tolerated; many rights of the child are or may be violated, such as primary consideration of the child's best interests, the right to association including to have friends, to non-discrimination, to play and leisure, to education and several others, including the state's responsibility to support parents in their primary caregiving role.

Reflecting their general invisibility (apart from in the UK), young carers are not visible as a group in EU policies, including in the area of early school leaving.

It is very difficult to find information on young carers at European or national levels. Eurofound's Quality of Life Survey covers adult young carers (18-24) but not younger carers. Their next Quality of Life Survey could potentially address this. The survey is targeted at people over 18, but it should still be possible to ask if there is a young carer in the household, and the survey covers at least 1000 respondents per Member State.

Margaret Tuite underlined the role of the European Network of Ombudsmen for Children, given the Ombudspersons' role in safeguarding the rights of the child and hearing complaints from children and on behalf of children. Every year ENOC focuses on a particular theme and in 2018 the theme is mental health. This theme is also relevant for young carers, and for young carers who are in that position because of mental health issues in their family. Young carers' associations should contact ENOC/their national ombudsperson for children. http://enoc.eu/?page_id=15

² <http://www.rte.ie/radio1/doconone/2010/0824/646491-radio-documentary-caring-for-mam/>

There are other ‘hooks’ such as the European Pillar of Social Rights, which explicitly refers to children. Principle 11 concerns child poverty and the right of children who are disadvantaged to extra support to ensure equal opportunities.

We must bear in mind that the EU and most Member States have ratified the UN Convention on the rights of persons with disabilities. Young carers may be young carers because of the lack of supports for persons with disabilities; we need systems to do much better to protect the rights of children in this respect. While being a carer may provide a child with some skills, it cannot be tolerated that children are required to take on such responsibilities, often as the main carer. State systems should support families and ensure that no such burden falls on a child. The ME-WE project, currently being implemented and referred to by some of the speakers, will also provide invaluable data.

She said she would be willing to circulate some information on young carers to stakeholders for the rights of the child in a forthcoming newsletter, to raise awareness on the issues, and invited participants to send her material in that regard (short description, URLs, contact details). EC-CHILD-RIGHTS@ec.europa.eu

Respondents

Turning to the respondents, **Sirpa Pietikainen MEP** first gave the floor to **Diana Eriksonaite (European Commission, DG EMPL)**, who stated that this topic is not new to her as she was a young carer herself and clearly recognised many of the topics and issues that had been raised by the young carers as well as by Saul Becker. She then provided the context of her work with DG Employment in relation to care provision, stating that the EU-level remit in this area is very limited. Care provision remains the responsibility of the Member States; however, the challenges are common and Member States have agreed common objectives in relation to long-term care. The work concentrates on access to, and quality and sustainability of health and care services, and while the Commission cannot push Member States, work is ongoing – as part of the Social Open Method of Coordination – to develop a portfolio of indicators in the field of long-term care. This work has just started.

There is a lack of data on young carers as well as a lack of common indicators and both of these are required to push for change and action. A Common Framework of indicators is being created and the topic of young carers could well find a place within this Framework.

The Commission is also encouraging the promotion and dissemination of good practice and it seems like the climate is changing: there seems to be a more interest and greater willingness on the part of Member States to discuss topics related to long-term care. The current discussions on Work/Life balance are a clear indication of this greater interest. In addition, EU funds a number of projects, which would be relevant to carers and young carers in particular.

Diana Eriksonaite ended her statement by underlining that, while caring can have many negative consequences, young carers also acquire many relevant skills – and these skills must be made more visible, validated and recognised. In many cases, carers themselves are not aware of these skills.

The second respondent, **Jana Hainsworth (Secretary General, Eurochild)** briefly introduced her organisation and expressed her appreciation for the topic of today's meeting; this truly resonates with Eurochild as there is a clear case to make these young carers more visible; they have the right to be heard. Eurochild aims to promote a greater consciousness of the skills of children and works with a network of children's rights organisations some of which are quite active ((e.g. Wales, Scotland).

Currently there is a momentum at EU level around the rights of children and investment in children; there is a recognition of how childhood experiences shape the life of an individual. There is a Commission Recommendation on investing in children, along with a policy paper and accompanied by a set of indicators. The ambition would be to have an indicator on children's wellbeing, and Margaret Tuite's suggestion to incorporate that in the next Eurofound Quality of Life Survey is very welcome.

Eurochild is involved with the European Parliament Interest Group on the Rights of Children, which is doing a great job on focusing on children's rights. Giving children a voice and the active participation of children is actively being sought in a number of ways, e.g. Eurochild's Children's Strategy, Children's Councils and National Children's Forums and many topics, also relating to vulnerable children, are being addressed.

Jana Hainsworth expressed her support for the notion to address families as a whole as the ecological framework that the child is growing up in should be empowered. Work around parenting interventions and training of parents, supporting the protection of children is a crucial part of Eurochild's activities. The current trend towards de-invest in community and family support is a negative development. Children should be enabled to advocate for their rights; they should have the space to express themselves and get the support they need.

Discussion

Sirpa Pietikainen MEP, introducing the discussion, underlined the relevance of the topic, stating that for her, the most striking feature is the invisibility of young carers to health and social care services. She asked participants to specifically address what could be done by the various stakeholders (Commission, Parliament, governments, NGOs.) to change the situation. In the discussion the following issues were raised:

- ✓ DG JUST runs a newsletter which is sent to 2000 relevant stakeholders. Persons and organisations active in the field of young carers were invited to contribute articles and statements.
- ✓ As a first step we need to raise awareness as many governments and services providers instances are unaware rather than unwilling. The Commission could have a major role in this respect, bringing together the different agencies, e.g. carers organisations, children's organisations, disability organisations. Such an awareness campaign should be broad and owned by all. The next phase would be focused research in order to develop policies and actions as the third step. The final step would be putting policy into practice.
- ✓ Research findings from one country are often not used in other countries. Cross- fertilisation is low. Reliable evidence should be better shared and used.

- ✓ Policies should be multi-sectoral and composed of different strands.
- ✓ For many participants, hearing about the sheer numbers of young carers was a real eye opener. Many participants spoke of how impressed they were by the statistics and the testimonials.
- ✓ It will be important to take a life time perspective in relation to young carers as what they take on in the childhood has a far-reaching impact on the rest of their lives.
- ✓ Showing an interest in young carers, asking how they are coping – it can be life changing. One interested person can change a young carer's life as it will provide him/her with a sense of having the right to feel what they feel and speak out.
- ✓ Attention should be given to the issue of transition. In Scotland for instance, young carers can have support – but when they get to the age of 18, there is no support at all.
- ✓ The skills acquired by young carers should be validated and recognised and put to use.
- ✓ Eurocarers has set up a special working group on young carers, which now comprises 21 members from 11 States. The idea behind this Group is to share experience, learn from each other and combine efforts to enable change. Eurocarers has also developed a policy brief which contains a number of recommendations for action and which is available at <https://www.eurocarers.org/Young-Carers>.
- ✓ Eurocarers is also planning a campaign around the next International Conference on young carers, which will take place in Brussels in 2020. All participants are invited to support this activity and help turn this into a success.
- ✓ The social media can be used to raise awareness more effectively.
- ✓ Young carers from vulnerable groups, such as ethnic minorities and migrants, should not be forgotten.
- ✓ Speaking in the discussion, three young carers from Ireland – invited by Marian Harkin MEP - provided moving, open and strong testimonials. Once again, the lack of support for and the invisibility of young carers was made clear. Their input was highly appreciated by all. It is crucial to hear the voices of those that are involved with caring on a day to day basis.

Conclusions

MEPs Sirpa Pietikainen, Marian Harkin and Heinz K. Becker all underlined this topic as a very critical issue, which is underestimated and under-understood. It needs to be acknowledged and addressed now – there is no time to lose.