

Young People as Young Carers



Innovative research on the basis of fact-based data enables...

There is little awareness about children, adolescents and young adults involved in caring for care-dependent relatives. Careum Research is now closing this gap with their research and development programme stretching over several years, developing specific proposals for demand-oriented measures to support.

Often when children, adolescents and young adults take on caring duties, the care-dependent person is a parent, but they could also be siblings, grandparents or other relatives with a physical, mental or cognitive health condition. The caring duties lead to a type of responsibility which normally would be associated with adults. There are many reasons why they take on the caring role, from the absence of other family members or friends to the lack of suitable, financially feasible and professional care arrangements.

There is a research gap regarding the situation of caring children, adolescents and young adults under 25 years in Switzerland. The number of caring children and adolescents, the kind and the extent of tasks, as well as their impact are unknown. The needs and wishes of the young people with a caring role and their families are also unexplored. Moreover, until now there has been no awareness of their situation. The research programme "Young Carers and Young Adult Carers in Switzerland" aims to close this gap in data and research in Switzerland. The programme began in



... measures to support young people in education with a caring role.

2014 and consists of several, consecutive long-term subprojects.

"learn & care" – a global phenomenon

International studies show that young carers and young adult carers are a global phenomenon. In countries for which studies are already available, the proportion of children and adolescents under 18 years with a caring role is between 2 and 4 per cent. For young adults under 25 the percentage is higher. Similar numbers are assumed for Switzerland.

Careum Research possesses long-standing expertise on caring relatives. Since 2007, research and practice projects have studied the compatibility of professional activity and care for relatives, which is labelled as "work & care". But questions of compatibility arise during the entire course of life. For that reason reliable data is required on the situation of children, adolescents and young adults in Switzerland who take on a caring role and are therefore confronted with the challenge of "learn & care". Data-based facts are the foundation to develop specific measures.

Existing studies from abroad demonstrate the long-term effects on children and adolescents who take on caring roles. For example, this can have a serious impact on education. The inability to concentrate on school work as a consequence of the lack of sleep, and frequent absence can lead to poor

results. Meanwhile in Great Britain, the country of origin of young carers research, the awareness of the challenges of children, adolescents and young carers has increased due to numerous projects. As a consequence, the impact on education is now being addressed. This positive development suggests that improvements for children, adolescents and young adults with a caring role in Switzerland are also possible.

According to existing international studies, not only health professionals but also professionals in education and welfare need to be sensitised to the situation, as these are the people who young people come into contact with, due to compulsory education and occupational training/professional education. The allocation of mechanisms of support for children, adolescents and young adults with a caring role requires (re) cognition. Therefore their sensitisation to this topic is crucial.

Subprojects

- *Qualitative investigation and practical tools:* The first subproject (1) of the research programme evaluates the nature and intensity of the care, the way into care, and socio-economic and demographic circumstances of caring children, adolescents and young adults and their families as part of a qualitative study. Also, the perspective of professionals who can provide prevention and sensitisation for this topic is examined. Based on the results, the second subproject (2) will develop specific tools to support professionals in health and social services (e.g. GPs, A&E departments, protection authorities for children and adults), which will support them in their daily work.

External funds: Ebnet-Stiftung

Duration: February 2015 until December 2016

- *Quantitative and qualitative data:* The aim of the three SNF subprojects is to obtain reliable data on the nature, characteristics and intensity of care and support activities. Furthermore, a nationwide online survey has been developed which examines the awareness of professionals in education, health and social services of caring children, adolescents and young adults in Switzerland. In order to assess the number of caring children and adolescents, and to document the tasks they perform, around 12,000 children will be interviewed using standardized instruments.

In subproject 5, semi-structured qualitative interviews will be conducted with affected children, adolescents and young adults and their chronically ill relatives from 20 families in order to consolidate and validate the results of the quantitative subprojects 3 and 4. With this research approach, the impact and importance of issues and topics identified in previously published studies can be explored directly with family members in need of care, and with

young people who have a caring role.

External funds: SNF Money Follows CH-UK, 10001AM_160355

Duration: October 2015 until October 2018

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Version: march 2017

