



## **Country's Awareness and Policy Responses to Young Carers: A Matter of Choice**

Prof. Dr. iur. Agnes Leu & Prof. Dr. Saul Becker

6th International Carers Conference, September 3-6th 2015, Gothenburg, Sweden

# Country's Awareness and Policy Responses to Young Carers: A Matter of Choice

---

1. Introduction
2. Needs of YC & YAC
3. Classification of country-level responses to YC
4. Key factors that influence a country's awareness and response to YC
5. Discussion

# Careum Research

## Objectives

---

- The objective of Careum Research is to have a decisive impact in the area of innovative and sustainable healthcare provision. It concentrates in particular on **domestic and inpatient long-term care and health services research**.
- Careum Research focuses consistently on **promoting the skills and participation of patients and relatives** and on the overriding issue of living with chronic illness.
- Careum Research campaigns for the transfer of methods and specialist knowledge from research to teaching, thereby fulfilling its mandate from the Department of Health of the Kalaidos University of Applied Sciences in its capacity as a **research institution**.

# Careum Research

## Strategy

---

- Since **2007**, the topic of compatibility has been sustainably established as a key issue and continuously expanded to include the following additional key research areas:
  - Care migration to private households in Switzerland
  - Coordination with service providers and cost centers
  - Promotion of self-management
  - Care and assistance in people's professional and private lives (double-duty caregiving) and distance caregiving
- Since **2014**, an additional key research area has focused on children, teenagers and young adults, one aspect of which is known as «learn & care» – the compatibility of school, basic vocational training and university courses with the caring role.

# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

---

Research in different countries shows a relatively **uniform** picture of

- characteristics
- experiences
- needs

of YC & YAC.



# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

---

## **Needs of YC & YAC (1/2)**

### **Advice, information and guidance**

Money, benefits, grants, careers, services, medical conditions, own health, keeping well, managing care safely, transitions, parenting advice and support

### **Services and support**

Counselling, relaxation, breaks, assessments, emergency planning, transport, housing, aids and adaptations, transitions support

### **Education and training**

Early interventions to reduce inappropriate caring and produce better outcomes, anti-bullying strategies, greater awareness and support in all places of education, advice and assistance about educational opportunities and finances, assistance with balancing demands of learning and caring

# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

---

## **Needs of YC & YAC (2/2)**

### **Job-seeking and careers advice**

Careers advice up to 24 years of age and sensitive to caring, advice about flexible training & learning opportunities, job-seeking support and skills training, carer-friendly employment practices and workplace support

### **Activities and peer support**

To promote physical and emotional well-being and inclusion/participation, local leisure services, affordable/subsidised, meet other young adult carers, social networking

# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

---

- C** Choice
- A** Access
- R** Respect
- E** Education
- R** Recognition
- S** Support





# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

	Classification of country-level responses to YC	
Level 1-6	Characteristics	Country Example
1 Incorporated/ Sustainable	<ul style="list-style-type: none"> <li>• Extensive awareness at all levels of the experiences and needs of young carers</li> <li>• Sustained and sustainable policies and interventions aimed at meeting young carers' needs and promoting their health, well-being and development</li> <li>• Responses built on a foundation of reliable research evidence and clear legal rights</li> </ul>	None
2 Advanced	<ul style="list-style-type: none"> <li>• Widespread awareness and recognition of young carers amongst public, policy makers and professionals</li> <li>• Extensive and reliable research base</li> <li>• Specific legal rights (national)</li> <li>• Extensive codes and guidance for welfare professionals and national and local strategies</li> <li>• Multiple dedicated services and interventions nationwide</li> </ul>	United Kingdom

# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

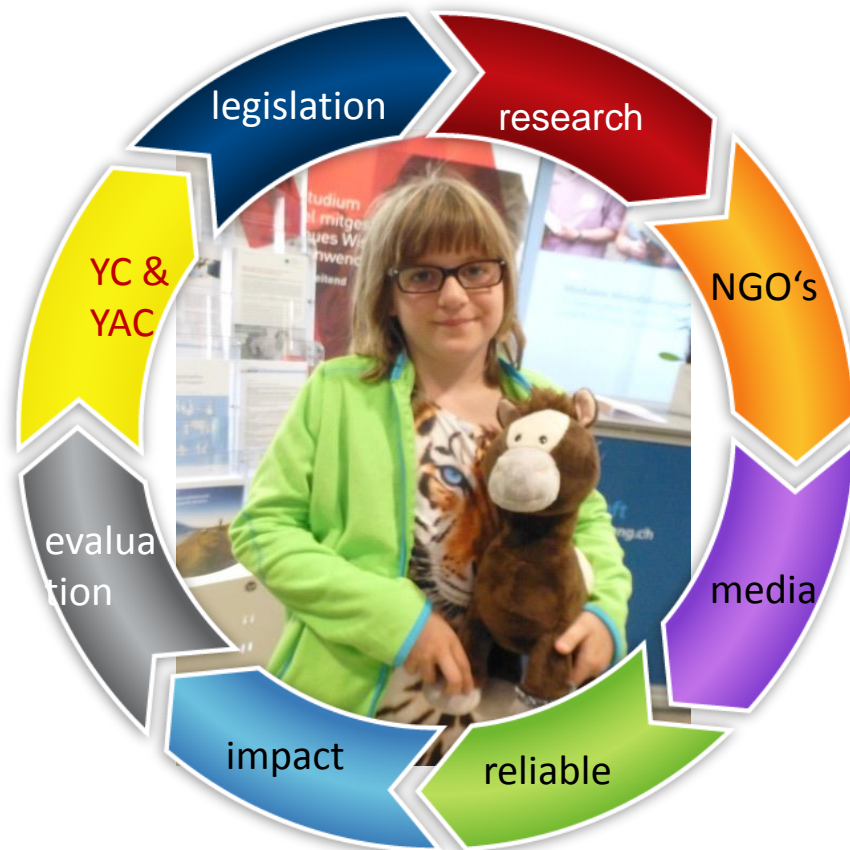
	Classification of country-level responses to YC	
Level 1-6	Characteristics	Country Example
3 Intermediate	<ul style="list-style-type: none"> <li>• Some awareness and recognition of young carers among public, policy makers and professionals</li> <li>• Small research base</li> <li>• Partial rights in some regions</li> <li>• Small but developing body of professional guidance</li> <li>• Some dedicated services and interventions nationwide</li> </ul>	Australia
4 Preliminary	<ul style="list-style-type: none"> <li>• Little public or specialist awareness and recognition of young carers</li> <li>• Limited research base</li> <li>• No specific legal rights</li> <li>• Few, if any, dedicated services or interventions at national or local levels</li> </ul>	United States Norway Sweden Germany Austria Switzerland Canada New Zealand France

# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

	Classification of country-level responses to YC	
Level 1-6	Characteristics	Country Example
5 Emerging	<ul style="list-style-type: none"> <li>Embryonic awareness of young carers as a distinct social group within the «vulnerable children» population</li> </ul>	Sub-Saharan Africa China Japan Taiwan
6 No-response	<ul style="list-style-type: none"> <li>No apparent awareness of policy response to young carers as a distinct social group</li> </ul>	All other countries

# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

**Key factors that influence a country's awareness and response to YC**



# Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

---

## **Key factors that influence a country's awareness and response to YC**

- Role of individuals and young carers themselves
- Reliable research evidence base - a «door opener» for policy transfer
- Legislation and initiatives - a commitment to children's rights
- Leading role of key NGOs and media

## Selected literature

---

- LEU A., FRECH M. (2015) Pflegende Kinder, Jugendliche und junge Erwachsene - Noch unsichtbar, aber nicht vergessen. *Krankenpflege* 8/2015, p.9-11.
- LEU A., SCHERRER A. (2015) Pflegende Kinder und Jugendliche leisten äusserst wertvolle Dienste. *Clinicum*, 12(2), 52–53.
- BECKER S., LEU A. (2014), Young Carers, in: Oxford Bibliographies in Childhood Studies. Heather Montgomery (Hrsg). New York: Oxford University Press.
- LEU A. (2014) Identifikation pflegender Schülerinnen und Schüler – eine neue Herausforderung für die Bildungsinstitutionen in der Schweiz? *Schweizerische Zeitschrift für Heilpädagogik* (SZH), Jg. 20, Nr. 9.
- LEU A. (2013) Caring without worrying – pflegende Kinder und Jugendliche in der schweizerischen Hausarztpraxis, *Primary Care* 4/2013.

Thank you very much  
for your attention.

# Contact

---

Further information <http://www.careum.ch/youngcarers>.

Please comment on our BLOG: <http://blog.careum.ch/blog/familycare-2/>.

Careum Research  
Research Institute Kalaidos  
University of Applied Sciences,  
Department of Health Sciences  
Prof. Dr iur. Agnes Leu  
Pestalozzistrasse 3  
CH-8032 Zurich  
Tel. +41 (0)43 222 50 56  
Fax. +41 (0)43 222 50 05  
E-mail [agnes.leu@careum.ch](mailto:agnes.leu@careum.ch)