

Collated responses to TOYAC Questionnaires from Ireland, Scotland, Italy, Germany and The Netherlands

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Method:

Ireland

7 responses were received from individuals/organisations, 4 of whom are working directly with young carers, 1 is involved in building capacity and interest within the wider NGO sector to develop support services, and 2 have a general interest in the carers area.

Scotland

4 respondents:

- Co-ordinator, The Scottish Young Carers Services Alliance representing a network of 38 young carers services. The SYCSA is the organisation which Scottish Government go to for information about Scotland's young carers. They are currently funded by Scottish Government to lead on the implementation of several of the national strategy's action points
- Young Adult Carers Workers, UPBEET project, Dundee Carers Centre a bespoke young adult carers service delivering a range of support to this young adult carers since 2006.
- Young Carers Festival Co-ordinator national remit to organise and deliver the national annual Festival engages directly with young carers throughout Scotland
- Scottish Mental health Co-ordinator, employed by the Princess Royal Trust for Carers in Scotland. The postholder works directly with carers of all ages, and with service providers throughout Scotland to support mental health issues affecting carers and young carers.

Italy

14 questionnaires collected: 2 members of condition-specific associations (Anfass and X fragile), 2 members of associations related to YAC ("I fiori sulla luna" and "Comitato Siblings Onlus"), 9 experts working in the social health sector in Emilia Romagna and Lombardia Regions (Social workers in Carpi District, local health authority supervisor, psychologist expert of carers self-help group management, public household services coordinator of Cesena)

Germany

As we could not find experts really focusing on this special group of carers, the TOYAC questionnaires were distributed to experts in practice and research who are interested in the topic of YAC, mainly as they felt the deficit for Germany compared to some other countries. We used the professional networks of the TOYAC Germany group to find potential experts for the questionnaire. A German translation for the questionnaire was developed by TOYAC Germany for experts to use in case of insufficient English skills. The questionnaires were distributed by postal mail and Email.

The Netherlands

The questionnaires were filled in by MOVISIE as the organisation who has an overview of the activities on national YAC activities. We also distributed the questionnaires to one Dutch researcher and an expert on YAC.

Question 1: Definition of Young Adult Carers

With regard to the definition of Young Adult Carers (YAC), the proposal is to use this definition:

'We define **young adult carers** as people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision."

→ Q	Countries	Ireland	Scotland	ltaly	Germany	Netherlands
1.1	Do you think it is necessary to adjust this definition for your country? Circle the correct answer.	Yes: 57% No: 29% Not sure: 14%	Yes: 50% No: 50%	Yes: 42% No: 58% One on the interviewees – a social-health sector pedagogy expert - said that in its district, within the disability department, the main carers are the disabled people 's parents. According to his point of view, parents usually take the whole care responsibility and charge in order to protect their "healthy" children. So that their children become carers when they are in their 40s. At that point they are unprepared to be carers and the emotional impact is very high and dangerous.	Yes: Yes (2 out of 6) No: No (4 out of 6)	Yes
1.2	In which way would you want to change this definition?	Expanding the range from 16-25 years of age The age of a young carer can be much lower than 18.	The quotes from the people who said yes: "We use a different definition – different age group and includes friends and wider family" 'A carer is someone who provides unpaid care and support to a partner, child, family member or friend who could not manage without their help. This could be due to age, disability, physical or mental illness or addiction. (The UPBEET project works with young adult carers aged 15-30) The definition should include friends as well as family members.	Majority: extending the age of the YAC (at least 28 years), especially in case of disabled people siblings. One person suggested to add that very often YACs provide care in cooperation with other carers and to integrate that behind providing care they promote the care recipients' autonomy.	Three experts suggested expanding the age limit in the definition. Two experts proposed including carers up to 30 years of age into the definition. One expert suggested lowering the age limit to acknowledge that the problems that YAC face are often rooted in early teenage years. One expert suggested including the aspect of 'Worrying' / 'Concerning about the carerecipient' into the definition, but without expanding on that or explaining it.	Young adult carers do not always provide or intend to provide care in order to be recognized as a young adult carer. Being worried about your family member can also be a burden. Not only providing care makes you a young adult carer.
1.3	Why? In your answer, think of social and cultural factors in your country as demography (age, gender, ethnicity, urban vs. rural areas, etc.) a. The image of age b. Health, of illness	NR: 71% Responses (29%): Many young people can effectively leave obligatory school attendance behind at age 16. Very often children are forced into becoming young carers.	e. Carers are entitled to a Carers Allowance from the state (£59 per week) once you are over the age of 16, so this might be a factor for young adult carers.	Young adult people live with their parents until they get married because of the Italian family organization together with the economical crises. This factor explains the reason why it's important to enlarge the YACs age. In fact during the period they live at home with their parents they are not asked to be responsible for a relative care, their parents will do that	Most of the respondents did not mention any specific reasons for the changes above. Only one expert argued with the fact that problems start much earlier, as already children take over responsibilities for care and continue as young adult carers.	1.2 does answer this question.

Countries • Questions	Ireland	Scotland	Italy	Germany	Netherlands
of relatives; c. The organisation of health care d. Social-economic situation e. Government policy f. Legislation g. Etc.			for them. Moreover in Italy, even the age when people get married is increasing (over 30) so that a carer providing care to his wife will be in his 30's.		
1.4 Among the following aspects which ones do you think play a role as causes of vulnerability? a. Limited opportunities, horizons, aspirations, educational and employment opportunities are often limited by the role they play in the family (educational underperformanc e (due to low attainment and attendance), barriers to paid work (because there is very little 'spare' time over and above caring responsibilities to actually go out and find or get a job, or keep it) b. Difficulties in leaving home: of the most challenging issues for all Young Adult Carers concerns their ability to leave home as and when they wish. c. Lack of understanding from peers, restricted friendships, limited	issue but certainly lowering the age to 16 would be significant in this regard though that may not be reflected in all jurisdictions in the study'.	All aspects according to all respondent.	 Yes: 75% YACs have problems in looking for a job because of their care charge No: 0% Yes: 50% No: 12% Young people in Italy stay at home with their parents until they are in their 30s because of the Italian culture and because they are unemployed. Yes: 58% No: 17% YACs are often isolated because of their difficulties in talking with other people about their situation. Yes: 75% No: 0% YACs very often perceive their role as a constraint, that because their parents or public services haven't trained them to become a carer. A balanced development The carer perception of himself as a misfit The lack of awareness in being manipulated The quality of the intergenerational relationships The caregiving responsibility The YACs partner doesn't understand the needs linked to the care activity (lack of awareness and understanding on YAC 	a. Yes: (4/5) b. Yes (3/5) c. Yes (4/5) d. (4/4)	Yes, all the factors mentioned are important.

→ Q	Countries	Ireland		Scotland		Italy			Germany		Netherland	ds
	opportunities for social and leisure activities d. Emotional difficulties					situation)/ Prob YAC in having a balanced relation with his/her par Psychological sofor YAC by pub	a onship tner. upport					
	Are there specific aspects of Young Adult Carers that should be dealt with in the definition that are not yet mentioned? Which aspect(s)?					services The guilt-feeling YACs towards to parents and the problems to lead parents' house	gs of heir ir					
1.5	Could you indicate the relevancy of			Ireland	Scotland	Italy	Ger	many				
	these aspects in your opinion by	Limited opportunities		2	1	1,9		1,3	2			
	ranking these aspects? Use the	Difficulties in leaving home		2,8	2	3,7		2,8	4			
	numbers 1 to 4 (1 = most important aspect; 4 = least important aspect)	Lack of understanding from peer restricted friendships, limited opportunities for social and leis activities		2,8	2	2,5	1	,8	2			
		Emotional difficulties		2,4	1	1,6	1	,5	1			
		depending on the i Limited opportuniti peers were identifi	ndividual si es were ide ed as the m	tuation.' entified as the monost important asp	st important for	actors, followed by e respondent in each	emotional case.	difficultie	es. Difficulties lea	ving hom	ssues are potentially re ne and lack of understar ent rated as above.	
1.6	Why are these aspects most / least relevant in your country? In your answer, think of the socio-cultural circumstances mentioned earlier	Three did not respond to this question. While one felt that the limited opportunities some young carers have was most important. Three gave specific and detailed comments namely: i) I would say that there are huge mental health issues for these young people as their role is neither understood nor recognised. Normal opportunities for development are hugely restricted and even more so in rural areas. As a result relationships suffer and young adult carers feel very much alone. Flexibility and understanding in educational settings is not	aware this g Scottle of at I service carers aware group exten service needs 2. We w yacs multip Our s aroun individ	is a growing eness of the need roup of carers in and, and we are a east 9 bespoke es for young adu so. Other services of the needs of and seek funding and improve the es to meet those	s of ware It are this g to eir of g, eeeds.	Emotional difficulties the most relevant: The Italian sociunresponsive to YAC situation and YACs are very left alone dealing his/her problems. There's no awa on YACs situating YACs role isn't recognize so the feel alone. Moreover, becautalian parents to protect their "he children" and puservices are all absent in this so YACs are unprest to carry out carry.	ety is of the often of with s. reness on, the at YACs use end to ealthy ublic nost ector, epared	German older as socially no proop service One ex 'emotio • YA the we exp who gran Anothe • Fin exc socially as the exp can be expected by the expected by t	eral, caregiving in my is associated ways, both politically. That is why there is for YAC. pert said this connal difficulties: C may have to do ir own feelings of Il as with the burd perienced by the pocares for the endparent in the far expert said this: ancial limitations clusion which can is the biggest present the biggest present in the farex.	with / and re are support cerning eal with loss as den parent, amily. lead to lead to thus	The emotional difficult the most relevant becoof YAC don't talk abous ituation at home, at swith others. They dea themselves. That's whabout 'hidden concerr sometimes also becar feel ashamed of the sA research by the Un Groningen tells that 1 of the children from pudiagnosed with cance serious emotional pro YAC's have limited opportunities. Research by De Veer shows for example the sometimes have less friends, sports or leist.	ause a lot ut their school or I with it by my we talk ns', use they ituation. iversity of 6 to 29% eople or have blems.

Countries • Questions	Ireland	Scotland	Italy	Germany	Netherlands
	being afforded to young adult carers and therefore many find themselves with limited opportunities. Many go on to work in caring careers, however many although having the opportunity to progress to third level feel that they cannot leave to pursue their own goals as their is no one to fill their role. Again this is particularly prevalent with young adult carers in rural areas. ii) The lack of general awareness among both peers and professionals may effectively cause (in my view) the isolation, poor support and limited opportunities. We do not have a culture of leaving home in Ireland in our young adult years; even when in college because of geography we tend to go home at weekends. We do have a culture of emigration particularly in current economic climate, so the caring role may impact on that possibility. iii) 'Due to the lack of awareness and support for young carers in school and in the community. Therefore the transition to adulthood is impacted by the effect of caring from a young age.' Can you give a short conclusion after reading these answers?	from this would not reflect a true picture of the whole population of yacs in Dundee.	activity. 2. Second most important are the "limited opportunities": • Because of the lack of public services support, YAC have less opportunity to keep studying or working than their peers. • The economical crisis is reducing the opportunities to find a job especially for YAC's who have a regular care responsibility and activity to carry out so that they cannot be flexible as requested by the labour market. 3. Third factor: "lack of understanding from the peers": • Moreover some of the interviewees pointed out the lack of social solidarity among the generations due to the economical crisis that has increased social injustice and economical inequality. Finally the aspect considered by the majority of the experts as the less relevant is the "Difficulties in leaving home" because in Italy young people usually leave their parent's house in their 30s (the reasons are mentioned above), so this situation concerns all Italian young people and not just those who have care responsibilities. Indifference to the YAC situation, social isolation and emotional charge. The problem that YAC become carer as a parents' substitute. He wasn't prepared to play this role. The economical crisis is a factor that is enlarging the emotional		activities. One out of three families with a chronically ill parent doesn't have enough money to go out once in 14 days. These parents can work less than healthy parents and sometimes they do less payed work because of there disabilities. Often, the difficulties of leaving home are not mentioned in the Dutch research or literature. YAC often feel lonely and do perceive both physical and emotional burden associated with caregiving tasks and illness-related worries. There is mounting pressure on family members to care for each other.

↓ Qı	Countries	Ireland	Scotland	Italy	Germany	Netherlands
1.7	Does your country	Yes: 14%	We have figures taken from the	 The lack of social recognition of the role make the emotional impact higher The characteristics of the labour market: insecurity and flexibility are difficult to be accepted by young people but especially by YAC that have a regular commitment with the relative care The poor support of the public and private sector (public services and private enterprises are not taking in consideration YAC problems and needs) The Italian family organization/tradition and the economical crisis make very hard to leave parents home for all young people and not only for YAC. In Italy we are loosing the solidarity among the generations, we have to pay attention to the social equality and justice among generations and to the wealth distribution. Yes: 8% 	No (5/5)	Yes
	have reliable figures on the number and characteristics of young adult carers?	No: 57% Comments: 'I would not say that the census figures for Ireland are reliable. A lot of young adult carers do not identify as young adult carers for various reasons.' 'Our census figures are the best we have. However, there are likely to be many YAC's who do not identify with the term and so are underreported in the Census figures.' 'When children reach the age of 16 and they have had poor attendance- they are no longer under the eye of the new and so can slip through the system.	national census in the UK in 2001. Experts in the field of young carers felt that the numbers which came from this under represented the actual numbers of young carers, as the form was often filled out by the parents who may be unaware of the care being given to them by their offspring. We are due to have the figures from the more recent census in 2011, made available to us later this year.	No: 75% Concerning the support given by grandchildren to their grandparents, one interviewee mentioned the following figures: 26,4% company activities 19,9% housekeeping activities 18,5% health care activities	Yes, but only concerning the characteristics of YAC (see next question) (1/5).	From research under children aged from 12-15, 25% is being raised in a family with a family member who needs care. (Youth monitor GG&GD Rotterdam and Utrecht). Research by Sieh indicates that 10%-13% of children is being raised by a parent who has a chronic medical condition. From research done in 2004 the following numbers emerge. Note: they define YAC from the age of 0-25. • 694.000 - 810.000 YAC live with an chronically ill parent. 409.000 -476.000 are younger than 18.

	Countries	Ireland	Scotland	ltaly	Germany	Netherlands
						About 95.000 - 190.000 YAC living at home give sometimes informal care tot heir parent. There are 1.200.000 YAC with a parent who has a psychiatric disability, 370.000 YAC with a parent with an addiction and 250.000-400.000 YAC with a chronically ill or disabled sibling (Tielen, 2004).
1	.8 When yes, what are the figures?	NR: 86% 1 R:See www.census.ie 10,005 people aged 15-24 described themselves as providing regular unpaid personal help for a friend or family member with a long term illness health problem or disability. 55% report providing 1-14 hours of care per week. See Appendix I for screen grab of Statistics) This is the closest age group available from the data.'	In Scotland, the numbers of young carers aged 16-17 were 5,482. The numbers of those aged 18-24 were 21,115. This is roughly 5% of the population in this age group.	NP	Unpublished results of a dissertation by Metzing: (Author's note: May refer to children, not YAC) YC have a logical understanding of the illness, disease They are empathetic and sympathetic Support with household chores and car for siblings Children rarely respond with anger or ignorance Children use unfavourable problem focussed coping strategies (favourable emotion focussed coping strategies) Desire for basic needs like health, harmony & safety Desire for appreciation, peer contact, relief of responsibility, opportunities for child-oriented play & games	See1.7
1	.9 When yes, which research shows these figures?	NR: 86% 1R: "see, http://www.cso.ie/px/pxeires tat/Statire/SelectVarVal/Defi ne.asp?maintable=CD850& PLanguage=0	This figures are from the Office for National Statistics Census 2001 data	Mentioned by one expert: G. Rossi e D. Bramanti (a cura di), Anziani non autosufficienti i servizi family friendly / Dependent elderly people: the family friendly services, FrancoAngeli, Milano, 2006, pubblicazione dell'Osservatorio Nazionale sulla Famiglia; G.Rossi e L. Boccacin (a cura di), Capitale sociale e partnership tra pubblico, privato e terzo settore. Vol. I. Casi di buone pratiche nei servizi alla famiglia / Social capital and partnership	The data above origins out of the project 'young carers Germany' in cooperation with the University in Flensburg. A study was conducted by interviewing 3 professionals and 11 children aged 7-12.	See 1.7

Countries • Questions	Ireland	Scotland	ltaly	Germany	Netherlands
			among public, private and no-profit sector. Vol I the good practices case within the services to families , Franco Angeli, Milano, 2007 FSS03: Indagine Multiscopo Famiglia e Soggetti sociali./ Multidisciplinary research on family and social actors. Anno 2003. Rappresentatività regionale. CPL07: Indagine di Ritorno sulle criticità dei percorsi lavorativi in un'ottica di genere./ Research on working pathways critical aspects in a gender perspective. Anno 2007. AVQ08: Indagine Multiscopo Aspetti della Vita Quotidiana./Research on daily life aspects Anno 2008. CDS05: Indagine Multiscopo Condizione di Salute e Ricorso ai Servizi Sanitari. / Research on Health condition and services. Anno 2005. EUSILC08: Indagine sulle Condizioni di vita. /Research on life conditions. Anno 2008.		

Question 2: Legislation and Support

Countries • Questions	Ireland	Scotland	Italy	Germany	Netherlands
2.1 Does your country have laws or policies focused specifically on young adult carers; do young adult carers have 'rights' or entitlements?	No: 71% Comments from 29%: Like older carers, they would be entitled to apply for financial and other supports for them and their caree, for example The Carers Allowance.' 'No - possibly but may not be enforced'	Yes: 100% Yes - In Scotland, the national Young Carers Strategy 'Getting It Right for Young Carers' has a distinct chapter about the needs of this group and action points to address those needs. All carers in Scotland (of any age) have a statutory right to an assessment of their needs.	Yes: 17% No: 75% Some of the interviewees point out the Law 104 that gives the right for a family carer to have special paid leave to take care of a relative with disabilities (according to the level of disability it's possible to have 3 days per month of paid leave, 2	No (5/5)	Yes: 100% In The Netherlands, there is no law specifically for young adult carers, but since 1-1-'07 there is a local law, the Dutch Social Support Act (Wet maatschappelijke ondersteuning or Wmo). The act aims at improving the service provision to citizens and

	Countries	Ireland	Scotland	Italy	Germany	Netherlands
			Currently the rights of young carers are within the UNCRC, but Scottish Government has asked the Scottish Young Carers Services Alliance to lead on the development of a Charter for Young Carers Rights. This work will begin soon.	hours every day, 2 years paid leave). The majority remark that there is no law either policy dedicated to young carers. So that they highlight that the YAC role is not recognized and underestimated.		clients. The Act gives municipalities and local institutions greater responsibility for the care and welfare of citizens. Among these citizens there are the familiy carers. The support of YAC can be seen as a part of the WMO, but is not documented as such. Each municipality can decide if and how much support they arrange for YAC.
2	2 Do public, private and voluntary organisations provide suitable strategies and services for Young Adult Carers?	Yes: 14% No: 57% Comments: 'I would imagine that generic supports are offered but that they may not be appealing to many young adult carers.' 'No not enough out there more funding needed'	Yes: 100% No: We are aware of 9 local authority areas which provide services for young adult carers. In the main, these services are based in the voluntary sector	Yes: 17% No: 75% One expert said there isn't a planned strategy but some on demand initiatives. Another one reinforce this vision confirming that services are provided on the basis of the needs and they cannot cover all the demand.	Very few. One expert mentioned a school education project by the German Alzheimer's Association.	Yes. But this also depends on the strategies of these organisations. Some organisations see YAC as an important target group, others don't. For example: professionals see that some children of people with a psychiatric disability need specific support. For this YAC group, the so called KOP-groups, They arrange interventions. in which YAC can share their experiences.
2	3 Young adult carers are often 'hidden carers'. Does your country use strategies to reach young adult carers? When yes, what kind of strategies? When no, why not?	Yes: 14% No: 71% Comments: 'Various organisations are beginning to address the issue. However from my own experience I have found it very difficult to make any significant progress. Having approached various organisations, networks etc to work on pilot projects there seems to be a blockage in firstly recognising that there is an issue and secondly a willingness to do any real work around it. There may be a perception that the issue is being addressed through mainstream services working with young people etc. However this is not the case. Young adult carers have specific issues and these need to be addressed in a stand alone manner. 'But the state has just set in play an initial Carers Strategy with elements aimed at young	'Getting It Right for Young Carers provides a specific strategy for supporting young adult carers – http://www.scotland.gov.uk/Publications/2010/07/23153304/0 The following resource highlights good practice: Equal Partners in Care http://www.knowledge.scot.nhs.uk/home/portals-and-topics/equal-partners-in-care.aspx	Yes: 0% No: 83% According to some experts in Italy there is no strategy because Italians believe that family problems have to be solved within family and they become family secrets. In that way YACs are invisible within the Italian society. Two interviewees belonging to siblings associations said that some support are offered by their associations. One interesting example is provided by one of them that reported the effort his association is doing in cooperating with the Hospital, the Municipality and the families f the YAC of disabled people, in order to create a local network.	No (5/5) One expert from the field of the work with elderly said, that this is not an issue in her field of work since carers for old people are usually older. Experts said that the focus of these strategies is mostly put on the primary carer. YAC are often not the primary carer. In general, the issue of YAC is not perceived in society and politics as a topic that needs to be addressed and since people don't see this as a problem, strategies will not be developed.	 Using the communication channels young people use. For example: placing information about YAC on a website like facebook and sites that are specifically created to support young adults. Some organisations ask people if they know YAC to let YAC know that they do something special. We try to involve schools in paying attention to YAC who might need some help or understanding. There are patient organizations and health associations that organize programs where YAC can meet each other and can receive help

	Countries	Ireland	Scotland	Italy	Germany	Netherlands
		carers'				
2.4	Which form(s) of caring are most recognised in your country?	Caring for older people. Other: Paid care work	(3/4) 1. Young carers, adult carers and older carers 2. We use the term 'caring' to include any type of unpaid care and support 3. Often it is where someone is looking after a person with an illness or disability which is 'visible'. Emotional support and caring is often overlooked or not even regarded as caring by those who are doing it. So those caring for people with mental illness and addictions are recognised, but not as much as those with physical caring roles. Also, the role of siblings is often unseen or overlooked.	The majority of the expert interpreted this question in general because, as it has been several time remarked above, in Italy there aren't specific policies addressed to young adults carers. Several experts point out the recognition of care provided to disabled people. Public services give support in terms of health services and economical grant. In particular the national law recognizes the social, educational and working integration and provided several services addressed to the care recipient but that indirectly support the main carer. (Law 104) Other experts mentioned the fund for dependent people (fondo per la non autosufficienza) that aims at guarantee at national level the essential care services provision for dependent people in order to create an integrated system between social and health services. In particular this initiative promote: the care continuity (protected discharges), the domestic care, physiotherapy, daily care centres, respite ,care checks) residential care (care centres with different intensity levels of health care assistance) 1R:Points out the recognition of care provided to people affected by cancer.	Caring for older people by professionals and family caregivers are the most common and recognized forms of caring in Germany. One expert stated that family carers are the "biggest nursing service of the nation", meaning that most care is provided by informal carers. Most of these informal, family carers do not use professional care service support.	Websites with information Groups for YAC's to share experiences Days out for YAC's Individual emotional support Attention from teachers at school
2.5	Why? Can you give an explanation? In your answer, think of the socio-cultural factors mentioned earlier.	Mental Health and Addiction issues were mentioned by a number of respondents. 'There seems to be very little recognition of the fact that a caring role can result from substance misuse or mental	(2/4) Scottish Government has taken steps to ensure that carers of all ages are recognised due to the economic value they contribute to the country. It also helps to support carers to achieve in	3R:They pointed out that the Law regulating the support to disable people care is based on the different level and type of disability. In particular, people with cancer have priority in receiving welfare checks	Demographic changes, increasing dependency Dependent people wish to stay at home Traditional role expectations! Caring for an older adult is morally and	The needs of YAC vary. That's why it's important to offer different kinds of support for specific needs. Not every YAC wants help and if they do, the scope of needed help is large. To illustrate, some YAC prefer support in the houdehold, some

Countries • Questions	Ireland	Scotland	ltaly	Germany	Netherlands
	health issues. The idea of caring seems to be very much focussed on disability or special needs.' Lack of awareness of supports was identified by one respondent. One respondent said: 'It is also more acceptable for an adult to care for a child than a child to care for an adult. '	education and employment to keep the economy as robust as possible, and to ensure that carers health is looked after to ensure that they can continue to provide care for their family member.	and benefits than other people with other kind of disabilities. Because the welfare system is unable to cover all the demand of support made by disabled people a part of the population in need don't receive any benefit. • One of them single out that thanks to this Law the role of the family supporting the disabled relative is recognized 1R:Highlights the poor resources of the Italian National Health System and the fact that in Piemonte Region several Foundations don't support economically NGOs or voluntary associations for the activities that they carry on in place of the public sector. Concerning the "Fund for dependent people" Fondo per la non autosufficienza) experts stressed different aspects according to their expertise/experience: • One of them highlighted the fact that this fund and in general the Italian welfare system have considered as priority to give support to the follow categories: dependent people, elderly people and disabled (on the basis of the seriousness of their conditions) • Another one said that in Italy there isn't a definition of care social levels at national level, so that each region has different definitions and regulation. Finally one expert made a consideration about the so called "Italian Family welfare", that illustrated the important	ethically accepted. So much that family members feel morally obligated to take over care. Caregiving is a taboo. It is a family problem, not a society problem Support services are little transparent, so carers often don't know them and are left alone with their responsibility Family caregiving is also a lot cheaper than professional care. "Quitting" on caregiving is very difficult	YAC choose counselling, while others rely on fellow sufferers.

▼ Ques	Countries	Ireland	Scotland	ltaly	Germany	Netherlands
				role of grandparents among the Italian families. They are very active and support their children through economical help and taking care of their grandchildren. It means that grandparents can cover the social support demand that public sectors is unable to satisfy.		
go po in de pre mu ad Ple wh pra me	e there any odd practices of olicy measures your country aling with evention for to uch/heavy orden for young ult carers? ease, indicate nich good actices and/or easures. If example: (Flexible) respite from care duties Having the needs of young adult carers recognised in the education system Services in regional and remote areas. Leisure time activities; One-to-one support The chance to socialise with peers; Effective co-ordination between staff of various disciplines, including social workers, mental health professionals, young adult carers' service workers and	Most RP: no Others identified respite care grants from the state. Other responses include; 'None specific to YAC's that I am aware of. However, we do have what is regarded internationally as quite generous financial supports for full time carers, although few YAC seem to be in receipt of these payments. I understand that third level educational institutions do have support and welfare services, that would be open to all assuming YAC's reach third level education.' 'We provide an annual 3 day break to teens living with a family member with multiple sclerosis many of whom would be informal carers'	The national strategy details action points for young adult carers. In response to those, the following is taking place: There are bespoke services in 9/32 areas in Scotland offering support to those who are struggling with their caring role. They offer a range of services, including Confidential access to information Personal development initiaitives Entitlement to benefits CV/interview skills Support to access flexible opportunities to combine their caring role with education, training and employment Short breaks Peer group activities One to one support The Scottish Young Carers Services Alliance are working with Scotland's colleges to assist them with the development of a benchmarking tool and awareness raising resources for their staff. The Alliance is a delivery partner in an Employer Recruitment Incentive (ERI) scheme for this group. The Trust employs a mental health co-ordinator to work with staff and external partners to promote mental health and well	 4R: Don't know 3R: In Italy there are policies for carers but they don't focus on young adult carers. In general the services provided for carers are the respite from care duties, the one-to-one support, the effective coordination between staff of various disciplines and part of the promotion of existing online resources. Other interviewees answered according to their experience: The professionals of the social and health care sector work on specific cases (i.e.: young single mother with an autistic child, sister of a disabled person, etc.), they don't have a modus operandi for YAC; The aspects nr. 5, 7 and 8 are desirable but she have never heard about similar measures in Italy he respite services are offered to all type of carers My organization has involved Municipality, professionals and volunteers in integrated actions to support young carers and it has promoted the socialization with peers Within the social services some key professionals intercept YAC and their situations and try to organize ad hoc experimental projects. 	Not many. YAC can use the same services as carers in general (e.g. respite and other long term care insurance benefits or reducing work hours at their job). There are a few online resources and model projects as well as support programs for specific groups of YC (for example for YC of drug - addicted parents or parents with a mental disorder). There are also a few leisure time activity programs and programs in remote areas. In general, counseling and support services don't specify their services to YAC. Financing of services is dependent on the fact to be assessed for the care insurance.	We have the community resources ('sociale kaart') which includes all organized care or possible information that YAC's need. Every region can use this recources and put their own organisations in it so that it fits to the regional or local situation. There are several interventions that aim to prevent sick leave and early school leaving. One of them is the so called M@ZL: Medische Advisering Ziek gemelde Leerling(medical advize on pupil reported sick). This intervention intends to reduce sick leave and early school leaving in class 1-4 on secondary school. In this intervention the school, the youth doctor and the compulsory official work together. Through this way, YAC's can be recognized and helped when needed. There are new initiatives focusing on early prevention of problem behavior in YAC. Sieh et al. developed Screening Instrument for Adolescents of Parents with Chronic Medical Condition (SIAPCMC), a short list of questions that identifies adolescents at risk for future internalizing problems.

↓ ▼ Qı	Countries	Ireland	Scotland	Italy	Germany	Netherlands
	 Promotion of existing online resources for young adult carers and professionals. 		being of young adult carers and assist them in the transition to adult services. Glasgow University has developed and adopted a Carers Policy – a move instigated by the Student's Representative Council. An Authorisation/Identification card for young carers is being piloted in 6 Health Board areas.			
	In your experience do the various support services work together for the needs of young adult carers? (Support services: services in education, employment, health and social care)	Yes: ? No: 57% No Idea: 14%	Yes: 25% No: 75% Yes: (1/4) – yes There is the beginnings of this on a national basis with employment staff from Skills Development Scotland to deliver the ERI, and also the above mentioned work with Scotland's Colleges. (3/4) – no There is work going on in Dundee to provide a joint action plan for yacs, but nothing yet.	No response	No (5/5) The issue of YAC is too new and unknown for service providers to work together. A first step would be to improve collaboration between youth service providers and health care services, says one expert.	Sometimes. When municipalities decide that they want to pay extra attention to YAC, they often work together with local organisations who can arrange this support, like organisations with volunteers, general practitioners, social work. However, the synergy between the various organizations involved should definitely be expanded. The coorperation between the organisations is often dependent on the personal commitment.
	How does your country raise awareness under (health care) professionals (for example teacher at school, General Practitioner, social worker) that they should be aware of young adult carers?	Carer organisations and a small number of staff in other organisations were identified as important in raising awareness. Other responses; 'Our new Carer Strategy mandates such a programme be developed'	1 was unsure, but said this was happening in their area because they were raising awareness, but did not reflect the picture across the country. National Festival Young Carers Strategy multi agency Implementation Group Teaching Resources for schools staff Work with Royal College of General Practitioners to produce information about carers of all ages. Authorisation card pilot. In development, national standards for carer training for professional staff across health and social work.	 5R: In Italy there is no policy to raise awareness on YAC situation under professionals. 3R: some initiatives has been carried out by NGOs/associations. 1R: many researches and projects have been developed on carers activities in general but she haven't read anything about YAC, the phenomenon is still hidden. 	Raising awareness has only just begun. Model projects try to disseminate their findings through the media and through conferences. Networking in the professional community is also another key element.	In the Netherlands, we have several national organisations intending to improve the support system for (young) informal carers. They try to arrange meetings with these groups, trying to convince them that they can play an important role in signalling YAC and supporting them. These organisations also make all kinds of materials that they can use, such as questionnaires to see if a YAC needs support and if yes, what kind of support. In addition, they also train professionals in their understanding and support of YAC's. Nonetheless, health care professionals still rely on patient-centered care, while a family-centererd approach is more recommendable for YAC.

Question 3: Risk factors and protective factors¹

In research many *risk* factors are mentioned:

	Risk factors	Number 1-5 Ireland	Scotland	Italy	Germany	Netherland s
Facto	ors concerning the person who is ill					
а	Lengthy illness duration of person who is being cared for	222	2	1,3	2	
b	Many limitations due to the illness	31	3		2,7	
С	Psychiatric problems of person who is being cared for	312	1-2-2		1,5	3
d	Low level of predictability on the progression of the illness	1	1	1,8	2,2	
Facto	ors concerning relations young adult carer					
е	Small social network, isolation	35	1-1-1	2,8	1,3	2
f	separation of the parent		5		3,8	
g	No recognition for the care a young adult carer provides	11434	1-1-2	0,8	2,3	4
h	Lack of bonding with the mother		4		3,5	
i	Single parenthood, the Young Adult Carers had one parent	1	5		3,5	
j	Low quality of marital relationship		4		4	
k	Parental depression		2-2-	1,3	1,8	
Facto	ors concerning the young adult carer itself					
ı	Few coping skills	252	1-1	2,0	1,7	1
m	Female gender of the young adult carer (girls are a greater risk for stress than boys)	5	5-5	2,3	3,6	
Othe						
n	High frequency of caring tasks	44	1	2,0	2,2	
0	Financial problems in the family	4435	1-2	0,5	2,3	
р	Little leisure time	554	3	1,3	2	5
q	Low socio-economic status (SES)		1-1	3,0	3	

Countries	Ireland	Scotland	ltaly	Germany	Netherlands
3.1 Could you indicate which 5 risk factors of all that are mentioned (not by category)		2 answers This would be too difficult without further consultation with young carers	Rankings are quite heterogeneous. Probably because in Italy there's no public debate on this issue and each professional follows	Although only six experts answered our questionnaire, some factors came up in at least two of the answers:	

¹ Risk factors raise the chance of negative influence on the young adult carer. Protective factors on the other hand decrease this chance.

Countries • Questions	Ireland	Scotland	ltaly	Germany	Netherlands
are the most important for Young Adult Carers in your opinion? You can do this by ranking these factors in the table above with the numbers 1-5 (1 = the most important factor; 5 = less important).		themselves. 2. We work with a number of young carers who differing multiple complex needs. Our support is tailored around those needs. What are difficult circumstances for one individual is not indicative of all young adult carers.	his/her own ideas and consideration, depending on experience and role.	 Psychiatric problems of person who is being cared for Small social network, isolation (mentioned by most experts) Few coping skills Financial problems in the family Lengthy illness duration of person who is being cared for 	
3.2 Can you explain why these 5 risk factors are most relevant for Young Adult Carers in your country? In your answer, think of the socio-cultural circumstances mentioned earlier.	Six responses (86%) 'I feel that these pertain to Ireland as we are starting from the very bottom here. In the Republic of Ireland at present it is all about the 'cared for' person and the carer is invisible. There is no holistic or whole family way of looking at the situation here. The carer's needs are totally ignored and therefore a variety of problems occur. ' 'I feel the risk factors are affected by the individual YAC, the family and their financial and social circumstances' 'Caring often begins at a young age and continues on into adulthood. As a child the caring may impact of school life, social life, emotional development, etc. As there are currently very little support and recognition of young carers under 18 this invisibility carries over when the carer turns 18.' 'I would imagine that psychiatric problems of the caree are likely to have a significant negative impact on a whole range of things for the carer, in particular if it is a parent they are caring for.' 'Poor understanding of the extent of care provided by young carers due to the level of secrecy, shame and lack of	As above	A common assumption of most of the interviews regards the peculiarity of the Italian welfare, the so called "familist model". In short: the supply of long term care for dependent people is traditionally characterised by a very low level of public provision, compared with other European countries. A highly selective public system, which provides social assistance for a small portion of the dependent people, has been set against a considerable capacity of family to internalise caring functions. In spite of its limitations, for many decades this model did not constitute an urgent public problem thanks to the strength of family ties. New phenomena are occurring today which greatly weaken the established system. A second common consideration regards the actually economic situation: the more financial problems are present in the family, the more family suffers and young carers are the most vulnerable ones. Other considerations: Factors concerning the person who is ill, such as lengthy illness duration, are very demanding factors for caregivers in general. In the case of YAC, they could have a devastating effect and represent the gateway to social isolation, drop out	This is what some of the experts wrote to the specific factors: •Psychiatric problems of the person in need of care are great challenges for an informal caregiver. Often professional skills are required. They change the behaviour of the person affected and thus also the relationship between the YAC and the person affected. •Isolation has a highly negative influence on caregivers of all ages, on young adult carers as well, as a study shows. Social support is one of the most important resources in coping with distress •Lengthy duration of the illness leaves little no time for rehabilitation and for "recharching" •Few coping skills: Without the knowledge of coping strategies stress of all kinds can't be tackled and the probability of mental problems of one's own increases One expert mentioned that social isolation in combination with a parent's depression can be very risky for the YAC. In those situations YAC might not be getting any recognition and credit for their work. They may feel like everything they do is never good enough.	All the factors are relevant. The ranking makes a list of the most important, but that does not mean that the factor on one is the only one that matters. 1. Few coping skills are the most important. 2. Small social network, isolation. A network can be of an enormous support. 3. Additional psychiatric problems of the person who needs to be taken care of. 4. No recognition for the care a young adult carer provides. Knowing that others recognise the care that you give can be very supportive. 5. Little leisure time, low amount of time to relax and emerging stress. This can be a threat for a healthy development of an YAC.

Countries V Questions	Ireland	Scotland	ltaly	Germany	Netherlands
	supports.' 'Because due to the nature of a long term disabling condition the young carer is likely to live in a family with reduced income and all the difficulties that living in poverty brings as mentioned above'		from education system and unemployment. Parental depression, and in general, psychiatric disease, is a very relevant risk factor for young adult carers; Young girls are more under pressure than boys for stereotypes and social expectations about their role inside family. It's a common opinion in Italy that this age group (18-24) is still to be protected by their family, that's why, in a paradoxical way, no facilities and services are provided for young adult carers. In Italy, children live with their parents until they get married, and are maintained by them so long as they stay in the family, even in families with a single breadwinner and weather they have a single income or not. Nevertheless, despite the fact the responsibility for maintaining and caring for children continues for so long and in spite for the moral and ideological emphasis on the family, manifested by all political parties, there is a general lack of family policy. The require of long term assistance for a YAC means the impossibility of planning one's own future. This condition of hopelessness is particularly severe if combined with financial problems.		
3.3 Are there any risk factors you miss? Which are these?	'Low level of awareness among family support professionals of the impacts - & + of the caring role; no formal identification or support pathways' 'There is a difference between caring for someone who is ill and someone who has a drug/alcohol difficulty. There is	1 answer The young adult carer's own health situation.	Yes: 40% No: 60% Law awareness about caring issues in places such as school, universities, enterprises. The persistence of the so called Italian welfare familist model and the resulting	One expert listed factors that mainly concern carers of cognitive-impaired carerecipients: Disorientation and verbal or physical aggression by the person in need of care towards the young adult carer. For example it is hard not to be identified as the	Yes: Physiological factors such as vulnerability to stress and personality issues. A very important risk factor is low quality of parent attachment (such as defined by alienation from the parent), and parentification (all processes involved in taking on

Countries • Questions	Ireland	Scotland	Italy	Germany	Netherlands
	also a difference between a child who is born into a family where an illness/issue is already present and one where a problem develops. The age of onset of the problem may have a large impact on the risk factor for the YAC'		practice of justifying and almost promoting the do-it-yourself in caring issues. • Factors concerning lack of policy	person you are. Another expert noted the issue of lack of social support referring to the topic being tabooed in family and society.	responsibility that may be burdening to healthy development and parent attachment).
3.4 Can you explain why this/these missing risk factor(s) is/are relevant for your country?	One key response was: 'It is very difficult to support a group of people not formally recognised or identified with recognition and needs assessments in place'	1 answer Worries about family and personal finances are a big concern are present as our welfare benefit system is under review and many families with disabilities are fearful of losing a vital source of income from those.	No specific policies and rules exist about YAC. Caring responsibilities, if not sustained, can give raise to severe dysfunction and problem in families till extreme situation such as abuse. Actually young generation is living a very difficult situation due to social crises and very high level of unemployment, especially in south Europe. If we add, to this structural problem, the personal experience of being a young carer, without specific facilities and help network, life could be really hard. The lack of programmes that promote and appraise the experience of caregiving.	Because of being a taboo in society, public aid and support is lacking. Especially programmes that are political (and financed by the states) only act, when distinct cases are reported (in the media; e.g. as in cases of child protection / abuse).	These risk factors are complex and need to be investigated further. They are relevant because they may play a decisive role in determining the risk for poor adjustment.

Protective factors:

In research many *protective* factors are mentioned:

		Ireland	Scotland	Italy	Germany	Netherlands
Prote	ective factors relevant for Young Adult Carers	number 1-5				
а	Social support from the social network	5413	1-1-1	2,4	1,3	2
b	Skills to find solutions	3	1-2-1	2,0	1,8	1
С	Cooperation between involved care professionals	121354	1-2-2	1,0	2,5	4
d	Appropriate assistance, counselling	252242	1-1	1,6	1,7	3
е	Participation		1-2	1,8	2,8	
Prote	ective factors relevant for society					
f	Raising public awareness	41513	1-3-1	2,8	1,8	5
g	Legislation and legal	3451	1-1	2,8	2	
h	Counselling services and support for YAC	3425	1-1-2	0,6	1,7	

\ ▼ Q	Countries	Ireland	Scotland	ltaly	Germany		Netherlands
3.5	Could you indicate which 5 protective factors of all that are mentioned are the most important in your opinion? You can so by ranking these factors in the table above with the numbers 1-5 (1= the most important factor; 5 = less important).	Two responses were given to this question; 'some young carers become victims of their own circumstances and unless the wider community in general is informed. People will live in ignorance and carers will hide in shame.' 'Appropriate assistance y/carers need to feel they are been listened to, that their opinion matter, and that there is some degree of practical support to help them in their situation.'	2 answers – 1 answer - Others were reluctant to answer this question, but from the ratings above, it would appear that: 1. Social support is most important 2. Appropriate assistance/counselling 3. Skills to find solutions 4. Co-operation between professionals 5. Participation 2nd answer – this is impossible for us to rate as a service provider. In our experience, these will vary for each individual young carer.	Answers split in two protective factors group: one who refers to norms and laws one who refers to social support and network.	Social support from the social network was mentioned by all of the experts. In addition, skills to find solutions, raising public awareness, counselling services and support for YAC and cooperation between involved care professionals were mentioned by at least two of the experts.		
3.6	Can you explain why these 5 protective factors are relevant for your country? In your answer, think of the socio-cultural circumstances mentioned earlier.	Responses were varied and were as follows; 'At present there is no cooperation whatsoever. Primary Care Teams are not working sufficiently and therefore community care is not effective. There is no crossover between the clinical and community aspects of the	2 answers Providing support and awareness raising helps identify young adult carers and provides evidence to identify gaps and inform service development	Support from family members and friends are most often described as caregivers' most important resource; Experts agree that when family network is not enough strong, services and professional must promote natural networks, such as neighbourhood and volunteers networks. Professional can promote programs which aim to	Social support from the social network is important because coping is easier if one is not alone. Raising public awareness results in increased recognition. Skills to find solutions are needed to enhance their own competence in caring. Counselling services and support for YAC are important	 2. 3. 	Skills to find solutions, among which stress management, coping skills training, cognitive behavioral therapy. Social support from the social network. This can help you practically and emotionally. Appropriate assistance, counselling. If the

\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \	Countries	Ireland	Scotland	ltaly	Germany	Netherlands
		HSE(Health Services). There is absolutely no awareness of young carers or perhaps an unwillingness to admit, for whatever reason, that this issue exists' 'Again it all starts with awareness raising for me. Creating the mechanisms to identify and support YAC and mitigate against the development of yet another silo of support all play a crucial role in improving protective factors in cooperative collaborative approaches' 'These counteract the risk factors. It is vital that there is recognition at political level in legislation to support the YAC or else it is done on the will of community services rather than with the backing of statutory support' 'A combination of these factors are important, again it will depend on the individual carer.' 'The current climate and culture doesn't try to empathize but rather to criticise, particularly when full circumstances aren't known.'		enhance the "total network" with the intervention working through the natural helpers within the network. Such natural caregivers are lay people to whom others naturally turn for advice, emotional support and tangible aid. They provide informal, spontaneous assistance, which is so much a part of everyday life that its value is often not recognized.	to provide or ensure the aspects mentioned above. Two experts stated that a combination of these factors would probably minimize the distress. Another expert mentioned that many good policies and services in these areas are existent in the general care area in Germany. They just need to be specialized for YAC as well.	assistance fits with your needs, it's easier to feel supported. 4. Cooperation between involved care professionals. Collaboration between caregivers work makes the situation easier for everyone. 5. Raising public awareness. This will help the recognition and support for YAC's.
3.7	Are there any protective factors you miss? Which are these?	NR	1 answer Access to adequate food and shelters	No: 70% Yes: 30% Economic help such as scholar ship Carer role recognition Maintain the continuity of caring, in particular after discharge from the Hospital.	 Information about the disease the cared-for person suffers from. Financial aid. At least one psychological stable, reliable parent Time-out / respite 	No.
3.8	Can you explain why this/these missing protective factor(s) is/are relevant for your country?	NR	1 answer As 3.6	The period after hospitalization is particularly at risk in case of severe disability. At the moment there are no facilities for YAC	 Information and education are important tools for coping. The lack of financial aid causes great distress. stimulates the resilience of the child/YAC (no explanation for "Timeout" was given) 	-
3.9	Can you give examples of good	NR	These would be the examples given previously as:	Majority: no	Only two experts were able to mention something here:	See the matrix with good practices.

Countries V Questions	Ireland	Scotland	ltaly	Germany	Netherlands
practices (of policy measures) in your country in which risk factors are tackled and/or protective factors are strengthened?		YAC support services Authorisation card pilot scheme Online schools resources ERI scheme Collaborative work with Scotland's colleges Glasgow University's Carer Policy	Concerning adult caregivers, many professionals describe that they are running self help groups on the basis of specific condition. In this context, young peer groups are rising too (groups for alcohol addicted sons and daughters, siblings, etc). Peer support groups can be an invaluable source of guidance, assistance, and encouragement. 2 good practices are reported and both concern self help group for siblings. Another experience is just draft because it is supposed to start spring 2013. The first is lead by the national siblings network and the second from local health service.	 Programs in schools that raise awareness for the needs of chronically ill persons or persons with psychiatric diseases amongst young people. Supakids (Hamburg) http://www.supakids.de/cms // Young carers (Schleswig-Holstein)http://www.youngcarers.de/ Seelenhalt (Hamburg) http://www.diakonie-hamburg.de/web/rat-und-hilfe/familien/erziehungsfragen/SeelenHalt-00001 However, all of those examples are focussed on young carers up to 18 years only. No specific offer of good practice for our target group could be found, only a booklet: 	

Question 4: Good Practices

	Ireland Matrix Good Practices 4.1. Different forms of support for Young Adult Carers					
Can y	Can you give good practices of policy measures in your country for support of Young Adult Carers?					
1.	Description of the good practice	One response was given;				
		'As mentioned above various organisations are now starting to look at the issue but unless you have buy in from the HSE, Schools etc. progress will be slow.'				
		Further: no response				

Matrix Good Practices 4.2. Different forms of support for Young Adult Carers No response

Can you give good practices of policy measures in your country for support of Young Adult Carers?

	Scotland Matrix Good Practices 4.1. Different forms of support for Young Adult Carers					
Can y	ou give good practices of policy measures in your c	ountry for support of Young Adult Carers?				
1.	Description of the good practice	3 answers - Youth Employment Strategy – Employer Recruitment Incentive				
2.	Goals: describe the main goals of the good practice	To provide a financial incentive to employers to employ a young adult carer				
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	Young adult carers – aged 16 to 24				
4.	Approach: describe the way in which the good practice is implemented.	Employers are given information about the funding available and the support available to the young adult carer. Employers are also given information about the issues affecting young carers – what may be barriers to them sustaining employment, but also about the skills and attributes they have because they are a carer. Employers may be approached by the young carers themselves, or by the service which provides support to them.				
5.	Who implements this good practice? Mention, if relevant, the organisation or persons who do the work.	The funding was awarded by Scottish Government to Skills Development Scotland to work with delivery partenrs. As the largest network of services in Scotland, The Scottish Young Carers Services Alliance (SYCSA) was invited to deliver this for young carers. The services within the SYCSA act as job coaches and job finders. The admin team for the SYCSA (through the Carers Trust) provide the administration for the sceme and make the payments to employers.				
6.	What material is available on this good practice (description, website etc.)	This is the ERI for Targeted Young people and young carers needs have been acknowledged as well as those of looked after children and young offenders.				
		http://www.skillsdevelopmentscotland.co.uk/our-services/services-for-employers/recruitment/employer-recruitment-incentive.aspx				
		There is also a leaflet available from the SYCSA (not yet online). We have also produced a Case study for the scheme which has not yet been put on line.				
7.	How widely is this good practice used in your country?	We have a target to support over 100 young carers into employment over 3 years. Starting in July 2012, the scheme has been slow to get staerted for young adult carers, as this is a new area of operation for the workers who provide support. However, we have successfully supported over 6 young people so far into permanent employemt, and have many new referrals as we speak.				
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).	These are yet to be collated into a report, but we have produced a case study of a successful young woman for our funders. This can be provided to appear to the ToYAC website.				
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.	Not yet				
10.	What are the success factors?	Employers are more aware of carers in the workplace, their issues and attributes and how they can be supported				

	otland		
	Matrix Good Practices 4.2. Different forms of support for Young Adult Carers Can you give good practices of policy measures in your country for support of Young Adult Carers?		
Can y 1.	Description of the good practice	2 answers:	
'.	Description of the good practice	The national annual Young Carers Festival – this is for young carers up to the age of 18.	
2.	Goals: describe the main goals of the good practice	To give young carers of all ages across Scotland the opportunity to have their voices heard through a variety of consultation methods. This includes them talking directly to local and national decision makers about the issues which affect them. A secondary goal is to give 500 young carers a break from their caring role.	
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	The event programme is targeted at young carers of secondary school age, but open to all young carers up to the age of 18.	
		Government Ministers, Members of Scottish Parliament, Local Councillors, Provosts, Chief Executives of Local Authorities and Chairs of Health Boards, the Children's Commissioner are also invited to come along on the last day of the event.	
4.	Approach: describe the way in which the good practice is implemented.	This is a yearly event, held in the summer. Scottish Government provide funding for the event, and also funding to cover substantial travel costs and staff costs for the groups attending. There is a training event prior to the festival open to 16-18 year old young carers to provide them with the skill s to run the Festival Radio station, and to help them develop interview skills. During the festival, they interview their peers, play music requests, and also interview invited guest, often government ministers. In 2012, 3 Minsters attended the Festival, and this was a record turn-out! The event is held at an outdoor centre, and accommodation is in bunk-houses for around 200 participants, and the others are camping in tents. An activity programme runs throughout each day and there is entertainment at night in the marquees. The festival is now a 3day event, in response to feedback from the young carers.	
		Consultation takes place during the 1st and 2nd days in various ways, interviews, writing on walls, answering questions, speaking to camera, or i-pad. On the 3rd day, the young carers engage with invited guests in 'political speed dating scenarios', round table discussions and a larger question and answer panel.	
		The issues raised at the event are made into a report and sent to Scottish Government and other stakeholders.	
5.	Who implements this good practice? Mention, if relevant, the organisation or persons who do the work.	The Festival is run by the Carers Trust, who employs the staff who organise the event. The event is directed by a mult agency steering group of national carers organisations, including the Scottish Young Carers Services Alliance, and other national children's organisations.	
6.	What material is available on this good practice (description, website etc.)	There are copies of the report and a dvd of the event available. Reports can be found on http://professionals.carers.org/young-carers/articles/the-scottish-young-carers-festival-report-2008,4200,PR.html	
7.	How widely is this good practice used in your country?	This event was established in 2008, and we are currently preparing for the 6th event in August of this year. It is open to all young carers in Scotland. Our experience is that about 500 attend.	
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).	Scottish Government has responded to the report from the Festival wigh additional funding for gaps identified, for instance, they fund a national mental health co-ordinator to work with young carers services, they funded an employability pilot and also national awarenessr raising resources such as the mascot figures, Eryc and Trayc and toolkits for staff in education. At a local level, young carers projects tell us that they have a much higher profile when decision makers from their area attend the Festival. We have also established a good relationship with the Children and Young People's Commissioner in Scotland through the Festival, who now regularly consults with the Scottish Young Carers Alliance on various issues.	
		We also try to undertake a little bit of research in advance of the Festival, so that we can contact the national press with this, and at the same time draw attention to the numbers of young carers in Scotland and the issues they face.	
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.	Only the reports as mentioned above.	
10.	What are the success factors?	Young carers get a break from their caring role and spend time with peers who have issues in common. The young people evaluate the Festival very positively. The national strategy for young carers was called, by the then Minister for Public Health, 'the baby of the Festival', as i was young carers views gathered at the event which informed the strategy. The funding from Scottish Government is also a big factor in the success, in that it costs relatively little for groups to	

	attend.
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	Italy Matrix Good Practices 4.1. Different forms of support for Young Adult Carers		
Can y	ou give good practices of policy measures in your c	country for support of Young Adult Carers?	
1.	Description of the good practice	SIBLINGS SELF HELP GROUPS	
2.	Goals: describe the main goals of the good practice	General goals are: providing emotional and social support to members; providing information and education; promoting resilience, raising awareness in siblings about their role in society and inside families, promoting empowerment and self-efficacy	
		Moreover some goals regard the social context and culture: raising awareness among professionals, training professionals about siblings issues, promoting cooperation and integration among different services and professionals.	
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	Young people who have a brother and/or sister with disability Families of children with disabilities Educational and health system	
4.	Approach: describe the way in which the good practice is implemented.	Support groups in pursuit of various mutually beneficial ventures have remained a major social strategy in human history. Common goals, cooperative efforts and common sharing of rewards have brought like minded people together as groups since centuries. The common good of members has been the motivating factor. In psyco social and health practice, Self help groups consist of individuals who share the same problem or concern. Members provide emotional support to one another, learn ways to cope, discover strategies for improving their condition, and help others while helping themselves. In siblings experience groups are homogeneous and meet up once a month. No professionals are present.	
5.	Who implements this good practice? Mention, if	YAC are invited to join groups by their brothers' or sisters' doctors. They join the group after a first motivational interview by the professional. COMITATO SIBLINGS ONLUS	
<u>.</u>	relevant, the organisation or persons who do the work.	It's a national private organisation who is organised in several local groups or representatives. Persons who do the work: facilitators, educators, trained volunteers	
6.	What material is available on this good practice (description, website etc.)	Website www.siblings.it Publication "the Sibling project: the experience of disabled children siblings"/ II progetto Sibling: l'esperienza di bambini con fratelli disabili"	
7.	How widely is this good practice used in your country?	Not enough. It's important to go further in lobbying and promotion	
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).	Siblings learn to live in a more serene way family relationships and become aware of their role inside family and society. They stop to be invisible and become resource. This change of perspective is very empowering for them and for their disable brothers and sisters too. We notice an evident improvement in other life spheres too such as school, peers relationship, ecc	
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.	No, even if there's a wide literature about self help	
10.	What are the success factors?	Promoting awareness Promoting collaboration between public and private sector National network of siblings Visibility and participation to national and international meeting	

_	Italy Matrix Good Practices 4.2. Different forms of support for Young Adult Carers		
Can y	ou give good practices of policy measures in your c	ountry for support of Young Adult Carers?	
1.	Description of the good practice	2013 – 2014 Support group for siblings	
2.	Goals: describe the main goals of the good practice	Share ordinary problems Learn to observe and accept resources and barriers of brothers and sisters with disabilities; Psychological empowerment trough participation, and sharing experience	
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	Young adult caregiver whom brother and/or sister are in charge to the local health service.	
4.	Approach: describe the way in which the good practice is implemented.		
5.	Who implements this good practice? Mention, if relevant, the organisation or persons who do the work.	Local health service and ASP Cesena valle savio Health professionals (psychologist and clinical pedagogist)	
6.	What material is available on this good practice (description, website etc.)		
7.	How widely is this good practice used in your country?		
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).		
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.		
10.	What are the success factors?		

Good	practice 1: Booklet: If Grandmother has dementia.	
1.	Description of the good practice	A booklet: Philipp-Metzen, H. Elisabeth (2010): If Grandmother has dementia. Support for Parents and their children. Series for the practice, German Alzheimer Association, Berlin. (Original language: Philipp-Metzen, H. Elisabeth (2010): Wenn die Großmutter demenzkrank ist. Hilfen für Eltern und Kinder. Praxisreihe der Deutschen Alzheimer Gesellschaft e. V., Berlin.)
2.	Goals: describe the main goals of the good practice	To provide guidelines for informal carers.
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	Young adult carers themselves, care providers, family, teachers etc.).
4.	Approach: describe the way in which the good practice is implemented.	It is an inexpensive booklet, which everyone can afford.
5.	Who implements this good practice? Mention, if relevant, the organisation or persons who do the work.	It is written by a researcher (research – practice – translation) and published by a national self-help organisation.
6.	What material is available on this good practice (description, website etc.)	The booklet.

7.	How widely is this good practice used in your country?	According to the publishing-house it is a best-seller.
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).	According to the reader's responses it is very helpful.
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.	Philipp-Metzen, H. Elisabeth (2012): Dementia in the family: the caring experiences of grandchildren. In: Journal of Dementia Care (Vol 20 No 1), January / February 2012: 35 - 37.
10.	What are the success factors?	Easily understandable language, focus on the situations in everyday life.

1. Critical discussion and propositions on how to proceed

The topic of young adult carers is not present in the public eye in Germany, it is a completely neglected group. Social services as well as education services have no specific support programs for YAC. It seems that the age group of carers between 18 years and 24 years is not seen as a separate group of carers in Germany. They seem to fall into the group of either young carers (with the implied image of children or teenagers) or adult carers in general. Some completed questionnaires reflect that when describing programs for young carers as good practice. But these programs do not explicitly address young adult carers as they are designed for underage carers. We therefore only mentioned these examples but did not describe them in detail.

Some comments in the questionnaires and feedback via Email show that the importance to address the group of YAC is not shared by everyone. The need to distinguish between young carers and young adult carers was not seen as necessary by some experts - with one comment being that educational limitations due to caregiving are constituted before the age of 18 when carers undergo high school. This may be an interesting point to consider since the German school system in some states still divides students into three school systems according to their output. That can predetermine their educational career and will limit chances of University access.

Still, however, YAC will have to make educational decisions concerning attending University (if eligible) starting an apprenticeship or continuing education and caregiving responsibilities may influence those decisions.

Some experts have pointed out that YAC are more common in the area of substance abusing parents or parents with mental disorders like depressions or bi-polar disorder in comparison to other "conditions" of the care-recipient like physical or chronic impairments.

It also seems that it is relatively uncommon that a YAC will be the single or primary caregiver for a relative with care needs. Mostly, they share caregiving tasks and responsibilities with other family members. But new research, where persons are asked to give their retrospective views on the time when they were young carers, puts this impression in questio.

To conclude: The German TOYAC group pronounced the need to raise awareness on this special target group with very specific needs and support offers. The practical work experiences and research findings with young carers under the age of 18 years could be used to develop new concepts. But more then that the group looks forward to learning from other countries.

The	The Netherlands Matrix Good Practices 4.1. Different forms of support for Young Adult Carers Can you give good practices of policy measures in your country for support of Young Adult Carers?		
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Can y			
1.	Description of the good practice	Talk groups for YAC (age 4-22) who care for a parent with a psychiatric disability or (an) addiction(s).	
2.	Goals: describe the main goals of the good practice	Sharing experiences in order to prevent psychiatric disabilities with the YAC.	
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	Young Adult Carers themselves	
4.	Approach: describe the way in which the good practice is implemented.	This course is being offered by many mental health care organisations in The Netherlands, sometimes they work together with youth institutions.	
5.	Who implements this good practice? Mention, if relevant, the organisation or persons who do the work.	NJI, MEZZO, Hogescholen, MOVISIE, steunpunt mantelzorg, MEE, researchers (Sieh, Meijer, Visser-Meily, Hoekstra, Visser etc)	
6.	What material is available on this good practice	http://www.trimbos.nl/webwinkel/productoverzicht-	

	(description, website etc.)	webwinkel/preventie/af/~/media/files/inkijkexemplaren/af0986 thuiszorg%20 en%20 ggz-preventie compleet.ashx See webiste NJI, ziekeouder.nl, MEE etc
7.	How widely is this good practice used in your country?	Widely. Every region offers one or more of these talk groups.
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).	It's a standardized intervention. From one randomized research it appears that the intervention has effect on risk- en protective factors, but not on depressive complaints from YAC. (Beardslee et al., 2003). http://www.trimbos.nl/webwinkel/productoverzicht-webwinkel/preventie/af/~/media/files/inkijkexemplaren/af0986 thuiszorg%20_en%20_ggz-preventie_compleet.ashx
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.	Not yet.
10.	What are the success factors?	By talking about the situation the participants can handle the situation at home better than before the course. They feel happier and have higher self-esteem than before the course. (Beurskens & Siebes, 1998; Ince et al., 2004).

The	The Netherlands		
Matı	Matrix Good Practices 4.2. Different forms of support for Young Adult Carers		
Can y	ou give good practices of policy measures in your c	ountry for support of Young Adult Carers?	
1.	Description of the good practice	www.zorgvoorjeouders.marokko.nl	
2.	Goals: describe the main goals of the good practice	Supporting migrant YAC. For many migrant young people it is traditionally common to take care of their parents. Therefore it is important to support them.	
3.	Target Group: describe on which group the good practice is targeted (for instance, Young Adult Carers themselves, care providers, family, teachers etc.)	Young Adult Carers with a migrant background.	
4.	Approach: describe the way in which the good practice is implemented.	It is difficult to reach migrant people. This website tries to reach their children, who are often YAC. By reaching and supporting them, they can also reach the parents.	
		The website contains information, interaction possibilities for YAC with the same kind of experiences, questions and answers, an online pharmacist and a physician.	
5.	Who implements this good practice? Mention, if	The initiative came from the Dutch Institute for responsible medicine use and the website www.marokko.nl	
	relevant, the organisation or persons who do the work.	The site is embedded in a Dutch national project concerning care for parents who are ill. This project had the goal of improving the care of people with complex care needs.	
6.	What material is available on this good practice (description, website etc.)	There is the website. On the website there is a description of the project.	
7.	How widely is this good practice used in your country?	The first 6 months, the website had 52000 visitors instead of the 150.000 the 2 organisations expected.	
8.	What are the results, outcomes, experiences with this good practice? Please mention the source(s).	 The website is successful http://tijdschriftgeron.nl/marokkaanse-zorg-voor-je-ouders/1023928 Young people said that they find information that's new for them. Besides that they talk about the things that they struggle with and what they need. They appear to have to much burden and that they do not always know where they can find help. http://www.nationaalprogrammaouderenzorg.nl/projecten/projectreportages/meer-mantelzorg/ 	
9.	Are there effect studies? Please mention the source(s) if the answer is 'yes'.	There no real effect studies. The intervention is however described as a good practise by MOVISIE.	
10.	What are the success factors?	The participation of 5 organisations who have expertise in the support of YAC or in the support and reaching of migrant people.	

More information on TOYAC available at:

www.youngadultcarers.eu