



7th International Long-Term Care Conference

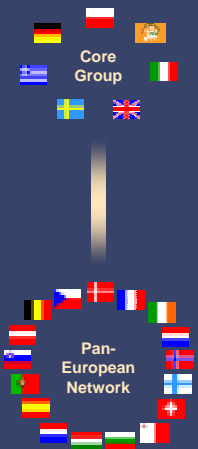
Torun, 21-23 September 2004

EUROFAMCARE

Usage of services supporting family carers in Europe

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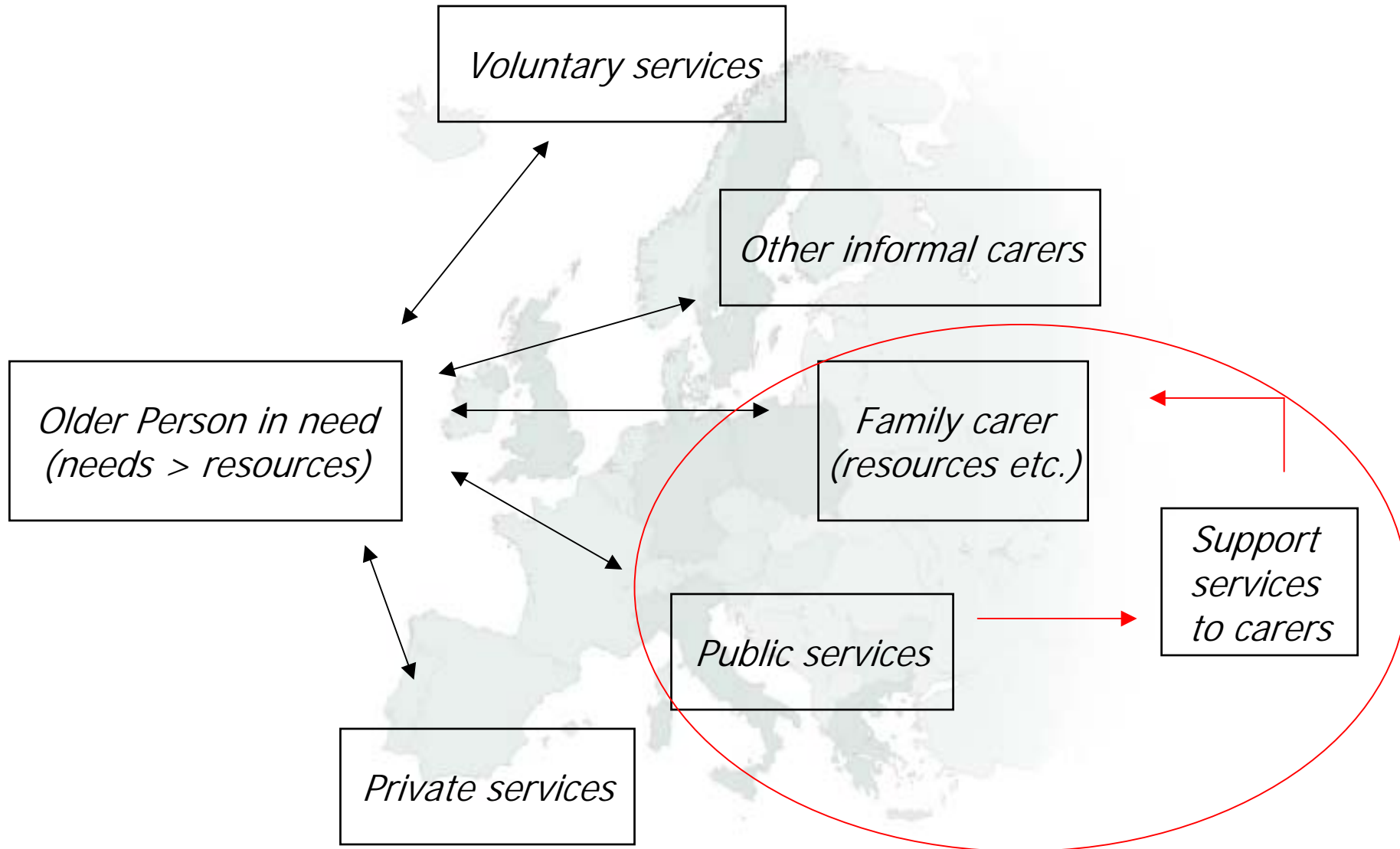
Contents

- the conceptual framework
 - methodology
 - findings (preliminary and descriptive)
 - final remarks
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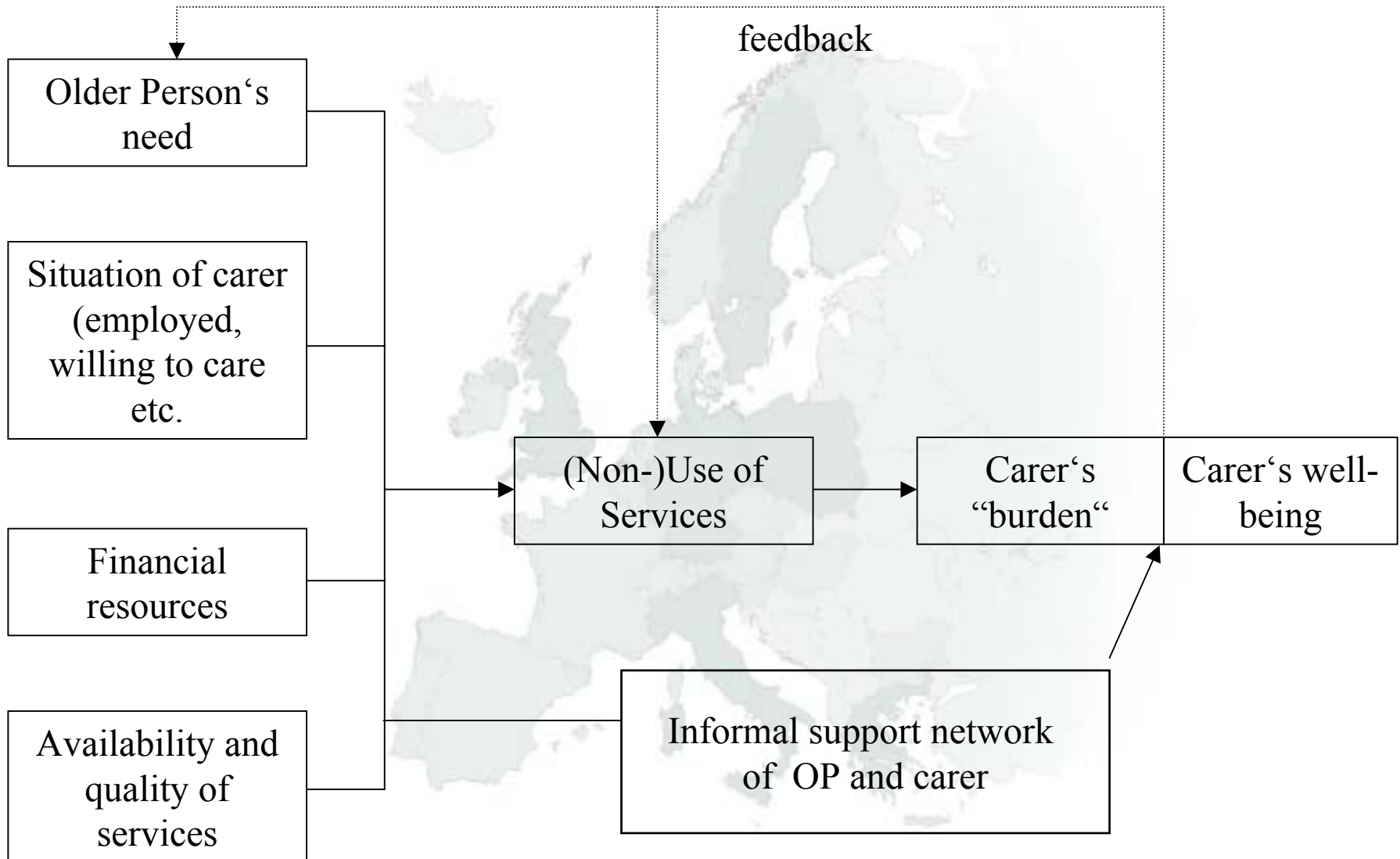
Conceptual framework: main questions

- which services do Older Persons (OP) and their carers mainly use in Europe?
- do these services meet their needs?
- which services have OP/carers stopped to use, and why?
- which services do OP/carers need but have never used, and why?
- what are the main difficulties in accessing services?
- what can be of help in accessing services?
- which types of support are most important for carers?
- which service characteristics are most important to carers?

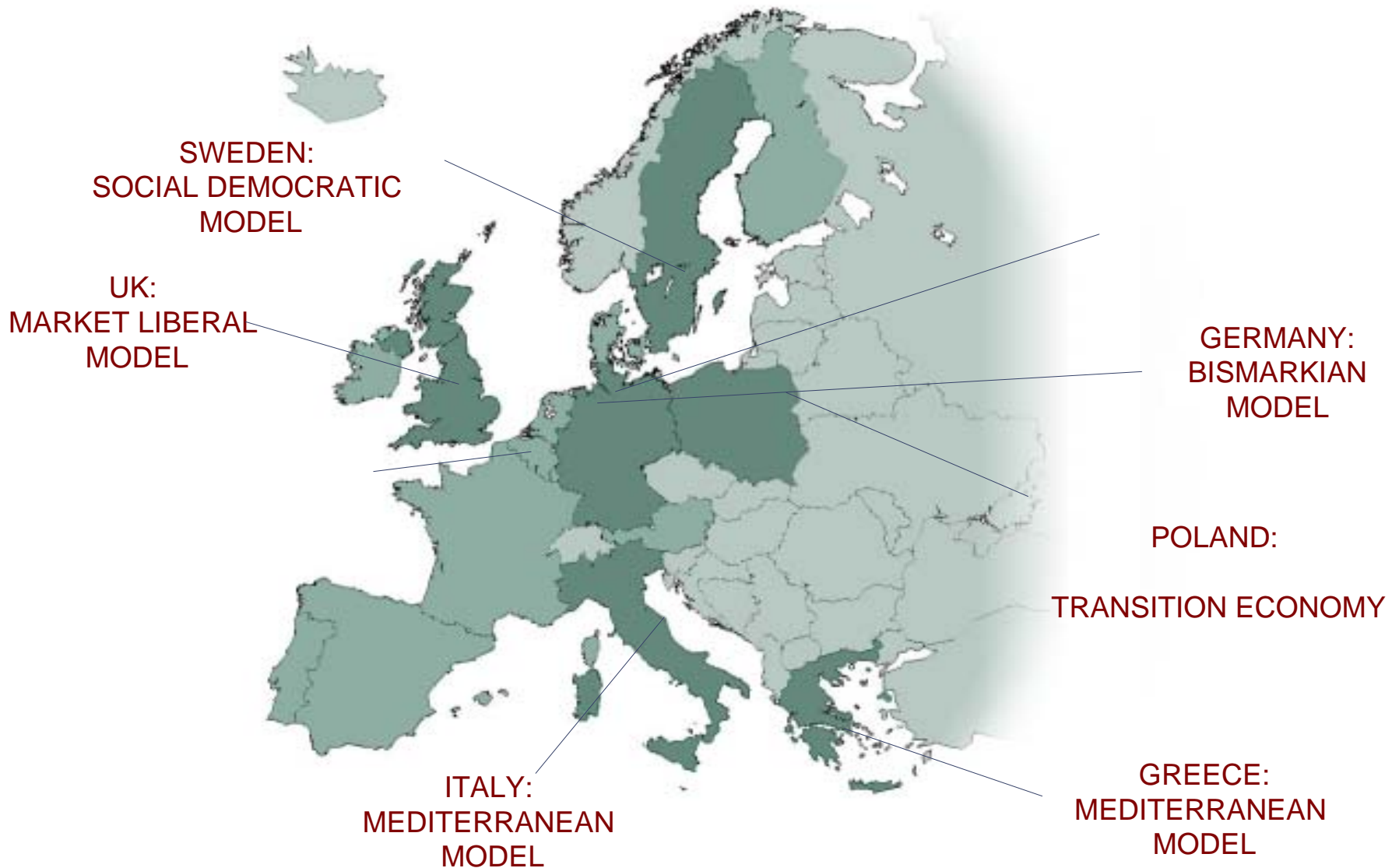
Conceptual framework: the involved actors



Conceptual framework: the “causal” model



Conceptual framework: the welfare state context



Methodology: indicators for service use

Domains	Indicators
Types of services used	National lists of services
Satisfaction with used services	Has this service met OP/your needs? Mostly yes/no
Costs of services or related to care	How much do you pay for this service? Any costs for home adaptation, travel or special medicines?
Frequency and amount of service use	How often do you use this service? How many times have you used it in the last 6 months?
Needed services stopped to be used: type and reasons	Possible reasons: too expensive, too distant, low quality, not available anymore, no longer entitled
Needed but never used services: type and reasons	Possible reasons: too expensive, too distant, low quality, didn't know, not entitled to use it
No use of services: reasons	Open questions recoded
Factors facilitating/hindering service access	Open questions recoded
Importance and availability of different support types	3 levels; mostly yes/no
Importance and availability of different service characteristics	3 levels; mostly yes/no

Methodology: European list of services

Services used by Older person

- 11 **Permanent Residential Services** (nursing homes, sheltered housing, old people's home etc.)
- 21 **Temporary residential Medical and Nursing** (admission to hospital, etc)
- 22 **Temporary residential Rehabilitation** (rehabilitation centres, etc)
- 23 **Temporary residential Social** (respite care)
- 24 **Temporary residential Privately paid assistance** in temporary residential institutions

- 31 **Ambulatory services Medical and Nursing** (nurse, GP, medical specialists, day care centre, diagnostic tests)
- 32 **Ambulatory services Rehabilitation** (physiotherapy, occupational therapy, day hospital)
- 33 **Ambulatory services Social/ emotional** (social work, help in organising care, counselling, psychologist etc.)
- 34 **Day care centre** with either health and social care purposes or both

- 41 **Home based services Medical and Nursing** (doctor at home, medical specialists at home, nurse at home etc)
- 42 **Home based services Rehabilitation** (physiotherapy at home, occupational therapy at home)
- 43 **Home based services Social/ emotional** (social worker visits at home, companionship, care attendant, help lines, etc)
- 44 **Home based services Domestic** (help with cooking, cleaning, shopping, laundry, meals on wheels etc)
- 45 **Home based services Personal Care** (help with bathing, toileting, hairdressing, nail care etc)
- 46 **Home based services Technical equipment/ aids/ building adaptation** (telemedicine, stair lifts, security systems etc)
- 47 **Cohabitant non-family carer**
- 50 **Transport services**

Services for carers plus additional services

- 71 **Emotional Support** (counselling, social work, family support or self help groups, crisis management)
- 72 **Respite care**, Supervision of elder at home
- 73 **Information** about the disease, caring, available services and benefits, Help lines, Internet services
- 74 **Training for caring**
- 75 **Assessment of caring situation**
- 76 **Dedicated services for family carers of different ethnic groups**

Methodology: from national to European services

National List of Services for Elderly People	National Number	European Category
Ambulatoryjne porady LEKARZA RODZINNEGO [ambulatory consultations of GP]	1	31
Domowe porady LEKARZA RODZINNEGO [consultations of GP at home]	2	41
Usługi pralnicze [laundry service]	29	44
Opłacanie rachunków i innych opłat [paying bills]	30	44
Posiłki dostarczane do domu [meals on wheels]	31	44
Usługi fryzjera w domu [hairstylist at home]	32	45
Usługi transportowe dla osób starszych [Transport services for older people]	33	50
Opiekun spoza rodziny mieszkający z podopiecznym [Cohabitant non-family carer]	34	47
Dochodzący opiekun spoza rodziny [private carer non-cohabitant]	35	43

“Prologue” to findings: need to differentiate carers

To understand how services can better address the carers' needs, it is necessary to identify what are the main differences among carers themselves

⇒ Need to **distinguish carers according to their well-being and quality of life** (see Barbro Krever's presentation)

“Prologue” to findings / 2:

3 clusters of carers with different well-being levels

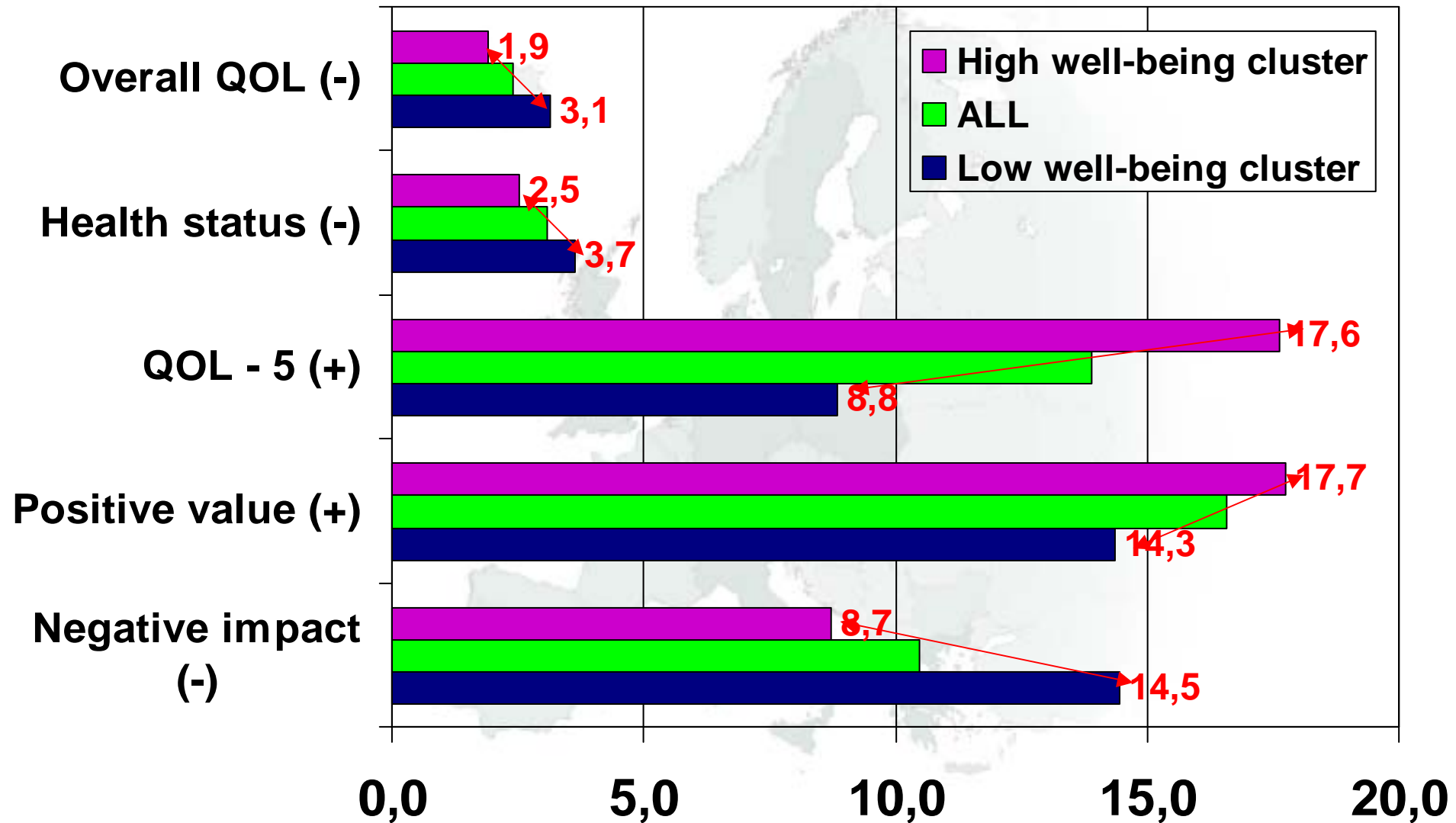
Cluster analysis on national samples based on:

- COPE Index - negative impact sub-scale;
- COPE Index - positive value sub-scale;
- carer’s perceived health status;
- carer’s perceived quality of life (QOL-5);
- carer’s overall rating of quality of life;

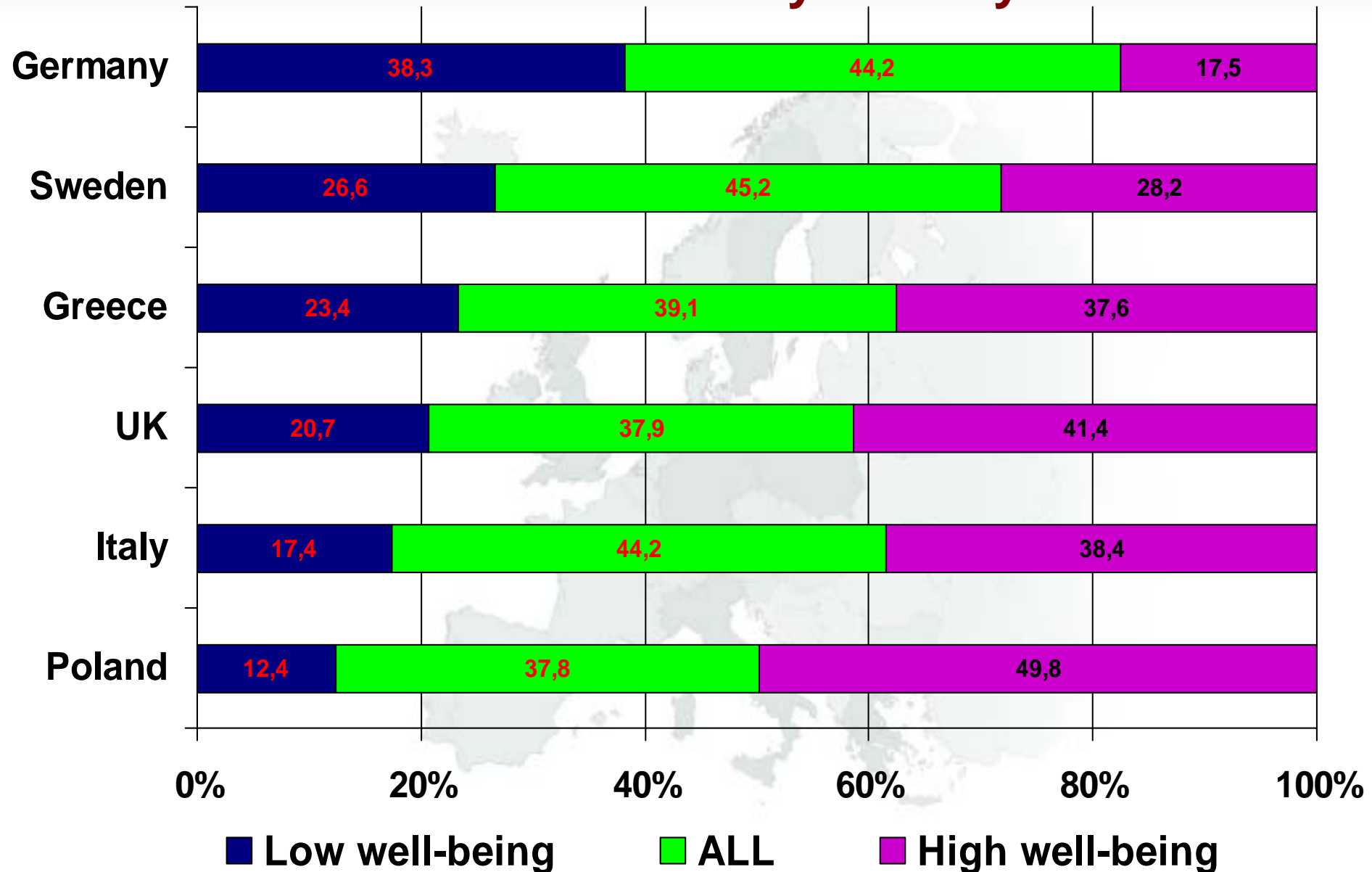
⇒ identified **three clusters** of carers (total n. = 5.649; missing: 298)

- **35,7%** carers with higher well-being (n = 2.014);
- **41,3%** carers with intermediate well-being (n = 2.333);
- **23,0%** carers with lower well-being (n = 1.302).

“Prologue” to findings / 3: carers clusters by well-being indicators

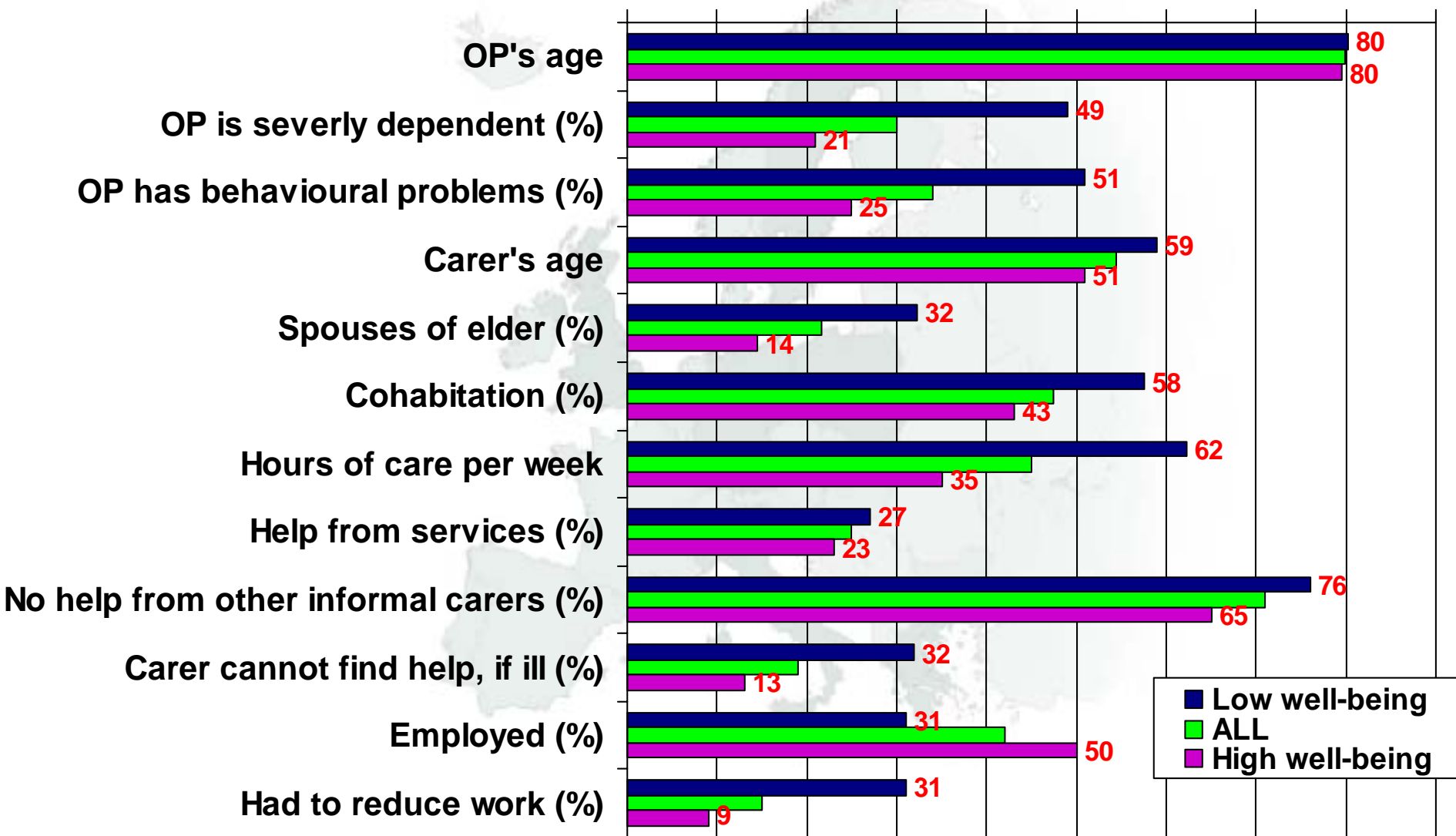


“Prologue” to findings / 4: carers clusters by country

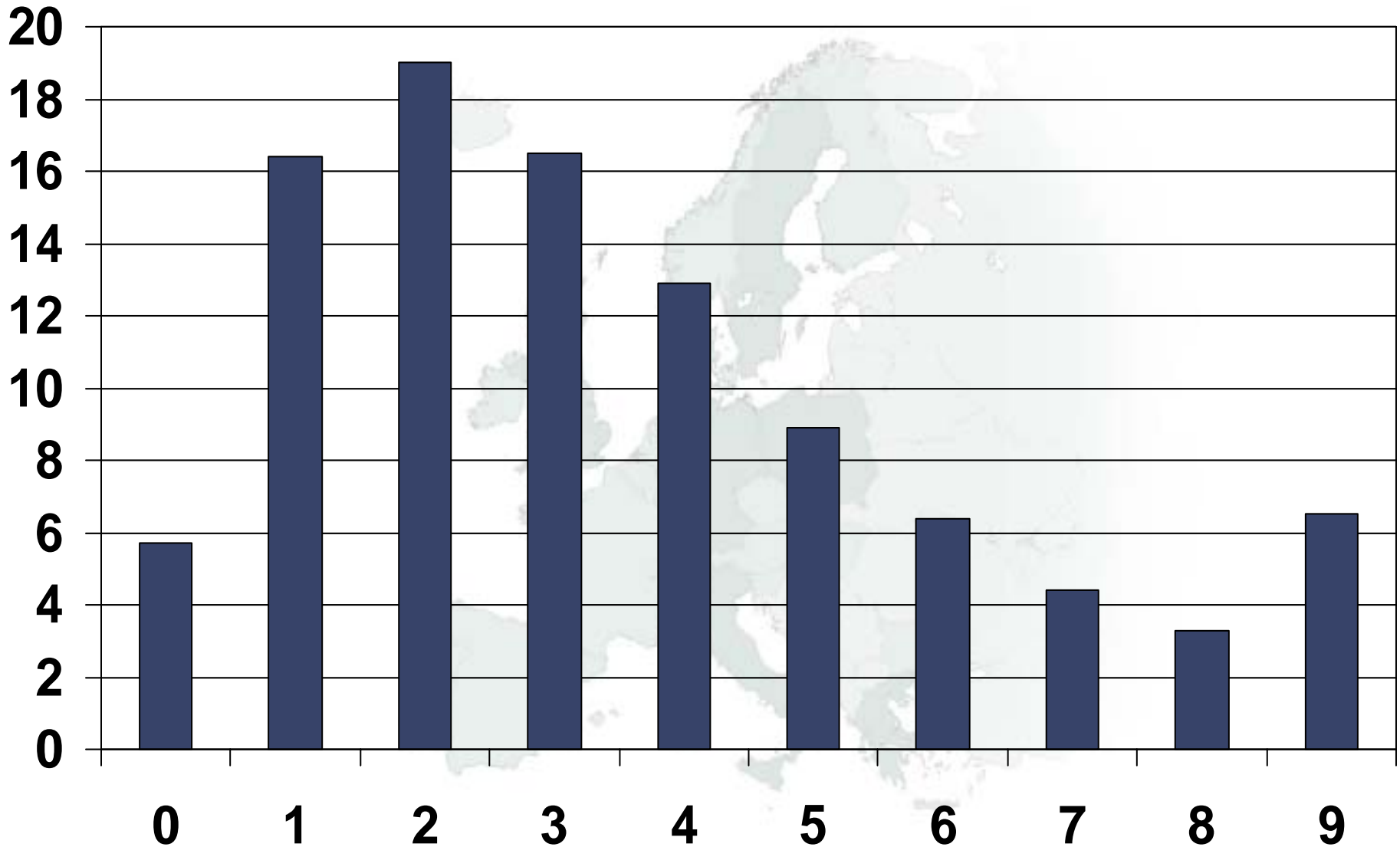


“Prologue” to findings / 5: carers clusters by main characteristics/differences

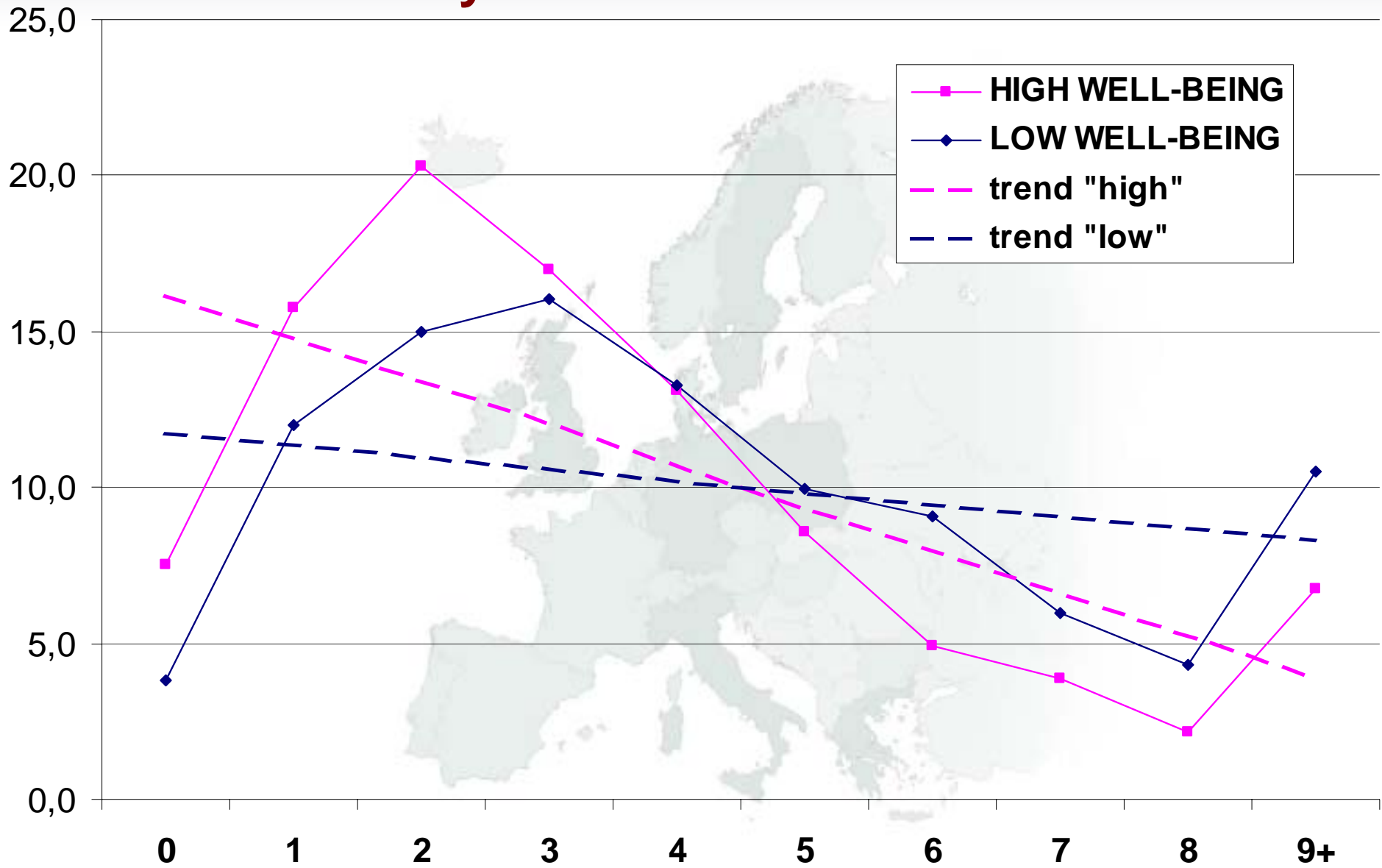
0 10 20 30 40 50 60 70 80 90



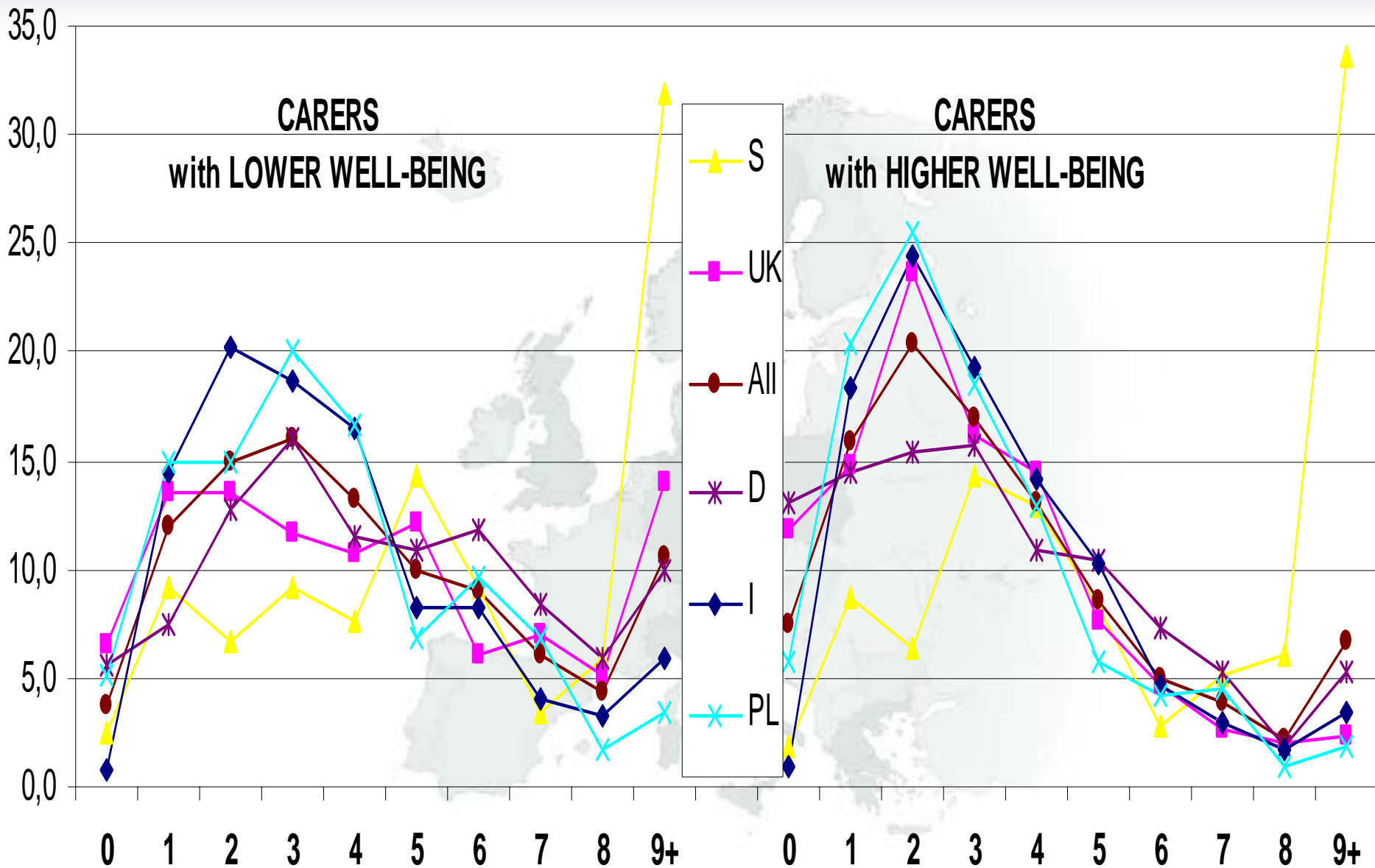
Findings: how many care services do OP use? (%)



Findings: how many care services do OP use?

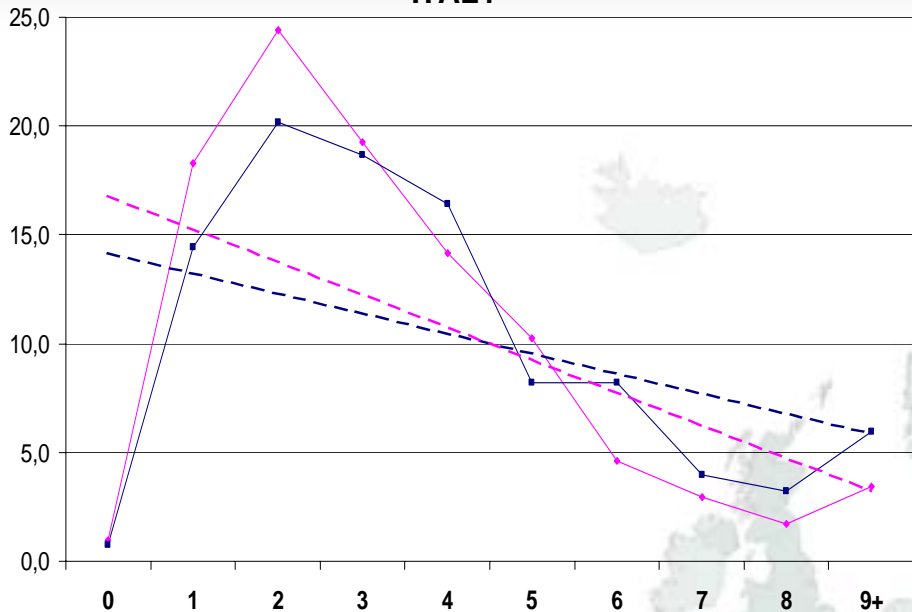


Carers (%) by well-being level, country & number of services used

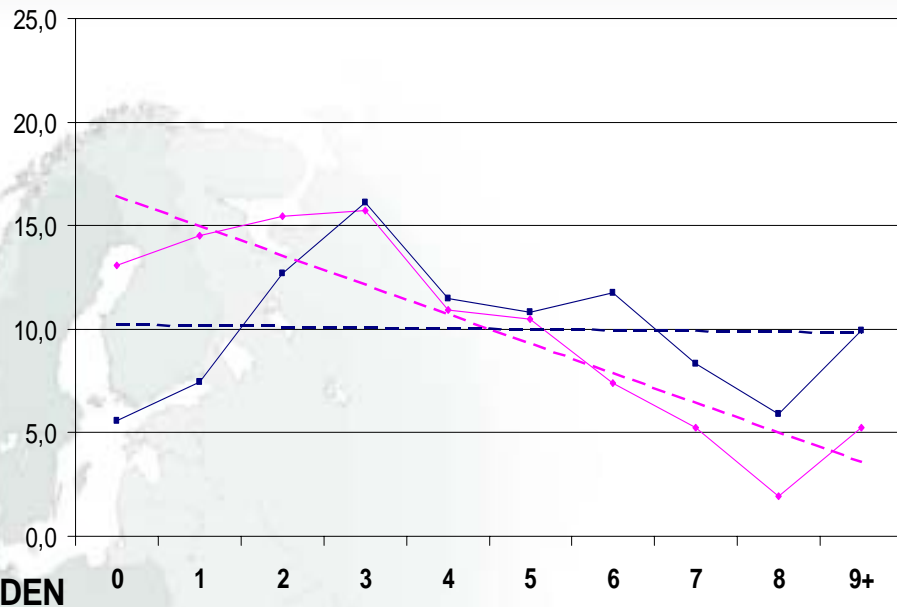


Carers (%) in Italy, Sweden and Germany by well-being level and number of services used

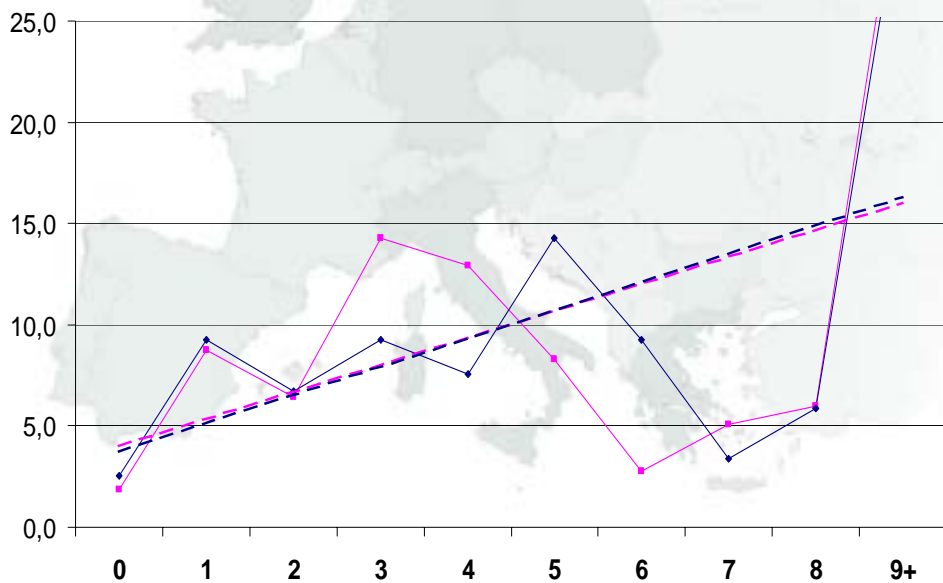
ITALY



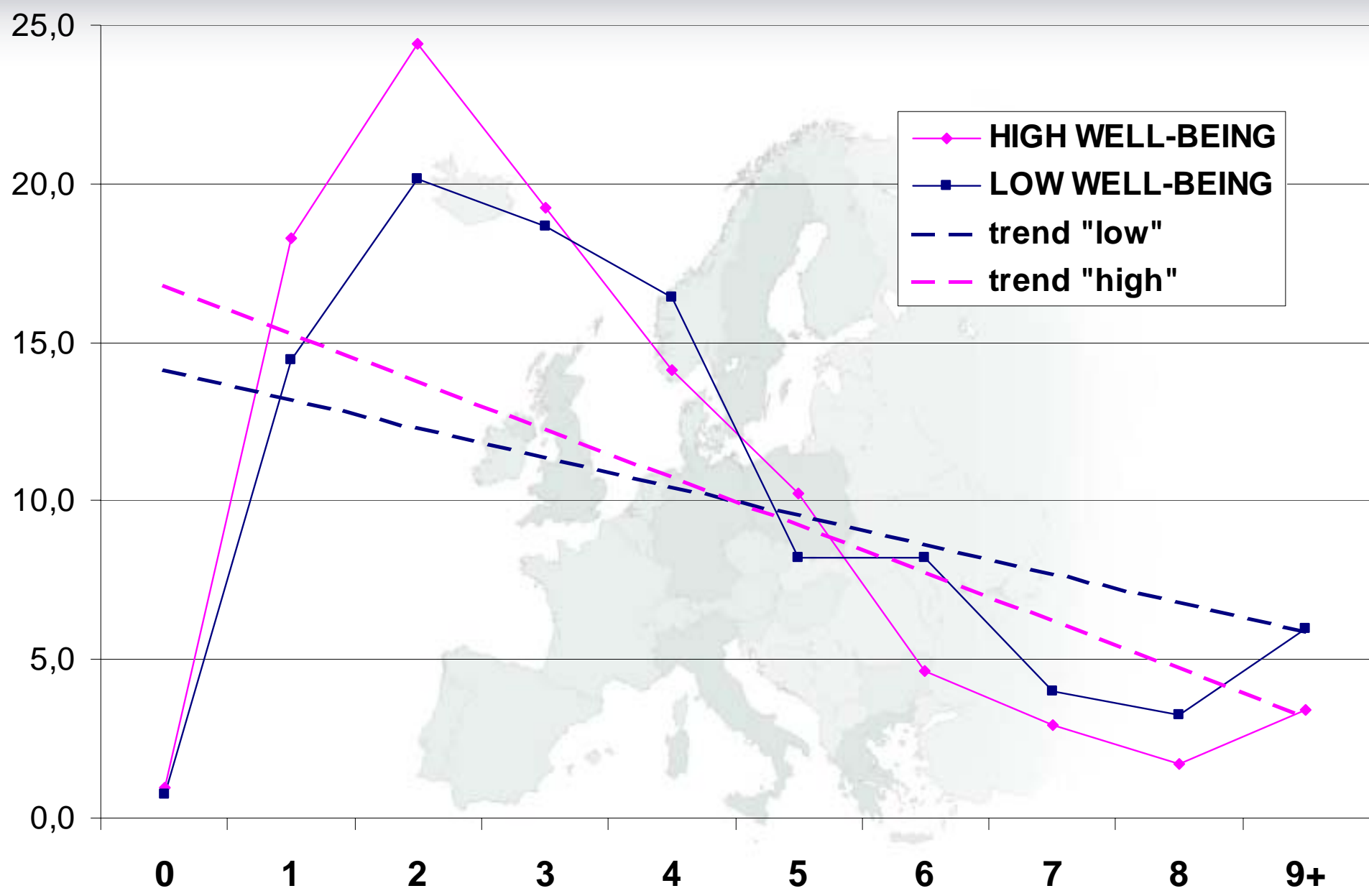
GERMANY



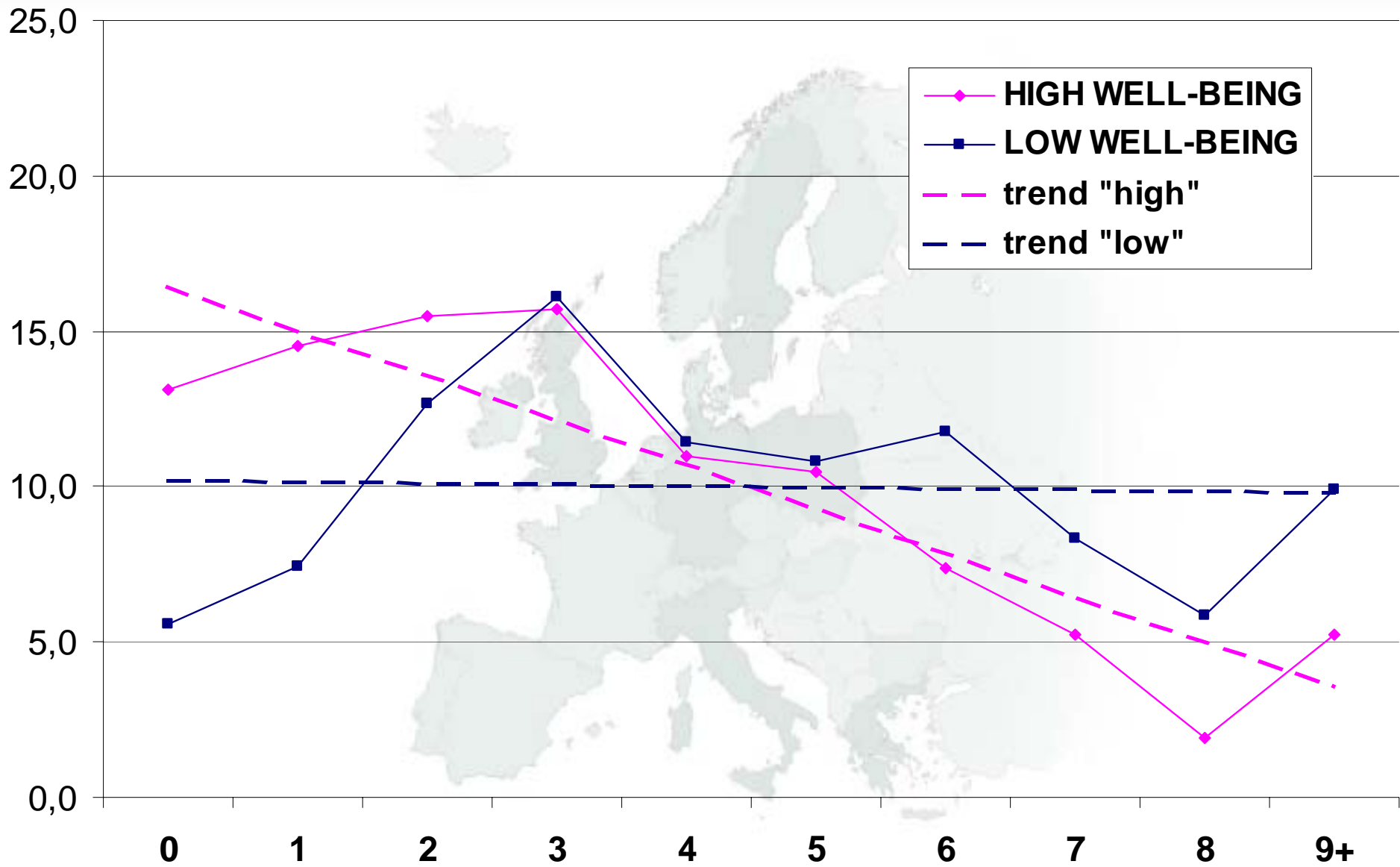
SWEDEN



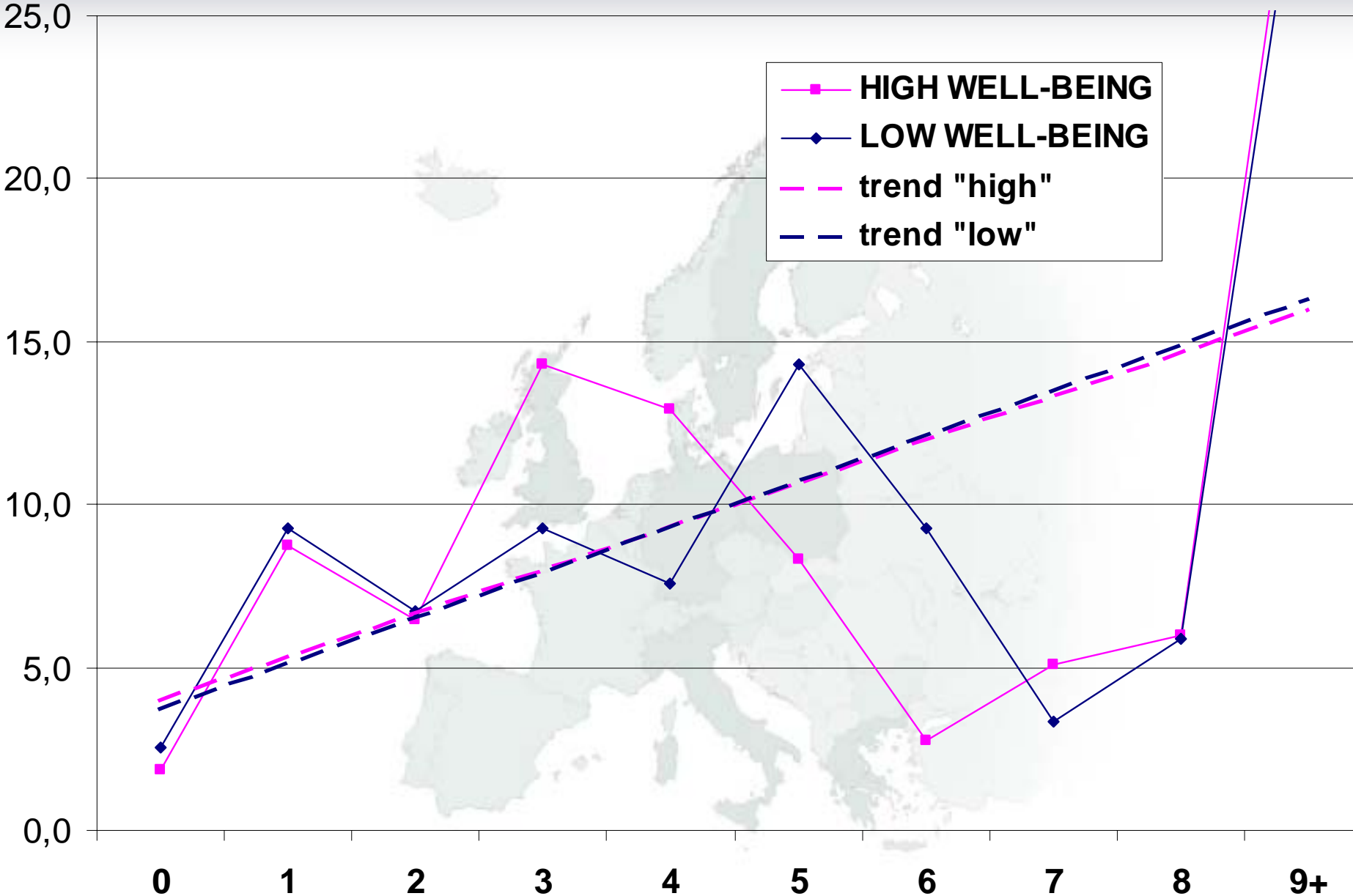
Carers (%) in ITALY by well-being level & number of services used



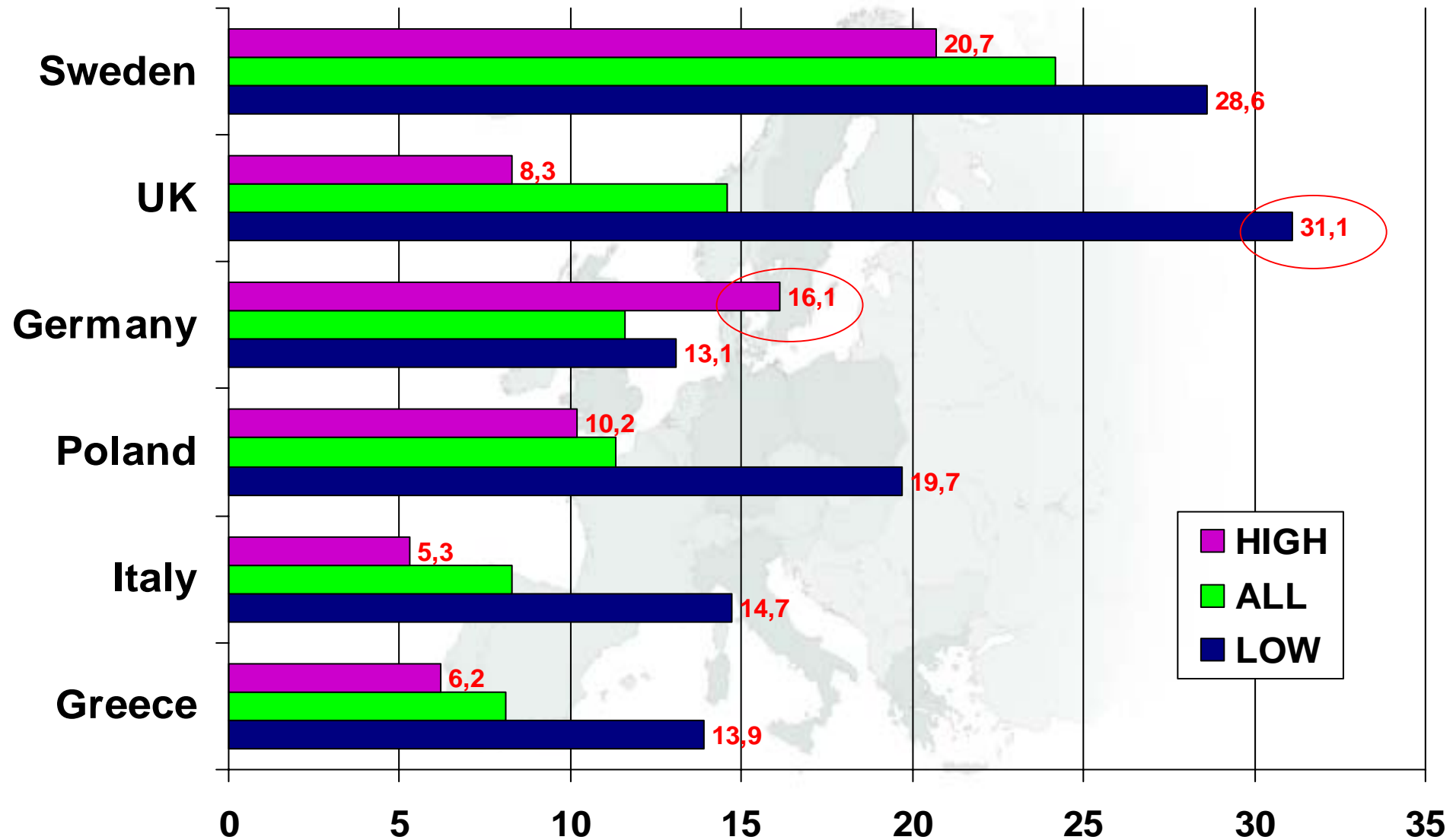
Carers (%) in GERMANY by level of well-being & number of services used



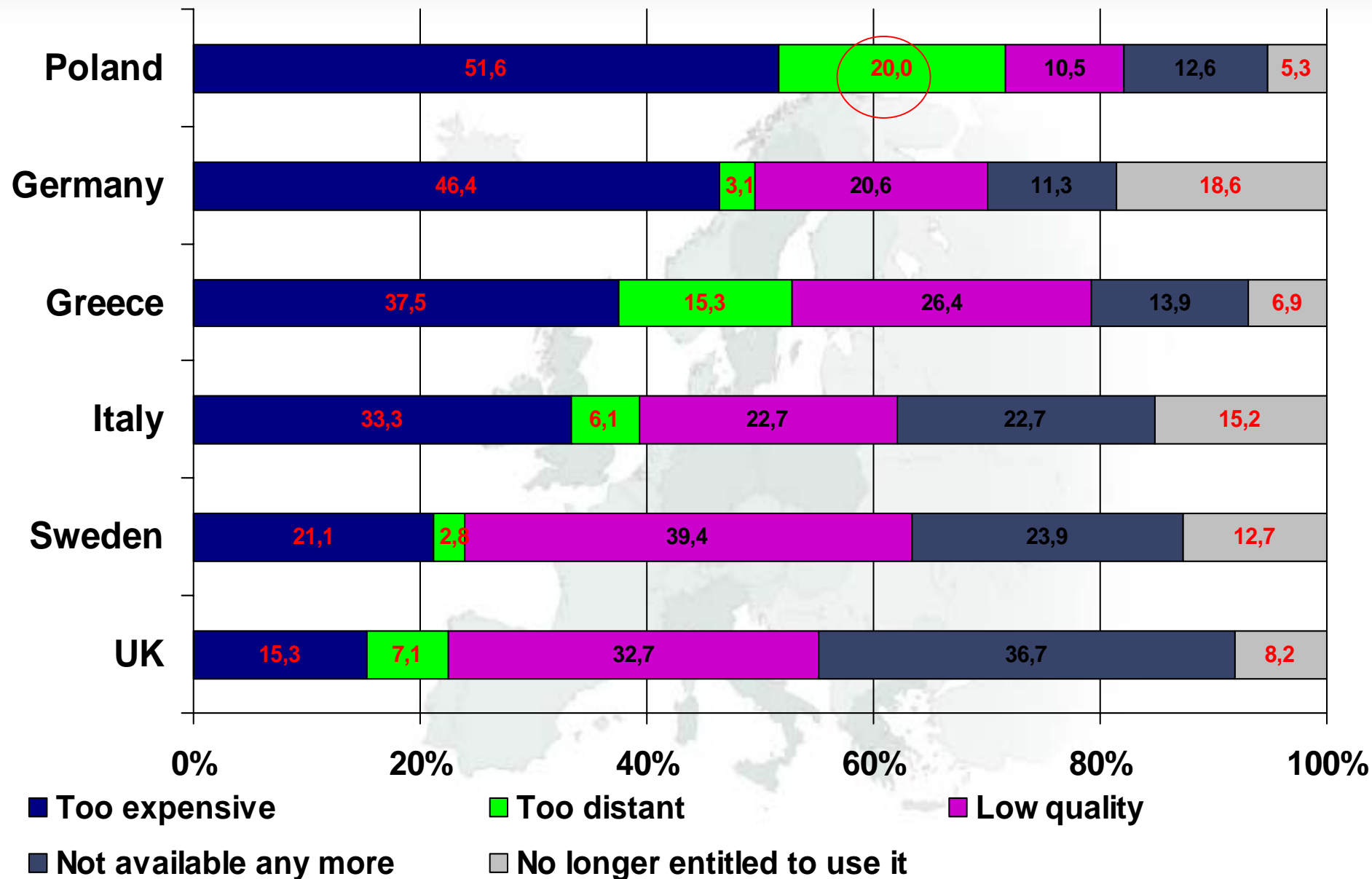
Carers (%) in SWEDEN by well-being level & number of services used



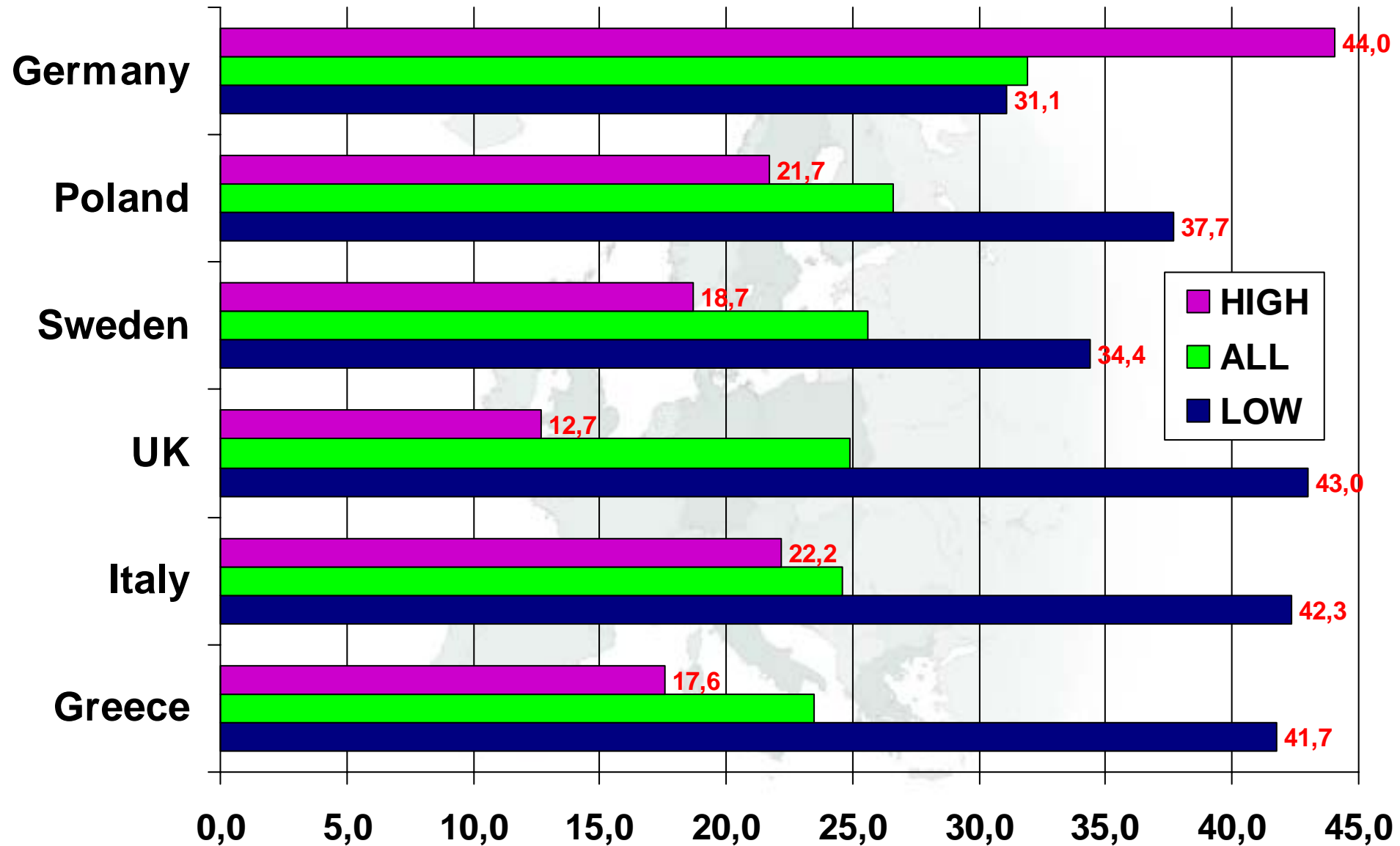
Are there any services that you/OP still need, but have STOPPED USING? (% of "YES")



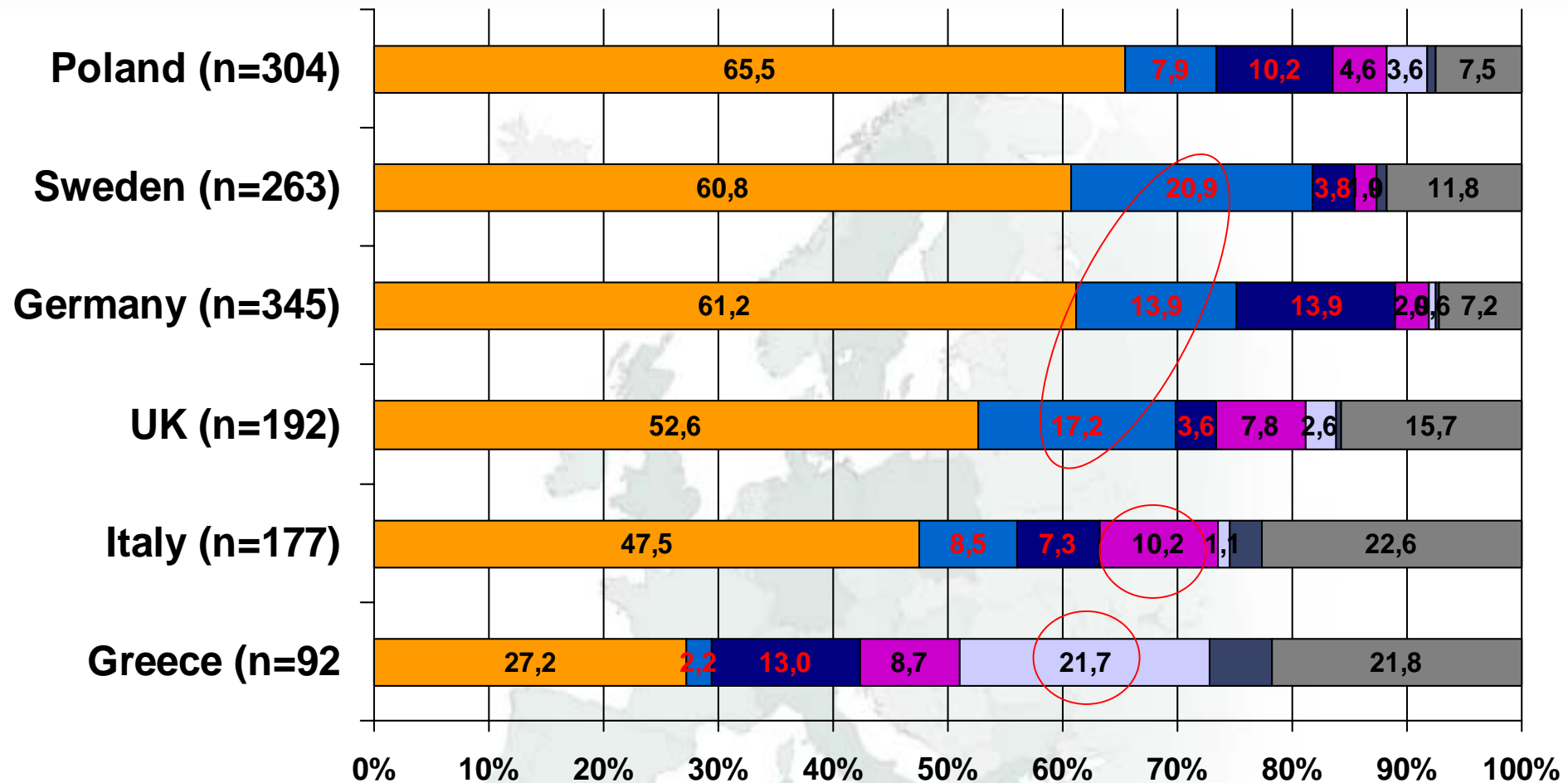
Reasons for stopping using needed services (n=723)



Are there any services that you/OP need, but have NEVER USED so far? (% of “YES”)



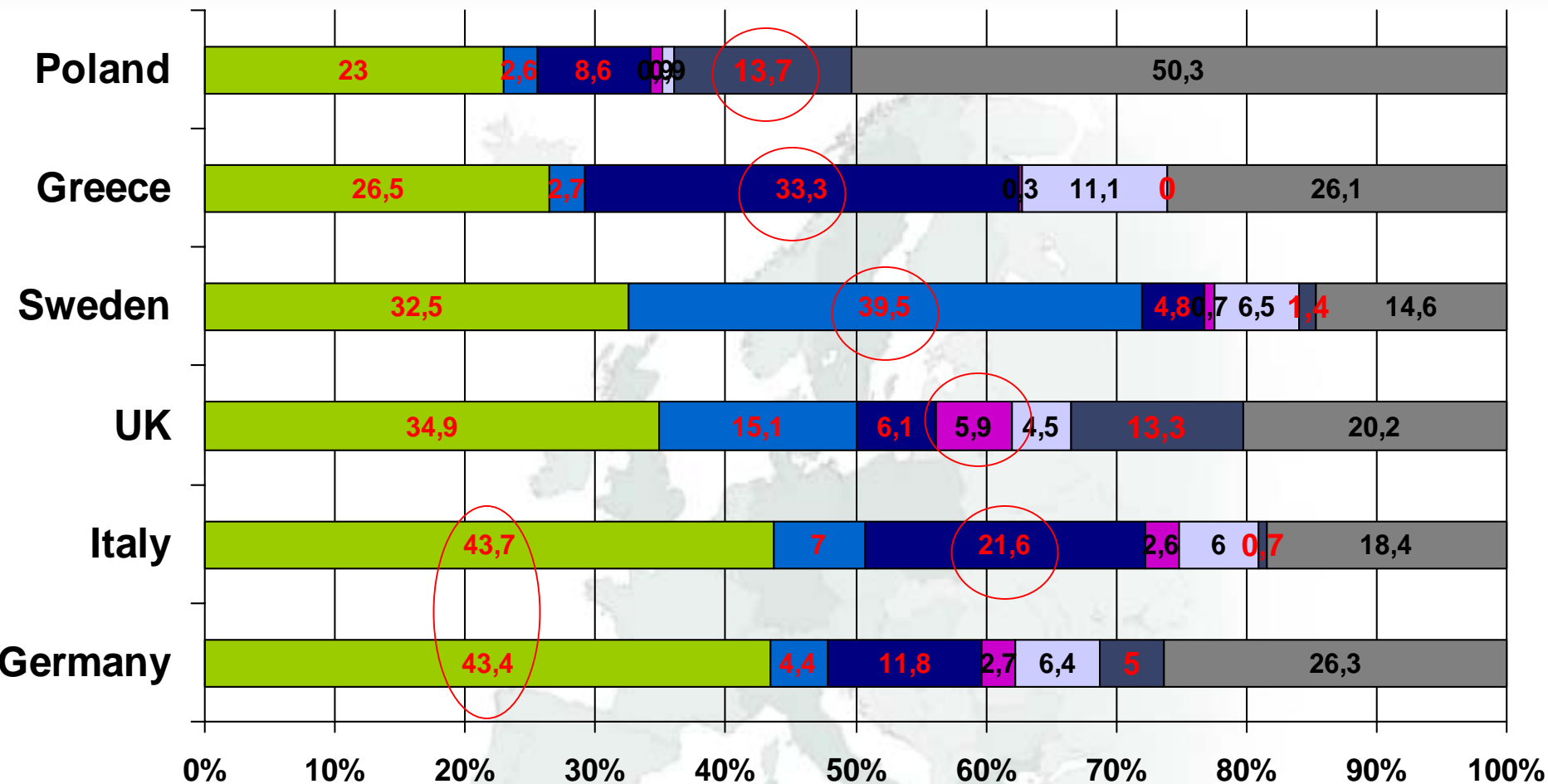
If you use NO SERVICES at all, what are the reason for not accessing them?



■ NOT NEEDED
■ HIGH COSTS
■ NOT AVAILABLE
■ OTHER

■ OP's ATTITUDE
■ LACK OF INFORMATION
■ MOBILITY PROBLEMS / BARRIERS

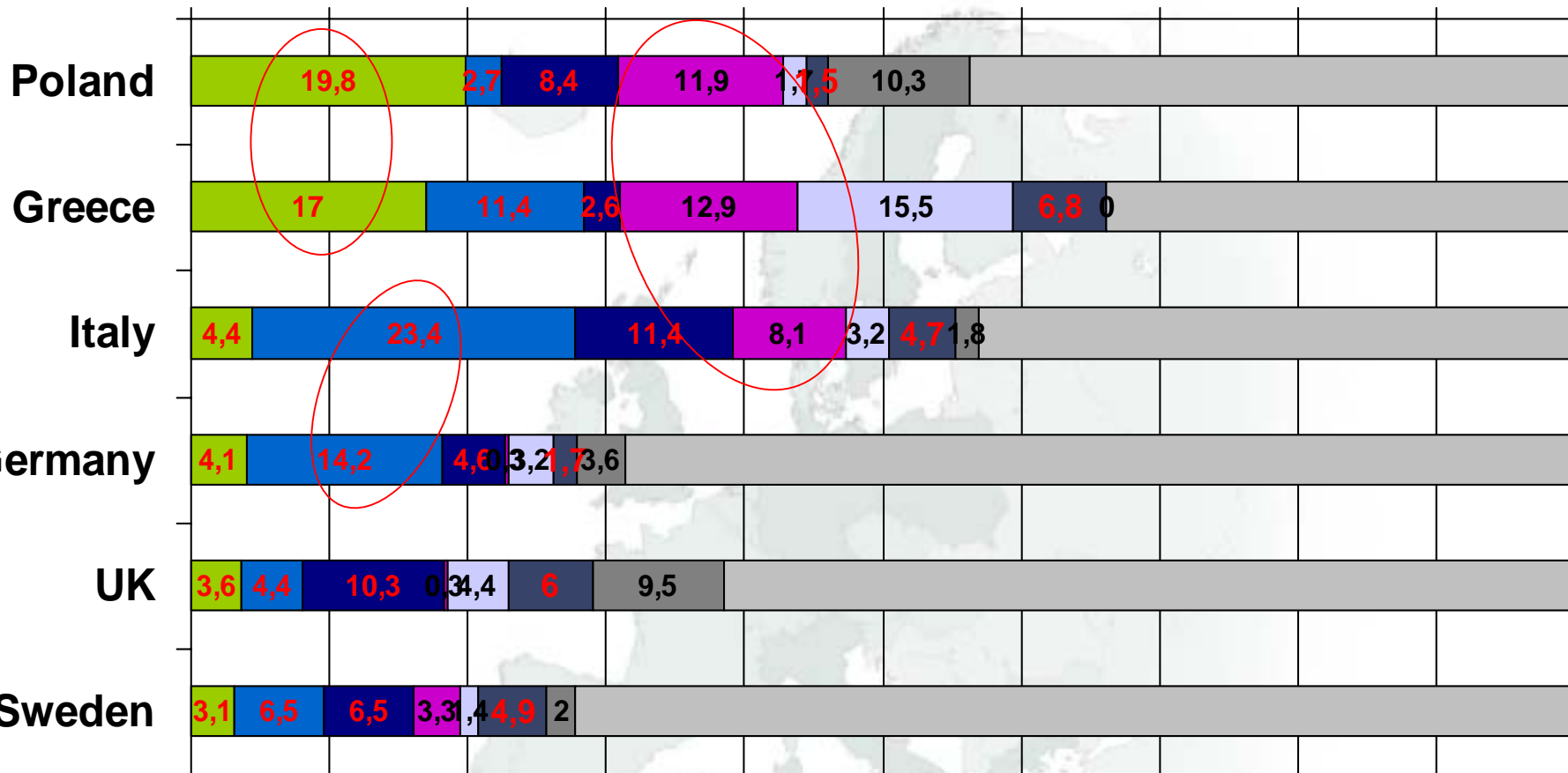
In your experience, who or what has been the **GREATEST HELP** in accessing services/support?



- Health care staff
- Social services
- Family, friends and neighbours
- Voluntary organisations
- Personal experience & knowledge
- Never tried to access services
- Other (including "nothing")

In your experience, who or what has caused the **GREATEST DIFFICULTIES** in accessing services/support?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%



- High costs
- Bureaucratic/complicated procedures
- Lack of information on services
- Long waiting lists
- Not accepted by OP
- Poor quality of services
- Never tried to access services
- Other (including "nothing")

Has caring resulted in any additional financial costs?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Greece

Poland

Germany

Italy

Sweden

UK

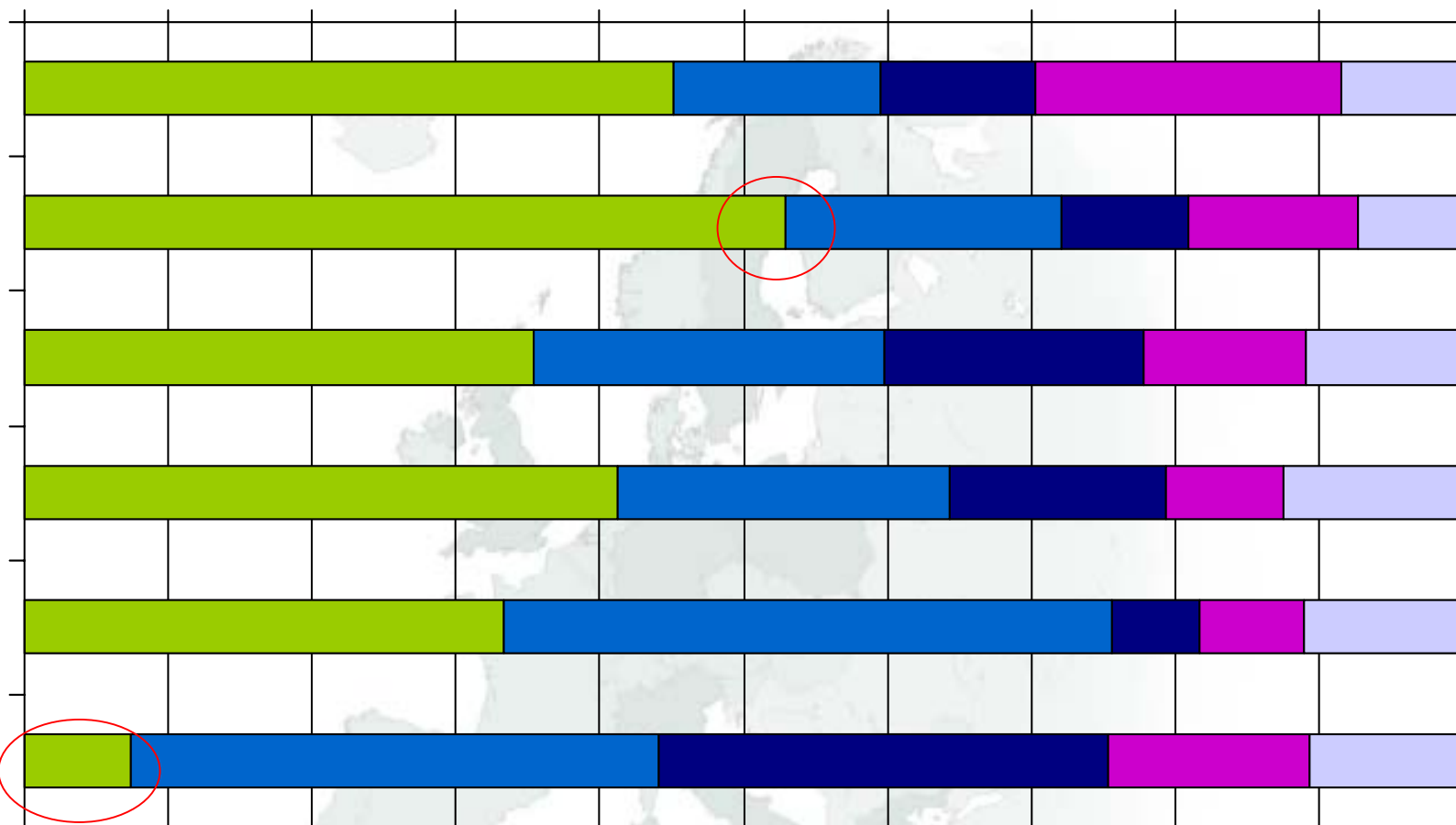
Medicines

Travel costs

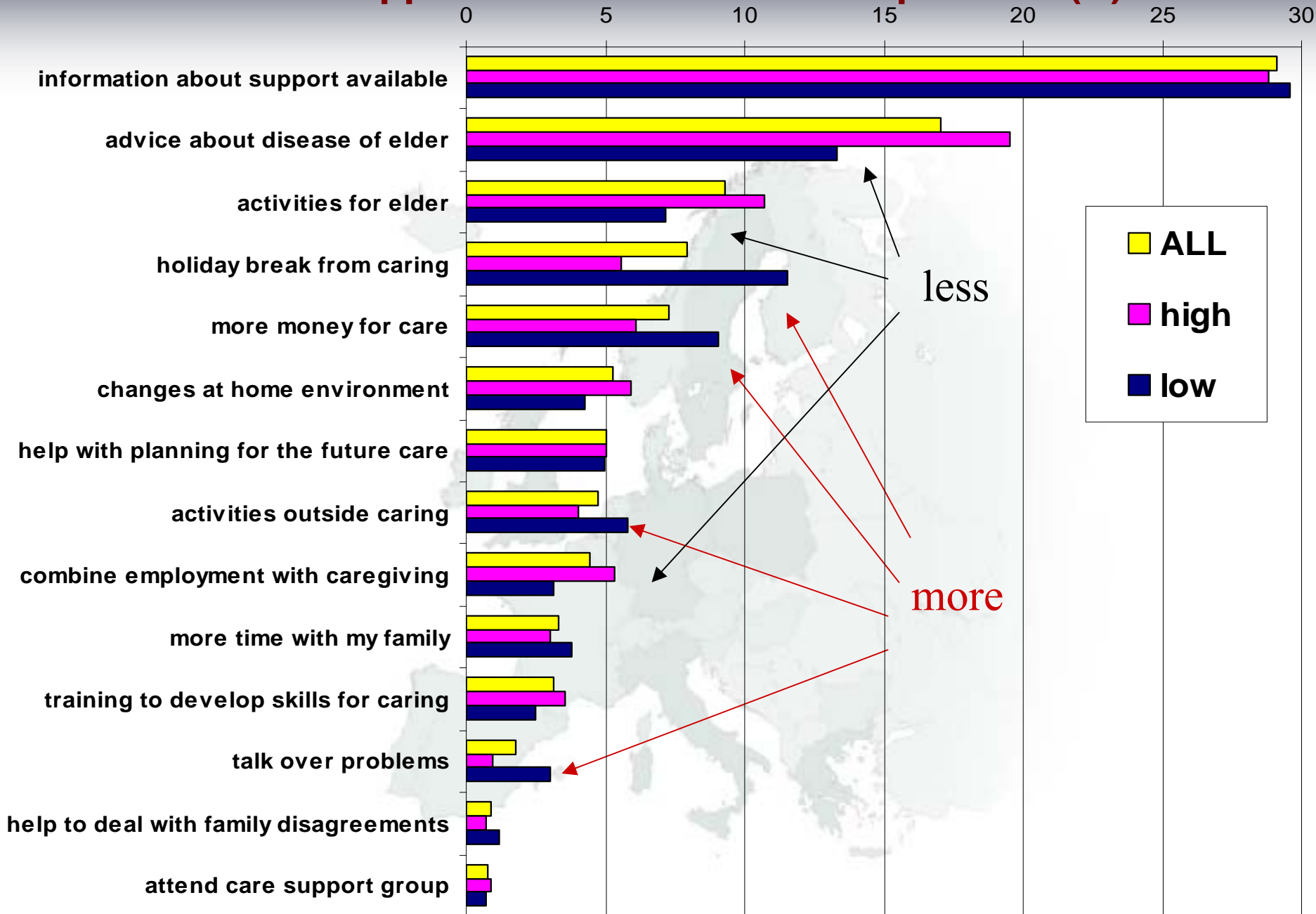
Adaptation of home environment

Special food

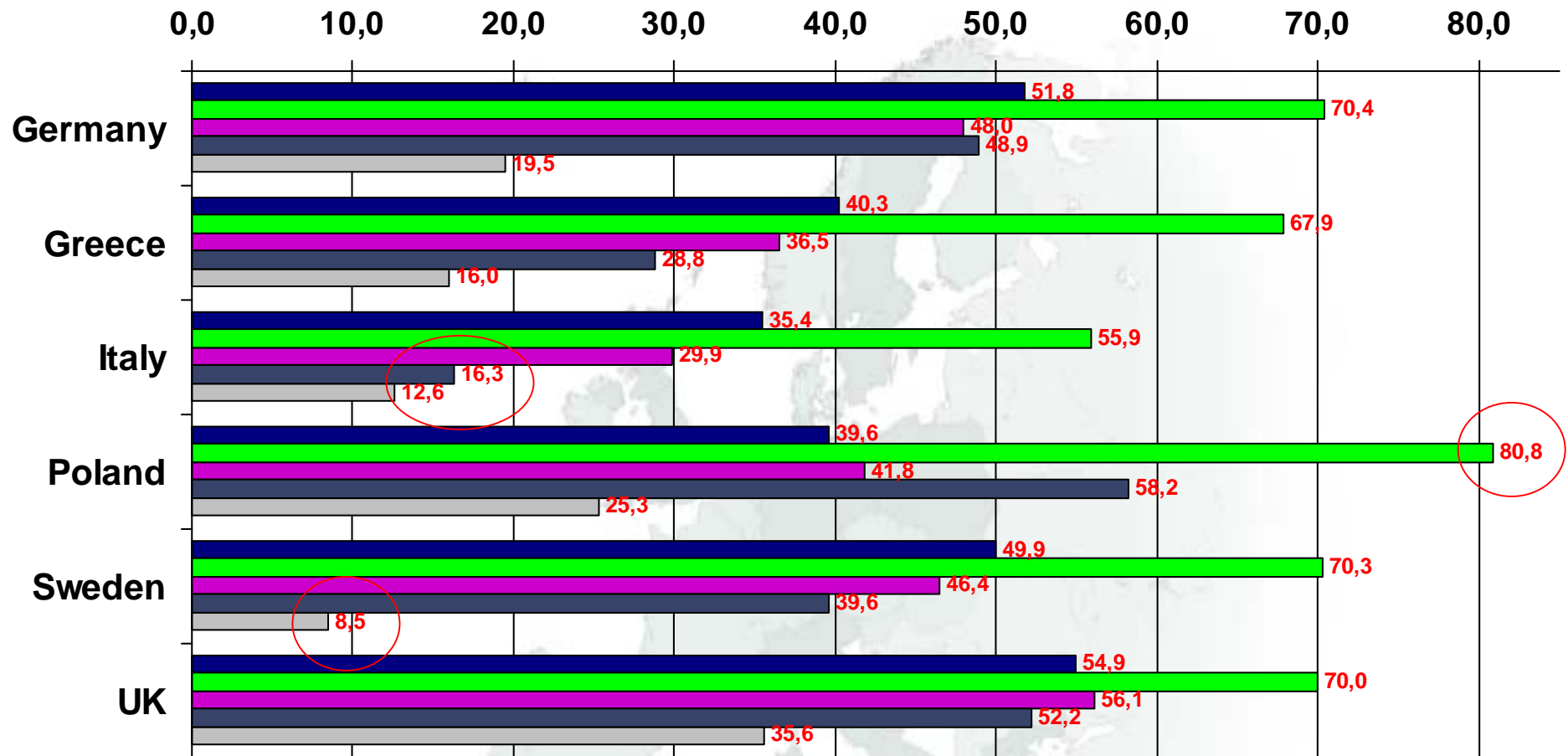
Other costs



Kind of support retained as "most important" (%)



Are these supports currently meeting your needs? (% of “mostly yes”)



■ information about support available

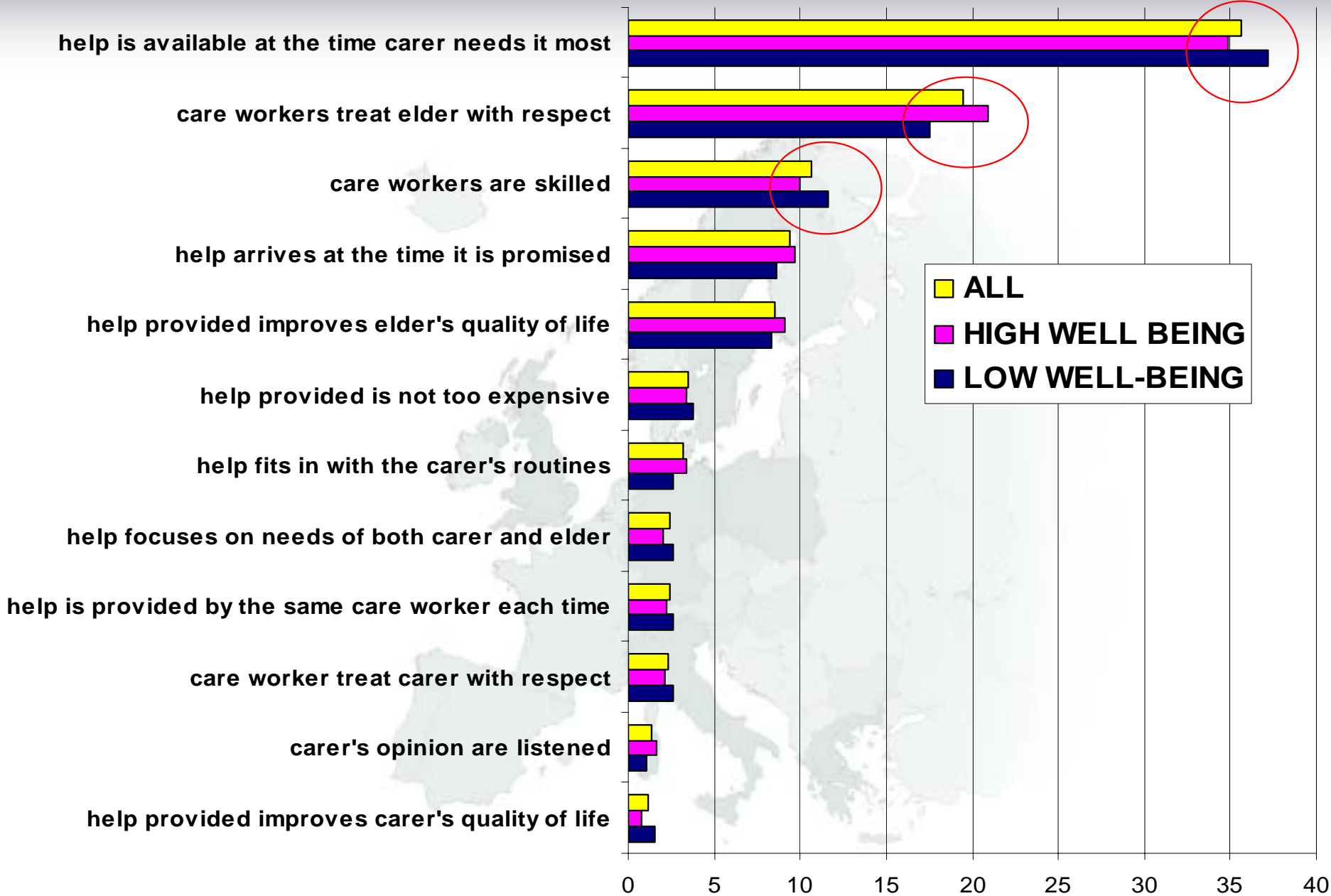
■ advice about disease of elder

■ holiday break from caring

■ activities for elder

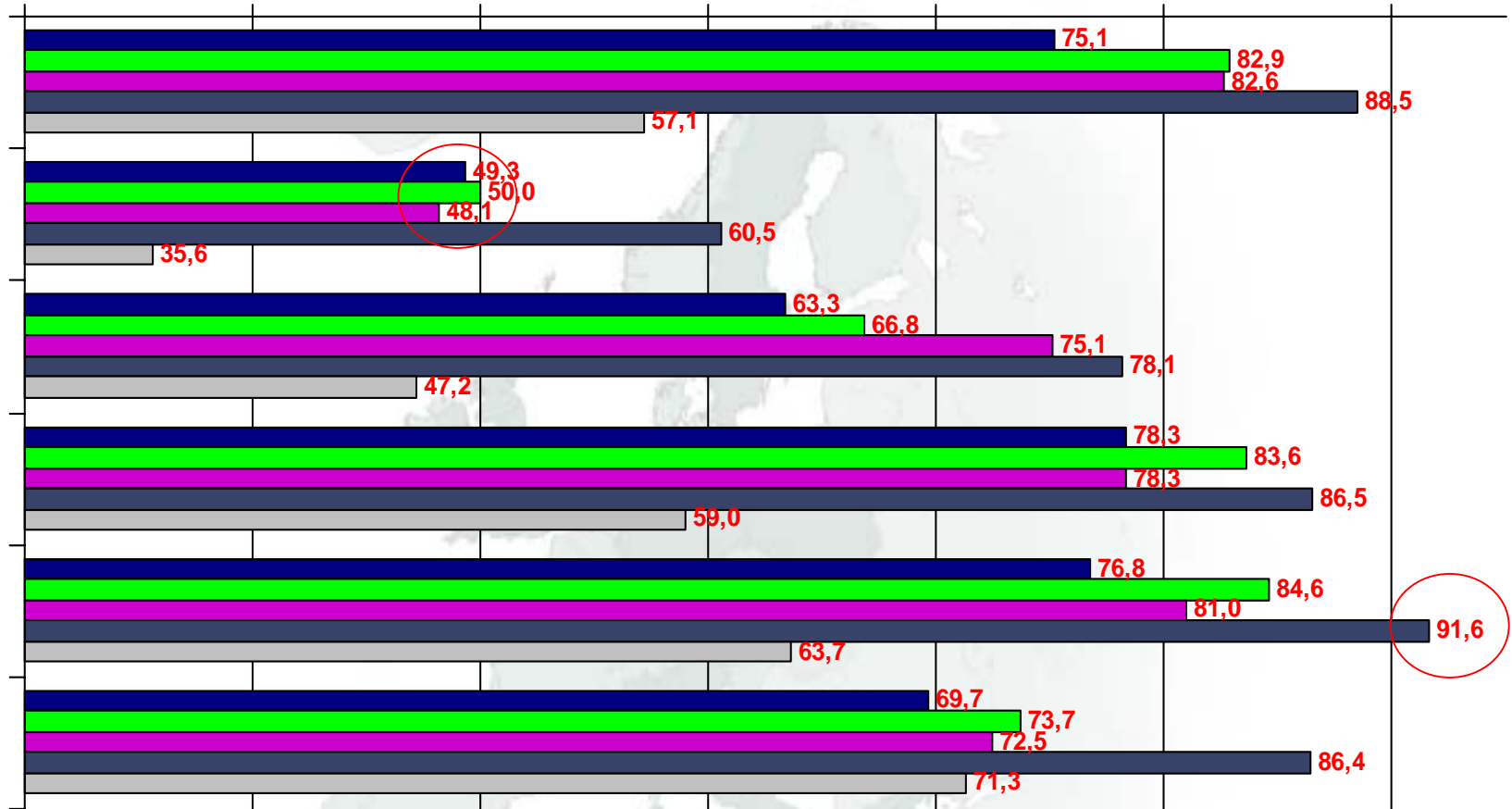
■ more money

Service characteristics retained "most important" (%)



Are these supports currently meeting your needs? (% of “mostly yes”)

30,0 40,0 50,0 60,0 70,0 80,0 90,0



- help is available at the time carer needs it most
- help arrives at promised time
- care worker are skilled and trained
- care worker treat elder with respect
- help provided is not too expensive

Final remarks

- analysis related to specific services is required to provide useful insights for each single country
- monetary transfers (care payments and allowances) need to be taken into account to provide an integrated picture
- cross-national variations in service use and preferences reflect also cultural, legal and economic differences in the various types of welfare systems
- in-depth analysis on determinants of services use and impact should control for co-existing effects exerted by relevant variables (such as carer's main socio-economic characteristics, dependency level of cared-for OP, strength of support network, regional differences etc.)
- one-year follow-up and feed-back discussion with service providers will provide insights on how to improve the system.



Core Group



Pan-European Network



DZIĘKUJĘ !