



Federal Ministry for  
Family Affairs, Senior Citizens,  
Women and Youth

# **Potential and Limitation of Independent Living in Private Households in Germany (MuG III)**

**Study on behalf of the  
Federal Ministry for Family,  
Elderly, Women and Youth**

**Summary**

## Summary

### Potential and Limitation of Independent Living in Private Households in Germany (MuG III)

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#### Subject

This Summary is a compilation of major findings of the project “Potential and Limitations of Independent Living in Private Households” (MuG III).<sup>1</sup> The empirical basis was provided by a research consortium funded by the Ministry of Family Affairs, Seniors, Women and Youth. State wide representative data collection was combined with in-depth studies targeting the situation of older people with dementia-related disorders, the diversity in care arrangements, monetary issues of help and care provision, regional differences and community-related perspectives. The consortium was headed by TNS Infratest Social Research (Munich), which was also responsible for the representative study arm. Additionally, the Central Institute of Mental Health (Mannheim) provided the dementia-related findings, the research group of Heinemann & Partners (Berlin) the study on care arrangements, the Institute of Social Research and Societal Policy (Cologne) findings on regional similarities and differences and the Jan Schröder Consulting Group (Bonn) insights on planning and decision-making processes on the community level.

Data was gathered in the years 2002 thru 2004, depending on the different arms of the study. While the representative data collection was completed already end of 2002 / beginning of 2003, the study with demented older adults only ended in the fall of 2004. The representative data are based on a probability sample of the German population amounting to 52,916 persons, from which those with at least one deficit in a range of activities of daily living (ADL) were selected for further analyses. This resulted in sample of 2,675 persons. In addition, a probability sample of 4.701 persons aged 70 years and older served to identify another 947 persons aged 70 years and older with at least one ADL-deficit. Both samples were combined and used as basis for population-

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<sup>1</sup> Schneekloth, U., Wahl, H.W. (Hrsg.): Selbständigkeit und Hilfebedarf bei älteren Menschen in Privathaushalten. Pflegearrangements, Demenz, Versorgungsangebote. Stuttgart (Kohlhammer-Verlag) 2006

based calculations. Besides structured interviewing, a cognitive screening test was conducted for the first time in Germany in a study of this magnitude.

## Results

As was found, persons with basic care needs (“Pflegebedürftige” according to the German Care Assurance) increased between 1991 and 2002 from 1,12 million to about 1,40 million. In addition, those with help and support needs in Instrumental Activities of Daily Living (IADL) increased from 2,15 million to 2,94 million respectively. However, the relative frequency of those with help and support needs in the IADL domain decreased significantly between 1991 and 2002 and this trend was particularly pronounced in females aged 85 years and older. In regard to those with basic care needs in the ADL sphere, no clear time trend supporting the assumption of competence gain was identified. The representative data also provided evidence for the ongoing readiness of family caregivers to support relatives with basic care needs in mostly stable long-term care arrangements. On the other hand, risks were as well related to this readiness, echoed in a high burden load and rather low use of available consultation and psychosocial intervention programmes for family caregivers. Important to note is also that a substantial portion of family caregivers, i.e., 33% was 65 years and older. Furthermore, nearly 50% of those with basic care needs also showed substantial cognitive impairment. The percentage of those with basic care needs living alone increased between 1991 and 2002 from 20 to about 29%. Meaningful increases regarding the availability of assistive devices and care-related housing adaptations between 1991 and 2002 were also found. Another findings is that care needs were mostly addressed well by the current private and professional care providing system. Deficits in the professional care providing system were nevertheless reported in substantial magnitude (18%) and had mostly to do with flexibility limitations and missing or underused case and care management strategies.

The study of older people with dementia-related disorders was based on 151 persons with the age of 60 and older, which were selected from the representative sample. A sample of 155 persons, which were identified as being not demented, were used for comparison purposes. Diagnostics was based on state-of-the art assessment according to DSM IV criteria. In addition, a full programme of neuropsychological testing as well as depression and caregiver burden measures were applied. Among the major findings of this study arm is that only a minor portion of those diagnosed as demented were also detected as being demented by their family physician and this was particularly pronounced in those with mild forms of dementia. Non-cognitive symptoms and behaviour problems such as aggressive behaviours, wandering or crying was found to be highly prevalent. This is important because symptoms of this kind are contributing much to the burden experience of the involved care providers. Care of demented elders mostly stood on the shoulders of family caregivers, while professional care services only played a minor supportive role. Stability of

care arrangements was nevertheless evaluated as rather stable in the clear majority of cases. Caregiver burden experience differed between the sexes, i.e., women experienced higher burden than men.

Findings also point to the need for an in-depth view of care arrangements. This study arm was based on semi-structured and structured interviewing of 84 older people with a diversity of living situation (alone, not alone), care needs (from low to very high) and care arrangements (private, professional, mix of both). As was found, private caregivers were mainly driven by an attitude that it is only natural to provide help to their loved ones and to support their well-being. In some contrast, professional caregivers more strongly reflected upon the aim of maintaining independence of the care receiving person. Time constraints related to the care were the major source of experienced burden of family caregivers and there was a tendency for a too late acceptance of professional care. Care problems such as pressure ulcers were also present and seemed not to be related to the involvement of professional care services. Care arrangements which may indicate the emergence of a “new culture of care” such as mixes of professional, semi-professional and non-professional persons revealed as powerful even in situations of very severe care needs. However, such arrangements still seem to be a rather seldom reality and this finding was also supported by the representative data.

The study arm focusing on the role of regional differences on the individual outcome of care provision and decision-making relies on six case examples taken from urban and rural regions both in the old and new (after German reunification in 1990) federal states of Germany. Findings are based on secondary data analysis of available data sources and interviews with social planning and care provision experts of the respective communities. Pronounced differences in the availability of care services and assisted living options between the regions were found. Shortcomings in flexibility and coordination of care services were as well detected. Taken all together, the view that regional differences are able to substantially contribute to the potential and limitations of private household care arrangements was supported. Gaps in service provision were also related to missing care management and a not efficient enough consultation and information providing system. As was also found, planning and decision-making processes on the community level frequently did not found much explicit consideration in those involved in such processes in the communities. Furthermore, the quality control of measures taken on the community level is often not controlled in a rigorous manner. It also seemed promising but still much underused to better involve the older people themselves and senior organisations speaking on behalf of those in need of help in community planning and decision processes.

In conclusion, the German care providing system with its strong focus on family resources still works well. What may be coined “new care arrangements”,

specifically mixes of private, professional and voluntary care giving, have already appeared at the horizon, but are still playing a minor role in quantitative terms. The family care system does however also show fragility particularly in circumstances of severe care needs, the prototypical case of which is the care of demented elders. The potential of professional treatment, care and psychosocial support still is not applied in its full dimension in the majority of care arrangements. In addition, it seems necessary to still better evoke the self-help and voluntary help potential in order to cope with the forthcoming care needs of an ageing society.