# SERVICES FOR PEOPLE WITH DEMENTIA (p. w. d. ) – A MAJOR CHALLENGE FOR SOCIAL WORK IN RAPIDLY AGEING SOCIETIES

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**Abstract:**

In this paper we propose to describe 4 aspects of services for people with dementia: the world is ageing; dementia as the dominating psychic illness in old age; demographic change: Diminishing personal resources and increasing (health) care demands and agenda for Social Work.

**Key words**: dementia, social services, elderly

## 1. The world is ageing

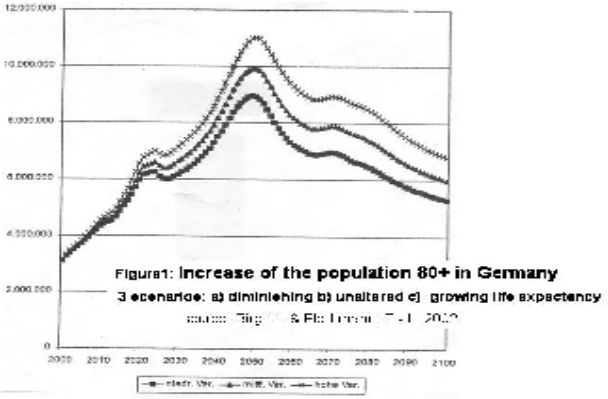



Fig. 1: Increase of the population 80+ in Germany from 2000 to 2100

Life expectancy at birth is growing almost all over the world – known as "the greying of nations" (WHO 1994, 4f.). Thanks to social and medical progress, there is a "compression of morbidity" (Fries, 1980), i.e. ever more people are spending a longer period of their "3rd age" in relatively good health – compared to elderly people 50 and more years ago. Gerontologists coined the term: "Adding life to years" (instead of a mere addition of years to

life) (WHO 1994, 23). Whereas the average life expectancy for women in Germany was 83 years in 2007, a girl born today can expect to live up to a hundred years of age.

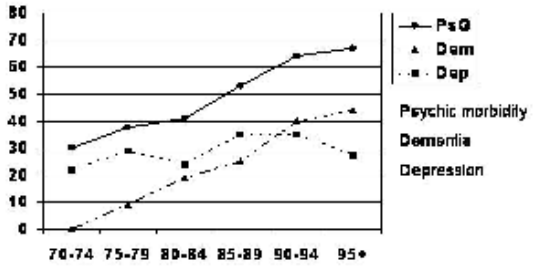
**2. Dementia as the dominating psychic illness in old age**

Dementia is a threat though to the individual and to society.

An OECD-study on prevalence rates (2004) shows similar results for Australia, Canada, England and Wales, Germany, Japan, Spain, Sweden and the US.

**Figure 2: Psychic morbidity in old age**

source: Helmchen, H. et al., 1996 (Berlin Study of Ageing )




Age-related psychiatric morbidity and prevalence rates of depression and dementia (sex-adjusted data)

Fig. 2: Ageing and psychic morbidity

Figure 2 shows the increasing curve (over age) of psychic illness on the whole as well as for the dominating "big two": depression and dementia.

Due to longevity, more than every third person will have to live with dementia in old age if no prevention or cure can be found in the near future.

Considering the age-related risk of dementia among the very old (80/85 +) in combination with the estimations of figure 1 (increase of rates of people 80+), we have to face an enormous rise in prevalence rates of dementia due to the extraordinary increase in the very old.

**3. Demographic change: Diminishing personal resources and increasing (health) care demands**

Germany faces a challenge that is not unique in Western Europe, namely an extraordinary growth of the very old due to the "baby boom" cohorts in the post-war decade while the birth rate decreased due to the invention and wide application of contraceptive drugs from the middle of the 1960s on. There was an additional – and more dramatic – slump in birth rates after the German reunion as the new political and economic system meant an unfamiliar uncertainty regarding the future (job situation and life perspectives) of young people – so many postponed or gave up their ideas of having children.

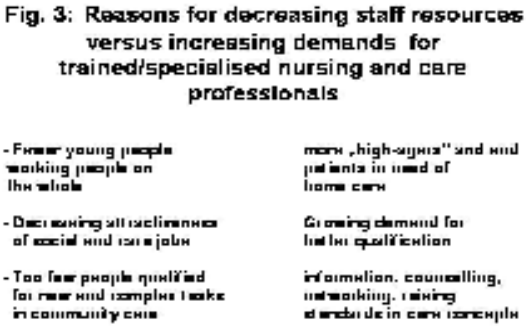



Fig. 3: reasons for the decreasing number of professionals versus increasing demands for trained/specialised nursing and care professionals

This means that already now – and more so in the years to come – we face a shortage of young people, and more so of people who are willing to be trained in professions rendering personal services to old and/or handicapped people.




Picture. 4: WHO-magazine 1994: "Health Care is Homeward Bound"

The WHO called for new health care policies and offered examples of adequate strategies to care for the elderly in their families and community settings as an alternative to nursing homes already 15 years ago.

The vast majority of people over 50 years of age wish to stay in their familiar surroundings till they die. Therefore for the last two decades German social and health care politics have set a priority goal: home care has priority over residential (nursing home or hospital) care; other West European countries (like Denmark) were more radical by closing down nursing homes and bringing people back to the communities a long while ago. Actually only 4% of the population 60+ in Germany lives in an institution, but: around 40% die there (in a hospital or nursing home or hospice).



Figure 5: **The carers of tomorrow will emerge from the group of the young elderly**
Source: World Health 47, 1994(4)

Picture 5: WHO, 1994: "The carers of tomorrow will emerge from the group of the 'young elderly'"

The issue of the already quoted WHO-magazine from 1994 also reports on the necessities of declining professional capacities due to demographic changes.

This means that highly trained care professionals and social workers supply people with information, counseling and relief services to the lay carers ("empowerment") and they engage in case management for individuals. Many international studies on stress

and burden report high levels of physical, psychosomatic and psychic disorders in caregivers, especially family members caring for p.w.d. and the highly underreported danger of physical and psychological elder abuse has been a topic in social work since the 1980s. We do know the feature of the most endangered persons to become victims: female, belonging to the "old old", suffering from dementia.

**4. Agenda for Social Work**

The late Tom Kitwood, British Social psychologist, was among the first to teach professionals and lay carers a "new culture of dementia care" (1997) by stressing the importance of an individualised optimistic, i.e. resource-oriented view on p.w.d.: *"The person comes first".* This means that the focus should be on the p.w.d.: her/his preserved competences, biography, life situation, assessment of well-being – and not on the illness, deficiency nor on the logic and rules of an organisation/institution giving help or care. He pointed out what contributions settings make to provoke "challenging behavior" – hitherto called "problem behavior". As p.w.d. by and by lose control and judgment over their behavior and its adequacy, the setting makes all the difference, and the setting is made up by people (family members, professionals, voluntary care support) who have to remember that

"A person becomes a person through other people" (Zulu saying).

The well-known professor of Social Work at the University of Stirling (Scotland) and former social worker Mary Marshall has – together with her colleague Margaret-Anne Tibbs -published the revised edition of a very helpful book that can be regarded a guide for social workers working with older people in any setting and with their families. It reflects the standards British dementia care (as one of the most advanced systems in terms of need-assessment and support) has set:

**Fig. 6a: The Principles of a good service (source: Marshall & Tibbs, 2006)**

- **Care** should be based on a **good knowledge of the individual**
- **People with dementia** should be **informed, trained and empowered**
- **Carers** should be **informed, trained and empowered**
- **Services** should reflect ethical practice, **balancing risk and protection**
- **Services** should be based locally **in the community**
- **Care staff** should be **trained and supported**

**Fig. 6b: The principles of a good service** (continued)

- **Day and residential services** should be delivered in **small, domestic, home-like settings and promote this philosophy of care**
- **Attention** should be paid to the **design of the built environment**
- **All services** should be **accessible**
- **Services** should respond **effectively in a crisis**
- **Services** should be **flexible and adaptable**
- **Services,** including **home care,** should be **available 24 hours a day, 7 days a week**

Fig. 6a and 6b: Standards of good service (Marshall & Tibbs, 2006, 163)

- information about the illness and its course: often families do not receive sufficient
  information resp. not adequate for their special support needs
- try to establish relief for carers (foster families, care supporters)
- assist younger p.w.d. to get proper diagnosis: doctors often do not consider the possibility

that problems people under the age of 60 or even 50 report might be indicators of dementia
symptoms
- help foster multidisciplinary assessment teams (Australia being the best model at the
moment: Aged Care Assessment Teams)
- advocacy for p.w.d. and promoting self-advocacy groups ("hearing the voice of p.w.d.")
- education for other professional groups
- do risk assessments.



Picture 7: Maintaining competence and intergenerational social contact in community-based family care

The family is *the* place of choice for most people – given a well-integrated, supporting family, trying to maintain the competences of their elders and granting intergenerational contact.

The majority of the middle-aged people in Germany though, giving or having given care to their mothers/fathers(-in-law), do not want to depend on their children when they themselves become frail and in need of care as they know the psychological cost of it (and sometimes the physical and financial burden on top).

Living together in small assisted living communities in the region has become a possible option for the last decade (the Alzheimer's Society of Berlin being first to introduce assisted living for p.w.d.), instead of being a "number" in a nursing home with 120 or more residents - although some of those try to remodel

their wards into smaller living groups for 12-15 p.w.d. each, giving people the chance of a "normalised day" instead of a day in a "total institution" (Goffman, 1960).

Tenants with special support needs – that is what they are – do not need "animation" but steady companions to help structure their day, while "simply living a life (almost) as autonomous as before with the care support weighing risks against freedom and relatives still in as close a contact as they can manage and community volunteers as additional companions for those p.w.d. whose relatives cannot come any longer. And this is what it looks like:

Pictures 8-16: daily life in an apartment shared by 6 p.w.d. with a 24-hour assistance
*(courtesy of Sigrid Fiedler, social worker, Neuruppin*)



Picture 8: preparing breakfast together




Picture 9: peeling potatoes for lunch in the kitchen



Picture 10: doing the dishes



Picture 11: preparing dinner together
(care assistant gives prompts only when necessary)




Picture 12: Playing cards in the kitchen

Paying a visit to the neighbour nextdoor



Picture 13: Paying a visit to the neighbour nextdoor

**Coffee break – with the loving help of a neighbour**



Picture 14: Coffee break –
with the loving help of a neighbour

Animal companions welcome!



Picture 15: Animal companions welcome!




Picture 16: Family and friends are welcome, too – any hour!

**Bibliography**


- Fries, J.F., (1980), Aging, Natural Death and the Compression of Morbidity. New England Journal of Medicine303, 130-135.
- Goffman, E., (1960), Characteristics of Total Institutions. In: M.R. Stein, A.J. Vidich & D.M. White (Eds.), Identitiy and Anxiety. Survival of the Person in Mass Society (pp. 449-479). New York: The Free Press.
- Kitwood, T., (1997), Dementia Reconsidered. The Person Comes First. Buckingham: Open University Press.
- Marshall, M. & Tibbs, M.-A., (2006, 2nd rev. ed.), Social Work and People with Dementia. Bristol: The Policiy Press University of Bristol.
- Mayer, K.U. & Baltes, P.B. (Hrsg.), (1996), Die Berliner Altersstudie. Berlin: Akademie Verlag.
- World Health Organization (Ed.), (1994), World Health, 47(4).