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FORMAL AND INFORMAL CAREGIVER SUPPORT IN DENMARK

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BACKGROUND: DENMARK AND DANISH HEALTH CARE

Denmark is one of five Nordic welfare states. The population is 5.6 million and GDP per capita is slightly higher than in the US and Canada (World Bank, 2013). Denmark operates a public and universal health care system. It is tax-financed and free at the point of delivery but with some co-payments for pharmaceuticals, dentistry, physiotherapy, etc.). Management and ownership of hospitals lies with the five regional authorities, whereas the municipalities are in charge of most other welfare services including home care, prevention, rehabilitation outside hospitals, elderly, infant and school health services, social care, employment services etc. General practitioners and practicing specialists are private, but receive most of their income from public funding based on general agreements between the regions and the doctors associations.

ADMINISTRATIVE REFORM TO BETTER SUPPORT HEALTH PROVIDERS

A major reform was implemented in 2007 aiming to strengthen administrative capacity at municipal and regional level, and to provide better opportunities for integrating welfare services (social, elderly, health, employment etc.) at the municipal level and between primary and secondary health care. In this sense the reform also aimed at strengthening the capacity for professional service delivery at the municipal level including home care services and institutionalized service. Issues of health care in general and discussions about frail elderly and persons suffering from chronic care conditions were central in the reform process.

The reform meant a reduction in the number of municipalities from 271 to 98, and the establishment of larger and more homogeneous municipalities. The idea was that larger municipalities would be better able to support professional staff and provide integrated services.

The regions remained in charge of hospitals and general practitioners. The number of regions was reduced from 14 to 5 (0.6-1.6 million inhabitants).

POLICY INSTRUMENTS TO IMPROVE COORDINATION AND SUPPORT PROVIDERS

A number of new instruments for improving coordination and strengthening the support for health professionals were introduced. The most important instrument at the governance level was the introduction of mandatory health agreements to be established between regions and municipalities in every election term (4 years). A structure of joint committees and working groups were set up to facilitate the negotiation and implementation of the agreements, and national guidelines, standards and indicators for monitoring progress have been developed.

The 3rd generation of health agreements are currently being negotiated. They must include detailed agreements about a set of mandatory topics (prevention, admission and discharge procedures, training and rehabilitation, health IT and work processes). The detailed

agreements must address the general issues of division of labor between regions and municipalities and different groups of health professionals; knowledge sharing and training; coordination of capacity; involvement of patients and relatives; equity; documentation, research, quality development and patient safety.

A number of patient pathway programs and standards have been developed to support the regions and municipalities in developing more integrated services for chronic care patients. Pathway programs have been developed for a number of chronic conditions including heart conditions, diabetes II, COPD, chronic back pain etc.

THE ORGANIZATION OF LONG-TERM CARE

Long-term care: Responsibility for long-term care is shared between regional hospitals, general practitioners, and municipalities. Hospital-based ambulatory chronic care is financed in the same way as other hospital services. Long-term care outside of hospitals is needs-based, and is organized and funded by the municipalities. Most municipal long-term care takes place in citizens' own homes, while the role of institutionalized care (nursing homes, "protected housing," etc.) has been reduced over the past decades in conscious and largely successful policy efforts to support citizens in "staying home" as long as possible.

Home nursing (hjemmesygepleje) is fully funded after medical referral by general practitioner or hospitals. It is meant to provide support for ongoing treatment and care activities and to prevent further decline in functional activity.

Home care (hjemmehjælp) is aimed to support a person's ability to maintain an active life and stay in their own home. It is granted by the municipalities based on an assessment of the citizen's ability to handle daily life activities, and their physical, mental and social situation. The municipalities will include assessments from GPs in their evaluation. Patients may complain to a national appeals board if home care is denied by the municipalities. Home care may also be allocated in order to relieve spouses, parents or other relatives that take care of a relative with physical or mental health problems in their own home. Home care must be organized in dialogue with the patient with the aim of providing maximal support for maintaining functionality.

Allocation of home care can be temporary or permanent. Permanent home care is free of charge once the municipality has determined that one is entitled to such care, while cost-sharing may apply for temporary home care if income is above DKK138,600 [USD 17,919][*] for singles and DKK208,200 [USD 26,917] for couples.

[*] Please note that throughout this paper, all figures in USD were converted from DKK at a rate of about 7.73 DKK per USD, the purchasing power parity conversion rate for GDP in 2013 reported by OECD (2014) for Denmark.

Municipalities are obliged to organize markets with open access for both public and private providers of home care, in order to accommodate choice of home care services (non-personal services). Patients may also apply for the right to select their own home care provider.

Institutionalized care in nursing homes, protected housing, etc., is organized by the municipalities. Some municipalities have contracted with private institutions for institutional care of older people, but more than 90 percent of residential care institutions (nursing homes) remain public. Providers are paid directly from municipalities and no cash benefits are paid to patients. Public providers are employed by the municipalities. Citizens pay 10 percent of their income (20% of income above DKK145,600 [USD 18,824] plus heating and electricity charges for staying in residential care institutions.

Relatives of seriously ill persons may take paid leave of absence for up to nine months. The period can be split over time and between several relatives. A similar scheme exists for terminally ill patients that no longer receive treatment.

Hospices are organized by regions and funded by regions and municipalities, and may be public or private. There is free choice of hospice upon referral.

SUPPORT FOR INFORMAL CARE PROVIDERS

According to the Law of Service (3, §118) it is possible for informal (often family) carers to get remuneration for the time spent caring for the patient. The right hereto, as well as the amount, depends on several factors, but it includes the condition that the period may not last longer than 6 months. The municipality in which the patients live is responsible for the contribution, but there can be various agreements/arrangements within the workplace of the carer which can alter these possibilities.

The remuneration is normally given for care at home, but can also be related to shorter stays in hospital (including hospital treatment abroad). The following persons can receive remuneration according to the Service Law:

- Children, adults and elderly with chronically reduced physical or mental abilities
- Persons with chronic or long term care needs (more than 1 year)
- Terminally ill patients.

Remuneration for care leave may be given to spouses, children, parents or others with close family ties.

Many employees have the right to such paid leave in their working place contracts. The public remuneration covers persons that are not included in general work place agreements.

The care-giving relative is formally employed by the municipality for a salary of DKK20,241[USD 2,618] per month, and can be employed up to six months. The period may be extended by three months given special circumstances. The period may be divided into several shorter periods.

The rules only apply if the alternative is full time stay at a care institution or the care need is equivalent to full time employment.

The services offered to informal carers vary, as well as for the patients, according to the municipality. It is estimated that 95 % of the municipalities offer activities for the carers. This mostly contains group meetings (90%), guidance/advices (95%) and informational classes on handling dementia (61%) (5).

A minor Danish study (DAISY, 2006) of patients with dementia and their carers showed that only a minority of the carers were aware of and used some of the offers for respite care, telephone counseling, supportive initiatives such as group meetings, and informational courses. Another Danish study demonstrated that the carers most often used the offers regarding social activities (31.9%) and participated in group meetings (30.8%) (5).

ORGANIZATIONAL INNOVATIONS AT THE REGIONAL/MUNICIPAL LEVEL TO SUPPORT INTEGRATED CARE PROVISION

Following the 2007 reform there have been significant investments and many organizational innovations in the municipalities. The following have been implemented in many municipalities in various forms:

- Acute/temporary care facilities in municipalities to prevent unnecessary admissions and readmissions (for frail elderly) and to facilitate early discharge
- Development of “everyday rehabilitation” programs aimed at supporting the patient in developing skills to remain in “their own life”
- Municipal units (or contact persons) embedded in regional hospitals (e.g., TUE at BBH)
- Follow home arrangements
- Co-location in health centers
- Telemedicine (250+ projects)
- Support and training of municipal staff
- Medical devices and aids, personal care, and assisted living

- Innovative ways of engaging with civic society volunteers, e.g. to provide physical exercise activities, social activities, transport, etc.

EVALUATIONS

Several of the "everyday rehabilitation" programs have been evaluated as having positive results (e.g. KORA, 2010). The health agreement indicators show some improvement, but time series are still short and there are data quality issues. Qualitative studies indicate that health agreements are largely viewed by municipal and regional managers as a useful instrument to create dialogue between regions and municipalities. However, there are concerns about the lack of integration of GPs. General survey data show continued high patient satisfaction in Denmark, also at the municipal level. Budget data from municipalities show that they are investing significantly in better health services, including training, new rehabilitation programs, temporary acute facilities, and health centers.

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