

Municipal obligations to support informal carers

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Introduction:

- From 'should' to 'shall' in municipal LTC obligations to support informal carers
- In 1998 a new paragraph in the national Social Service Act was introduced
 - The paragraph stated that the municipalities should support informal carers
- Today we have a paragraph that states that municipalities shall support informal carers



The change in the paragraph is important – but also the context (why)

- The scope, focus, and organization of care of older people have changed significantly over the past decades in Sweden
- Developments that had contributed to the change:
 - Increased number of people in need of home help, but the number of clients that receives help decreases
 - Results from research on “burden of caring”, made a need explicit
- As a response:
 - Several programmes have been initiated by the government and managed by The National Board of Health and Welfare (NBHW) to improve the conditions for those who deliver informal care

Programmes in brief

- A combination of research projects and very practical projects at a local level:
 - 1999 -2001: Anhörig 300, programme to develop support to family carers . (100 million SEK/year, about €9.5 million)
 - 2002 -2004: Informal carers in the national action plan to develop health care (100-150 million SEK/year)
 - 2005: Additional programme to develop support for family carers (25 million SEK)
 - 2006-2007: Continuation (125 million SEK/year)
 - 2008: The programme of support became permanent (100 million SEK/year)

What are/were the effects?

- The main purpose of several of these programmes has been to highlight the role of being an informal carer and develop direct and/or indirect support to reduce the burden for caregivers
- Overall these programmes have led to the result that virtually all municipalities have a variety of different forms of:
 - Respite care
 - Different forms of personal support; counseling or supportive conversations, family groups and the incentive funds have also enabled a wide variety of activities, provided by municipalities
- The new act (from should to shall) can be seen as a result of the work and research carried out in the different programmes

Municipalities co-operation with other organizations, regarding informal carers

Co- operation partner	2005	2008	Difference
Pensioners' Organization	65	81	+16
Red Cross	64	78	+14
Religious communities	60	77	+17
Disability and patients' associations	-	59	+10
Informal carers associations	42	55	+13
Immigrant Associations	7	14	+7
Other municipality	46	67	+21
Primary care (GP)	48	66	+18
Other primary care (Rehab)	25	31	+6
Inpatient care (County councils)	22	30	8+

Forms of support to informal carers offered by municipalities

Form of support	2005	2008	Difference
Respite care on short stay home	100	99	-1
Respite care on day centre	92	93	1
Respite care in home	94	98	4
Coaching	81	90	9
Groups for informal carers	76	90	14
Training of informal carers	33	78	45
Informal career centre	40	65	25
Voluntary centre	-	37	-
"Feel good" activities	18	57	39
Health check ups for informal carers	2	4	2
Other support forms	34	46	12

Strengths and limitations

- The notion that the Social Service Act - and the paragraph - changed, but the municipalities still decide what kind of support they offer is a threat and may create differences in forms of support between municipalities.
- Informal carers are protected in the legislation is strength in itself. This gives the citizens the right to apply and (appeal if the support is rejected by the municipalities).
- The level of support offered by the municipalities is transparent. If not granted, and if a municipality has to deal with many appeals from their citizens it can be considered a problem. This can be seen as an opportunity from the informal carers' point of view.

Conclusions

- The change from “should” to “shall” is something that manifests the outcomes of all programmes
- Informal care in Sweden has gone through a transition from not being recognized to being a part of the health care system: Informal care is included in the National guidelines on dementia.
- A possibility for each informal carer to enforce support provided by the municipality