Nka™
Nationellt kompetenscentrum anhöriga

Linnéuniversitetet

Indicators of informal care – Swedish Case

Joint meeting of the Eurocarers Research and Policy Working Groups

8-9 September, 2022 Ljubljana, Slovenia, hybrid event

Elizabeth Hanson, Lennart Magnusson, Francesco Barbabella

Swedish Family Care Competence Centre (Nka)

First National Carers Stategy in Sweden

Main goal of the strategy:

”It shall help municipalities and regions to:

i. Strengthen a carer perspective in health care and social care

ii. Make the support to informal carers more tailored to their individual needs and

iii. More comparable over the country”

It’s premised on the fact that ”carers’ efforts and participation are voluntary”.

Källa: Regeringskansliet promemoria 20-04-13. S2022/02134

Rationale for focus on indicators

- Strategy recognises that current knowledge about the extent and quality of support offered to carers in Sweden is poor
- This is due to the lack of documentation (mainly for legal reasons) making it difficult to map, follow up and evaluate support to carers
- Ministry of Health & Social Affairs has commissioned the National Board of Health & Welfare (NBHW) with advice from Nka to devise how best to follow up carers support that municipalities and health care regions offer

They clearly state that it shall:

– include *quantitative and qualitative methods* as well as *indicators, measures and key figures*

They expect and specify that this will:

– enable *gender based systematic follow up* with regards to the level of a) accessibility, b) quality, c) individualisation and support the intention of the carer strategy

Report to the Ministry at the latest 1 October 2023

Källa: Regeringskansliet promemoria 20-04-13. S2022/02134

Planning phase, ongoing work by Nka

- Planning and consulting sessions held with Nka by the NBHW- start phase, September 6 - onwards

Group discussion-Nka staff:

i) Key message: not to ”re-invent the wheel”, make use of existing channels and get in questions on carers within existing established databases, audits, surveys etc. For example:

ii) ”öppna Jämförelser”-’open comparisons of quality within health care and social care in Sweden

iii) National quality registers within healthcare, Eg. ”SeniorAlert”

iv) Existing carer module within IBIC, assessment of care needs by Needs Assessor

v) SIP- Coordinated Individual Planning

Our role would be to provide/advise on the content of the questions/items relating to carers.

- All examples of a more ”top down” approach

Källa: Regeringskansliet promemoria 20-04-13. S2022/02134

Example of a ”bottom-up” approach – in progress by Nka: Database project

Initiated by carer advocates working in the municipalities, in collaboration with Nka.

Aim: contribute to an evidence based approach within Swedish carer support

Goals:

1. Develop templates for gathering data with a focus on individual supportive conversations and carers support groups
2. Develop a database for collecting data on carers support at a municipality level
3. Develop indicators for following up the quality of carers support with carers

Nka supports the process by:

- helping with building the database,
- holding sessions with carer advocates and
- heading up the carer engagement/feedback during the process

Process of the Database project

- Suggestions for indicators designed by a working group (six carer advocates and two Nka staff) based on items within COAT (Carers Outcome Agreement Tool) co-created in 2006, Hanson et al., together with carers and professionals
- Use of esMaker questionnaire tool
- Three focus groups with carers
- Test period at two different weeks within 40 municipalities during the Autumn followed by refinements
- Test in larger scale during the Spring 2023

Nka™
Nationellt kompetenscentrum anhöriga

Examples of questions

Nationella nätverket för anhörigkonsulenter

THE CONVERSATION HELPS ME…	Do not agree at all 1	2	3	Fully agree 4	Not relevant 0
to get information about what sorts of help and support I can receive as a carer	1	2	3	4	0
to get information about what sorts of help and support I can get for the person/s I care for	1	2	3	4	0
to be able to talk openly about my caring situation	1	2	3	4	0
to be able to emotionally manage my caring situation	1	2	3	4	0

Nka™
Nationellt kompetenscentrum anhöriga

Examples continued

Nationella nätverket för anhörigkonsulenter

The conversation helps me to feel less lonely.	1	2	3	4	0
The conversation helps me to feel more secure in my caring situation.	1	2	3	4	0
I feel I'm being listened to during the conversation.	1	2	3	4	0
I have the opportunity to have a chat when I need.	1	2	3	4	0

Overall quality, 1-10: Think about how satisfied you are overall with the support and help you receive via the conversations/support group. Place a X with the alternative that best fits with your opinion: 1 = I'm very dissatisfied….. 10 = I'm very happy with the help and support I receive……..You're welcome to comment on why you answered as you did!

Nka™
Nationellt kompetenscentrum anhöriga

Linnéuniversitetet

Contact and information

Elizabeth Hanson
Email: elizabeth.hanson@lnu.se