

Blended Learning Networks: An intervention for developing support for carers of people with mental illness – implementation and evaluation in a Swedish context

6th International Carers Conference
Gothenburg 4-6 September 2015

Eva Gustafson

Mats Ewertzon

Swedish Family Care Competence Center
and

Linnaeus University

Ersta Sköndal University College

Content

- Blended learning networks (BLN)
- Carers experiences and needs for support expressed in BLN
- Evaluation of one national BLN

Key Objectives of the Blended Learning Networks

	Individual level	Municipality level	National level
Short-term objectives	<ul style="list-style-type: none"> •Everybody's voice is heard •Increased knowledge and awareness about their own situation •Increased knowledge and awareness about other stakeholders' situation •Identification of areas for development or change 	<ul style="list-style-type: none"> •The voices of all groups are heard •Enhanced knowledge about how it is to be a caregiver •Enhanced knowledge about the situation of family caregivers in the municipality •Identification of areas for development work or change 	<ul style="list-style-type: none"> •Increased focus on caregivers and their situation •Enhanced knowledge about the situation of caregivers nationally •Data for inspiration material to disseminate and use in the workplace/ organisations
Long-term objectives	<ul style="list-style-type: none"> •Changed situation •Enhanced quality of life for family caregivers 	<ul style="list-style-type: none"> •Development within family care support •Increased quality of family care support 	<ul style="list-style-type: none"> •Further development and improvement of family care support •New services and increased quality of family care support

Local BLN: 10-14 partners contributing to the discussion with knowledge and experiences from:

Carers first-hand experiences

Practitioners and leaders within health and social care services

Organizational and policy knowledge amongst decision makers

Voluntary organisations



The organization of BLN



From the BLN: experiences from carers

- **A feeling of being "marked"**
 - **Always be on watch**
 - **Be surprised and taken for granted**
- *"Feelings of guilt that one puts on oneself and get from others"*
 - *"one is considered a bad parent"*
 - *"Worries are always there, even during the calm periods and one continually lives the question – what's going to happen?"*
 - *"Nagging: "Have you gotten out of bed yet? Have you gotten cleaned up?, Have you cleaned, washed the dishes?"*
 - *"Periodically everyday life goes well, but in the background there is the feeling that you are on your guard and ready for action"*
 - *"They (staff) expect that I can take her home now but that will be devastating for me. I have told them that either she must be accepted to an alternative living situation or she has to stay at the hospital. I am old and sick and I don't have the stamina any longer".*

continuation....

- **Waiting**
 - *"One was made to wait and I had to work hard at getting him psychiatric care and help"*
 - *"Waiting requires patience but stimulates sadness, disappointment, feelings of powerlessness, and anger"*
- **Being in the way**
 - *"At times you feel that you are an idiot and an underdog. I want to be a part of the solution – not at part of the problem!"*
- **Living with enormous responsibilities**
 - *"It feels like I am going under myself. I try to turn-off more and more, but can't avoid it."*
- **Being alone**
 - *" Friends and associates disappear and at times it can lead to a divorce"*
- **Learning for good and bad**
 - *"I have learned a lot on my own, but little at time, I have learned more about the illness, the consequences and my part in the whole thing. One matures and develops a greater insight"*

Carer support

What is missing and what do carers want?

- **Guidance**
- **Relevant and accessible information:** regarding the organization of the psychiatric care, to whom one can turn to regarding support for carers, primary and community care, psychiatric health care services, the National Employment Agency, National Health Insurance Office (verbal, written, on-line information)
- ***Someone that is present through the process:*** like a coordinator, case manager, "spider in the net", pilot, mentor, guidance counselor, primary care team, carer ombudsman etc
- **Development of an individual crisis and plan of action:** with the aim to support and facilitate the carers' or families' situation IF problematic situations should arise

Carer support

Meetings with others and meeting places

- **Security in having others**
- **Social contacts:** to listen to other's experiences, give and take advice and concrete tips on how to solve problems
- **Carers support groups and education:** contacts with self-help groups and volunteer organisations, open meeting place without any requirements, possibilities to have get-togethers, and other social and health promoting activities
- **Psychiatric and mental health professionals:** to be observant and attentive, to be included and continually be informed and to be invited to participate in care planning and evaluations

Carer support continued

- **Education -to learn and understand (Carers/staff)**
- **A need to focus on oneself and other things**
- **Regarding the illness:** the consequences of the illness, treatment, rehabilitation and approach in everyday life as well as problematic situations
- **Specific education days or evenings:** informal meetings to learn more regarding different diseases, suicid, and to express own concerns
- **Regarding attitudes:** collaboration and participation questions
- **Recreation, respite and relief:** from one's own regular duties, in one's home
- **Having a job outside the home:** assignments, routines and colleagues
- **Possibilities to receive counseling:** or someone to talk to
- **Possibilities for the relative:** to have meaningful occupation, daily activities, modified work environment or tasks as well as support and education

Evaluation of BLN in relation to the objectives

Study I: 15 national BLN (111 local networks)

- Qualitative content analysis of documentation
- Survey by local network leaders

Study II: 2 national BLN (16 local networks)

- Survey by all members who participated in these BLN, when the network was completed and after six months

Evaluation of one national BLN

“Carers of people with mental illness”

Result in summary

Short-term objectives

<u>Individual level</u>	Largely/ certain extent
• Everybody's voice is heard (n=51)	98 %
<i>Participation in BLN contributed:</i>	
• Increased knowledge and awareness about their own situation (n=14) (Carers)	63 %
• Increased knowledge and awareness about other stakeholders' situation:	
The carers situation (n=50)	86 %
The healthcare professionals work with carers support (n=50)	80 %
The decision makers objectives with carers support (n=50)	60 %
• Identification of areas for development or change:	
Carers (n=14)	64%
Healthcare professionals and local networks leader (n=16)	81%
Leaders, politicians, and members of a voluntary organization (n=22)	91%

Result in summary

Short-term objectives - continued

Municipality level

Largely/ certain extent

Participation in BLN contributed:

- Enhanced knowledge about the situation
of family caregivers in the municipality (n=51) 53%
- Identification of areas for development
work or change (n=51) 57%

Result in summary

Long-term objectives (six month follow up)

Individual level

Largely/certain extent

Participation in BLN contributed:

- Changed situation

Carers (n=7)	43 %
Healthcare professionals and local networks leader (n=8)	87 %
Leaders, politicians, and members of a voluntary organization (n=10)	40 %

Result in summary

Long-term objectives - continued

Municipality level

Largely /certain extent

Participation in BLN contributed:

- Development within family care support (n=25) 60 %
- Increased quality of family care support (n=15) 80 %

Conclusion

Conclusion, our experience is that BLN is a method that may lead to improvements in support for carers at individual and municipality level. It provides the opportunity for mutual dialogue. Which may increase knowledge of carers' situation, could lead to identification of areas for improvement, and hopefully with a higher quality of daily life for carers

Thank you!

Information and contact:

www.ansoriga.se

Eva Gustafson

eva.gustafson@ansoriga.se

Mats Ewertzon

mats.ewertzson@ansoriga.se