Different voices in evaluation - user participation in psychic health care

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The topic of the presentation:

- Design and execution of evaluation research required to address the voices of users in psychic health care

Focus and attention

- The focus is <u>methodological</u>
- Attention is devoted to challenges of:
1. <u>design</u> when attention is devoted to users is psychic health care
2. <u>measurement and interpretation</u> that one encounters when intended effects of social-political programs are evaluated through the users voices

The program in focus

- The National mental health program 1999 – 2008 (Opptrappingsplanen for psykisk helse)

- Main goal:
  - To improve the services, - both qualitatively and quantitatively to users with psychic disorders
  - Promote the users independence and their abilities to deal with their own lives

User involvement is crucial in the program and consists of…

- Information about the services, as well as of diagnosis, prognosis etc.
- Involvement of and information to close relatives
- Development of individual care plans and responsibility groups
- Improved co-operation between different kinds of services
- Continuity in the treatment

Evaluation questions posed:

Have the users experienced improvements in conditions related to user involvement during the period of time that the Mental health care program has been working?

In what manner can the users voices indicate if the program has reached its main goals?

Methodological issues

- There are essentially nine methodological issues that have to be taken into consideration, and that have to be included in research designs that focus on the users voices, and on potential changes

- They are on different levels and represent different kinds of challenges

Methodological issues related to __design__ of the project

1. Bottom-up perspective
2. Qualitative methods (semi-structured interviews)
3. Small samples – different actors, different regions
4. Recruitment of psychiatric users: several challenges
5. Different actors in addition to the users – both relatives and health care workers – to get additional information from different points of view

Methodological issues related to measurement and interpretation

- The question of comparison: success or failure?

  1. Evaluation criteria, mainly based on goals set up by the program-owners – but also on program theory
  2. Time-series design (first phase focusing on status and second phase focusing on change)
  3. Panel study
  4. Triangulation: different approaches - as well as other projects

  Main idea: Comparison along the time-axe as well as between different regions – and panel study to keep constant as many variables as possible

1   The bottom-up perspective

- To listen to the voice of the users means to take a bottom-up perspective:

- Has its main concern on the users and on their participation, and on how users express their needs, interests, experiences, attitudes and rights

- The concepts of user-orientation and user-adaptation are used when action is taking place to produce change in the interest of the users and directed towards their needs

2   Qualitative methods to..

- ..understand attitudes, feelings, choices, relations and processes related to the people involved in the program

- ..understand what the real problems are, according to the users

- ..explain the relationship between actors, structures, context and processes between them

- Semi-structured interviews based on an interview-guide. Length: from ½ hour up till 3 hours

3   Sample: size and localization

- Small samples were required
- Sample consisted of four different groups of users:
    - 16 adult users
    - 8 relatives of adult users
    - 8 adolescent users
    - 8 relatives of adolescent users
    - 6 health care personnel
    - Total of 48 interviews – from <u>two different regions</u> in the country (north and east, town and country-side)

4   Psychiatric users as informants:

- Not everyone can be interviewed because
  - their condition will not allow for it
  - they might not have sufficient insight in their own situation
- Research should not
  - interfere with their mental condition
  - upset them or be provocative
  - interfere with their treatment
- Interviews should be
  - conducted at a neutral place (not home and not related to the treatment)
- Users should have
  - some experience as users and the health care system
  - have received psychiatric services over some time – and with probability continue to receive psychiatric services at the second interview stage

5   Evaluation criteria and program theory

- Success, failure and impact was defined according to evaluation criteria related to the goals of the program

- Program theory was a useful tool in developing evaluation criteria

- Main challenge: had changes and improvements occurred?

6 Measurement of effects and impact elaborated along the following lines:

1. Comparison in the time axe
2. Comparison in the context (benchmarking with different regions in the country)
3. Information from informants other than the programs main target group (relatives and health care workers)
4. Comparison with results from other studies

7   Time-series design..

- Generally such designs usually involves measurement of outcome variables at periodic intervals – and therefore allows for comparison as regards changes and improvements

- <u>Dilemma</u>:
    - the <u>longer</u> interval between the phases the better as regards the implementation process of the program –
    - BUT:
    - the <u>shorter</u> interval between the phases the better as regards the mental health condition of the users – and still receive psychiatric services

- The chosen interval in my project was 1 ½ years – which turned out to be a good choice

8   Panel study to..

- To keep constant as many variables related to the participants in the study as possible, a panel study was preferred

- Re-establishing contact with the informants was uncomplicated

9   Triangulation consisted of..

- Interviews of several different groups of actors (users, relatives, health care personnel) based on slightly different interview-guides
- Drawing the lines between different kinds of studies related to evaluation of the same program and with attention to some of the same questions and topics

- This made it possible to draw more potent conclusions about the effects of the program as such

Conclusions?

- The results are obviously not representative in a statistical manner, but

- when all these methodological issues are taken into consideration, we have a point of departure to conduct research on a topic where main attention is devoted to the users and the insight they offer

- Also this approach contributes with systematic knowledge and experiences from the users lives related to the means and goals in the program that cannot be grasped otherwise.

Information – empirical results

- The majority of users with say that the flow of information between the different service-sectors is insufficient
- Both the users themselves and their relatives express dissatisfaction with this, and they feel the lack of information as a burden
- This view is particularly expressed by the relatives – both to adult and adolescent users. They tell that they need information about the psychic disorder, prognosis, diagnosis, future aspects in general. Because they want to support!
- The users themselves also express a need for more information: about the disorder, prognosis, and of possibilities and options they might have related to their situation

Information: changes?

- No changes or improvements have been reported in interviews in the first and second phase. Dissatisfaction is heavily stressed.

- The same has been reported in other different studies conducted during the same period: all studies that focus on information point at the same pattern.

Information: challenges

- There are huge potentials for improvements on all levels concerning all aspects related to information:

  - To both users and their relatives
  - About diagnosis and prognoses
  - About the treatment and various possibilities related to it
  - About medication
  - About rights, as for instance the right to read ones own record, and the rights to complain and how to do it, the right to work etc.

Individual care plan – empirical results

- Results from 2005: Developing ICPs is not a priority task – the majority of the users had not even heard of it

- Some of the users who had an ICP said they had to do the work related to developing the ICP themselves – hardly any assistance to receive from health care personnel

- They were critical to this

- Still; those who had an ICP reported that it was a useful tool for them – because responsibility related to different aspects of their treatment was pointed out

Individual care plan – changes?

- Some changes can be noted from 2005 to 2007:

  - A tendency that more users have started to develop an ICP or even have made it already
  - Overall: it is still not a priority task – and the process is slow working
  - The main change from 2005 to 2007: ICP has been put on the agenda – and increase can be noted
  - Increase mainly among those with severe psychic disorders

  - Results are supported from similar results from several other studies

Individual care plan – challenges?

- Health care personnel stress that ICP represents a huge challenge:
    - it takes much time, money and resources both to develop and to follow up

- Giving priority to those who have the right to an ICP will therefore easily get in conflict with the general need for available psychiatric assistance and treatment for those who need that

- How can this dilemma be solved?
    - It is a matter of resources and priority of capacity

Relatives – empirical results

- Relatives to adults users do not experience that health care personnel consider them a resource in the treatment of the users. They are very critical to this.

- Many relatives want to help and support, but experience that they are not invited to do so by the health care personnel. This is particularly the case for relatives to adult users, and less so for relatives to adolescent users.

- Relatives express that they would like to have more contact with the health care personnel

- Relatives often feel that their efforts to help and support and contribute with information is not appreciated by health care personnel

- Relatives constantly stress that they get too little information in spite of the role they often have in taking care of the users at home

Relatives – changes?

- Relatives express powerlessness – both related to the situation in itself, but also because the general lack of information from health care personnel

- No improvements can be registered from 2005 to 2007 – changes were rather related to an increased feeling of powerlessness and resignation

- Some reported that they felt close to a breakdown themselves

- Similar results on all studies that focus on relatives

Relatives – challenges

- No one in health care sector seem to be responsible for relatives
- Relatives are not considered to have their own needs
- They are not appreciated as cornerstones in the psychiatric health care
- There are no contributions of any kind (information, supervision, financial support, vacations) to relatives

- The role of immediate family must be clearly defined!

Co-operation and continuity

- Users generally experience lack of co-operation, continuity and coordination on different levels in the service sector

- Users often have to take care of this themselves and often function as coordinators between the different services involved

- A minority have been asked directly how they themselves identify their needs

- Some changes had taken place between the two interviews – and resulted in a feeling of improvement and less frustration, but still a lot can needs to be done

Regional differences?

- Users in the northern part of Norway experience more often than users in the eastern parts that they have to co-ordinate the services themselves
  - There seems to regional differences with more and broader services in the eastern than the northern regions of Norway

- Satisfaction with the services differ accordingly
- These differences have increased between the first and second phase of interviews

Ideals and realities

- The ideals of a program are formulated in the goals that are set up – the correspondence between these and realities have to be investigated by systematic research

- Status for the time being is that some goals have been reached – or probably will be reached – by the end of the program period, but still a lot needs to be done

- In listening to the voice of the users a lot of insight can be gained, and through this also a better understanding of where future effort has to be strengthened

Main question was..

- How can conclusions be drawn about the effects of the program based on what individual users have to say?

Concluding remarks

- The link between individual level and system level is not easy to point out scientifically.

- And even more difficult is it t claim a causal relationship between the two.

- Still, when effort is put into all the methodological issues drawn up, and with particular attention devoted to time-series designs and triangulation, a lot of informative analyzes can - and has been done.

- And light will be thrown on the importance of listening to the users voice.