



Evaluation on historical, practical and end-user's viewpoint

Sidsel Sverdrup, Professor PhD
Diakonhjemmet University College

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Draft:

- Historical viewpoint: some developmental traits
- Practical viewpoint: with emphasize on user-participation and user-orientation
- End-user's viewpoint: collaborative, involvement research - related to mental health as illustration



Historical viewpoint: some developmental traits

- Early phases:

- The first known evaluation study – about conditions in a prison – was conducted in 1840
- From 1910 - 1920 researchers started to look closer into different social-political programs, conditions in the education sector, in prisons, etc.



Early period – around 1920..

- A rapid growth after 1917: due to a need to register who were qualified to do military service in World War 1.
- Political conditions as developmental force in the field of evaluation



The 1950's and 1960's

- Gradually stronger focus on education and social-policy – with growth in other sectors as well - at the end of the 50's and beginning of the 60's
- Goal introduced as a point of departure of the evaluation studies



The period from 1960

- Possible to trace that evaluation is slowly achieving status as a specific field
- The first academic book in evaluation research in 1967
- Increasing need in society and politics to establish systematic knowledge about the successfulness of all the various programs



The 1960's..

- Implementation of a large number of expensive social reform programs – particularly related to social legislation
- Ambitions and goals were extensive: eliminate poverty, reduce juvenile criminality
- Therefore: an increasing need to find out if the means were successful, or not: the answer was to evaluate



Expectations:

- Social scientists and social science are important contributors with solutions to all kinds of social problems (flattering of course!)
- The period has been characterized as "The experimental society"



Expansion of reforms

- a growing need to find out if and to what extent goals were obtained, but at the same time
- a beginning recognition could be traced, focusing why evaluation results were not used



Challenge

- Therefore a new important question was posed:
 - How can we ensure that evaluation results are being used?



The 1970's..

- Slowly, as a reaction to this concern:
 - there was a change of focus from goal to process
 - and later on – and in line with this change –
 - also on utilization and more specifically on user-orientation



The 1980's and 1990's

- The field grew in the 1980's and expanded in the 90's:
- The reason probably that it had established a strong position in academia



Since then..

- ..activity has been steadily increasing; the field has developed along several lines – both academic and practice



Utilization focus and user-orientation in evaluation..

- ..developed as a response to a growing demand for evaluation results to be used – and to be democratic
- The answer was to involve different kinds of stakeholders and users



The last 10 years..

- User-involvement has explicitly been introduced as an important concept on the social-political agenda..
- ..and hand in hand also on the agenda in evaluation



User-orientation in evaluation studies is an..

- approach where the main idea is to give voice to the users of different kinds of services
- to contribute to capacity building
- to evaluate and enhance user-participation and user-involvement



User-orientation and user-involvement

- In further development with focus on users, the concept of user-involvement arises
- And in line with this: several research strategies to involve users - not only as research units or cases, but as participants and collaborators in research



These aspects are reflected in
several directions of research:

- Action research
- Process evaluations and formative evaluations
- Utilization-focused evaluations
- ..



..and even further and more explicit in..

- Dialogue research
- Participant evaluations
- Responsive evaluations
- Empowerment evaluations
- Democratic evaluations
- Collaborative research/involvement research



Question from an evaluator's point of view:

- How to conduct evaluations that pay particular attention to the users and their needs?



Question from the user's point of view:

- How can users be heard - and also be involved in developing the services they receive?



User-involvement and user-participation

- Important concepts that are used to illustrate that..
 - ..action is taken in practice - in order to produce changes and improvements that will benefit the users and that are directed towards their needs – they way they express them



These concepts..

- ..have been part both of research concepts as well as of social-political concepts (at least in Norway) for several years – and particularly in the field of mental health
- The question is how to convert these concepts into practice?



This challenges researchers to..

- understand attitudes, feelings, choices, relations and processes the way it is experienced by the users
- understand what the problem is and/or what functions – or not, the way it is experienced by the users
- suggest and implement changes in cooperation with the users



Answer to these challenges calls for research that..

- .focus on change, involvement, improvement and inclusion:
 - involvement – of users/clients in collaboration with researchers
 - dialogue
 - a qualitative approach
 - a bottom-up perspective
 - a process perspective



A recent, growing interest in so called

- Collaborative research (involvement research)
- The fundamental idea is to involve the users, but not only as targets of research as such, but as real collaborators in the research process



Collaborative research

- A new paradigm of collaboration and partnership
- Policy decision making often leans on research and evaluation results
- Therefore every effort has to be made to include users in the evaluation process



Collaborative research is important

- The role of the professional researcher, as well as the researchers control over the research process, is reduced – and even to some extent put aside
- Clients/users have influence on important topics related to what kinds of questions are posed,
- as well as how research results can be understood and put into practice



Collaborative research also calls for

- A theory of change that actually allows involvement of the users in a sense that include them throughout the whole research process
- and that actually tries to develop new practices for individuals and politics in line with the user's needs and their points of view



Focus is on..

- Deliberation: reasoning about relevant topics
- Dialogue: both stakeholders/users and researcher engaged in dialogue
- Inclusion: evaluation design includes all relevant interests
- And how to give voice to vulnerable groups



Focus is also on development, learning and improvement

Phases in order to improve

- Training
- Facilitation
- Advocacy
- Illumination
- Liberation (!)



Co-operation

- A close co-operation between researcher and individuals with user-experience indicate that it is possible to succeed with producing a new kind of knowledge



Collaborative research for knowledge about mental health

Collaborative research is particularly important in this field:

- How can knowledge be developed about mental health problems, and about what works when problems arise?
- Research with people instead of research about people is the core idea of this approach



Main ideas

- To include the user's perspective in research, but in a broad sense:
- Individual's own experience is valued: they have a unique knowledge about the problems related to mental illness as well as to the consequences for everyday life
- In this respect they are particularly qualified to define new and important research questions



Individuals with mental health problems..

- ..often experience traditional research as suppressive
- .. have expressed needs for information about the situation of users in the development of knowledge
- ..are concerned about how research can contribute to change in practice



The value of users as partners in research and evaluation

- Including users and their input leads to posing research questions that are of most concern and relevance.
- Users can help determine whether research protocols are appropriate and likely to be acceptable to others.
- They can facilitate the recruitment of others to research projects.



Advantages

- Involving users as much as possible in research and evaluation have several advantages
- It strengthens the research process
- It leads to greater utilization of research findings
- It improves public administration planning and management
- It takes into account the voice of vulnerable groups in a new way



User-participation in mental health: ideals and realities

Own project (bottom-up, but not collaborative) conducted in Norway posing these questions:

- How do users experience the health service in mental health sector?
- How do relatives feel they are cared for by the health service?
- To what extent are the users satisfied with the information they receive?



And these..

- What is the users opinion about coordination among various parts of the health service, including responsibility groups?
- To what degree is the requirement on individual care plans implemented?



Research design in the evaluation

- Purpose: Listen to the users voice – and evaluate both quality on what they receive as well as change/improvement
- Main idea: comparison (benchmarking) of change/improvement both on an time-axis with a defined baseline, and between different regions in Norway
- Question related to comparison: success or not. Evaluation criteria: based on goal-formulations from Norwegian government



Design..

- Qualitative interviews – based on a structured interview-guide (1/2 - 3 t)
- Five different groups of informants: adult users and their family, adolescent users and their family, therapists; total of 50 informants. To regions: North-and East in Norway, both urban and countryside



Design..

- Time series study – 1½ year between t1 and t2
- Panel study – the same informants. Reestablishing of the sample at t2 was unproblematic. Total of 100 interviews



Adolescents as users

- Adolescents were mainly satisfied with the services they received – but it took too much time to get appointments for therapy
- Parents, however, did not feel they were included – they hardly received information about the condition, prognosis etc
- Parents did not receive sufficient support



Adult users

- Waiting for treatment for a long time
- A feeling that no-one takes responsibility for them – too little continuity in the treatment they receive
- Big differences in the amount of and quality related to the services
- The same is the case with satisfaction related to them



Adult users

- Tendency that there is too little help, too little support, too much medication and too little individual therapy
- Hardly anyone have been asked what they want and need during the treatment process



Adult users

Lack of contact and coordination between different sectors– users have to coordinate this themselves

- Responsibility groups can be a supportive means, but few users have this
- The same is the case with individual care plans – slight increase at t2
- There is a general lack of information – both at t1 and t2



Relatives to adult users

General tendency that relatives feel that their presence is not appreciated by the treatment-system

- Relatives want to contribute – with relevant information – but are not allowed or invited in by the therapists – they feel that they are not appreciated



Relatives to adult users

- Often relatives have important roles as caretakers, but they still don't receive enough or adequate information that can make the situation as caretaker easier
- Relatives often express feelings of powerlessness: they feel that the situation is very difficult



Relatives to adult users

- And at the same time they get responsibility for relatives with mental health problems that society does not take for them
- Relatives feel they are not included as users by the treatment-system – and not considered to be a group with their own needs and wants



Relatives to adult users

- No-one has responsibility for relatives to users with mental health problems
- Relatives usually don't receive help or assistance with problems they experience, related to having a family member with mental health problems



What happened?

- Results from five different evaluation research projects that were conducted during the same period, all of them related to mental health problems and user-orientation, were analyzed in combination. Both top-down and bottom-up, both surveys and qualitative interviews.



What happened?

- Based on this, the Norwegian authorities produced new information and hand-books to therapists and the treatment-system on what to do in order to increase user-participation and involvement of users



But even if research in the area of
mental health has developed,

- ..this is not always reflected in practice and in social-policy, - at least not as reported in the experiences of (many) users



But still;

- There is reason to be optimistic:
Development has to start somewhere –
and change is not produced from one day
to the other
- The challenge, both for research and
politics, is to keep on developing practices
that are good for the users and that
eventually will benefit all users



Development

- From practice to research – to analyzing – to presenting for the authorities as well as therapists – to develop into new practices that enhance user-orientation, user-participation and user-involvement
- And new research paradigms that explicitly focus on the users, contribute to give voice to the users