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

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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 (½ - 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.