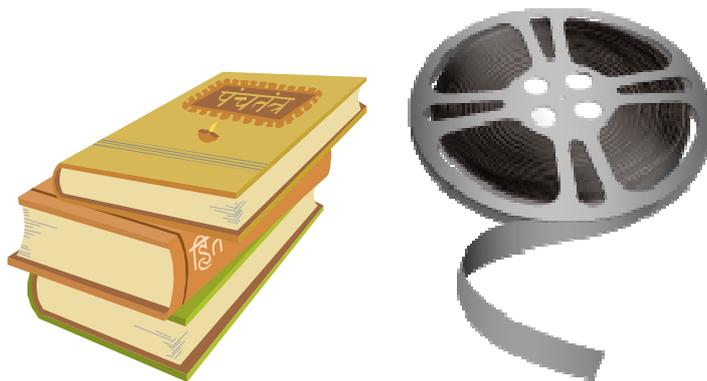


Mental Health Service User Voices in Text and Film

- learning about mental health from a user perspective



Project Plan

Associate professor Inger Beate Larsen & Professor Malvern Lumsden
Mental Health Research and Development Group
Faculty of Health and Sports Sciences
University of Agder
Norway

[June 2010]

Summary

The purpose of this investigation is to expand our knowledge of mental health and mental health work. The focus is on (a) service-user perspectives on mental health and "unhealth" and (b) users' experiences of their contact with the health care system. This should provide material on how users believe the services should be organized. A further goal is cooperation in competence-building and professional development between service-users and the teaching staff at the University of Agder which will ensure that a user-perspective is maintained at both bachelor and post-graduate levels of the teaching programme.

The following research question will be examined: What are the concerns of potential and actual mental health care service-users when they communicate their experiences through text and film? How do professionals in the field textualize their contacts with users?

The study will describe the content of text and film made *by* users, but also the content of text *about* users. Text and film analyses will be made through a collaborative network made up of: the Mental Health Research and Development Group at the Faculty of Health and Sports Sciences, University of Agder (lead agency); Råd og Muligheter (ROM – Agder) ("Advice and Possibilities", a local community user organization); the service-user project in Livorno, Italy; the National Centre for Practical Experience and Competence in Mental Health (erfaringskompetanse.no)¹ and Centre for Caring Research – Sothorn Norway (SOF).² The research programme involves five sub-projects:

- a) An investigation of historical and current Scandinavian literature written by users of mental health services
- b) A study of how children's voices in literature indicate how mental health problems can develop in adult life
- c) A study of how young people communicate experiences of mental distress on YouTube
- d) A comparison of Norwegian and Italian professional journals where user experiences are central or an important element
- e) A study of nursing reports written *about* users *by* professionals in the local community health sector

Goal of the project

¹ ROM is a user-led mental health competence centre, primarily in Kristiansand and Arendal, Agder, southern Norway. Livorno is an Italian city with well-developed locally-based mental health services and extensive cooperation between service-users and local health care services. For a number of years there has been collaboration between ROM-Agder, the local community in Kristiansand, the University of Agder and the University of Pisa. Erfaringskompetanse.no is a competence centre established to give credibility to and spread the notion of practical experience and competence in the mental health field in Norway.

² SOF will strengthen research and development linked to care services in Norway and to develop practice-related knowledge in close relation to the municipal sector.

The main goal of the project is to expand our knowledge of the experiences of people in mental distress in their meetings with the health care system. Several approaches will be used, including the analysis of literary and film texts. We shall also examine how literary texts can give voice to children in distress and how they see actual or possible future contacts with the care system. We hope in this way to gain new insights into possible improvements in the organization of the health care system, in particular by increasing the participation of users.

The projects goals can be specified as follows:

1. To focus attention on the voices of people who have given expression to their experiences of mental health and distress and how the perspectives they have relate to the organization of the care services.
2. To place user voices in a social and cultural context both by making use of historical sources, by making comparisons with user voices in Italy (Livorno region), and by examining what professionals write about users.
3. Analyse text and film in close collaboration between user-researchers, researcher-users and university teachers, all involved in different ways in working with community mental health in a teaching and research context.
4. Write (at least) five research articles to be submitted to international, peer-reviewed journals.

The dissemination plan is in two parts. Firstly publication of articles in peer-reviewed professional journals such as *Journal of community mental health*, *Vård i Norden*. Here we intend to reach the research community. Secondly we intend to publish summaries and conclusions in major national newspapers to be read by political and health service planners, as well as the general public. Here we intend to reach people who are responsible for planning of the mental health services as well as the users of them.

Background

The voices of those who have themselves experience of mental distress and care services has been – and is still – a neglected topic in Norway. Our society still has some way to go in order to give voice to users of the mental health and social services, both with respect to the organisation of services and in the context of research.

The idea of starting a research project on user experiences arose at the University of Agder, which has had a post-graduate diploma programme in community mental health for many years.³ In 2000 Senior Lecturer Anders J.W. Andersen took the initiative to start a research and development group in the mental health field. The goal was to create a forum where current research questions, literature and research studies could be discussed, with a clear focus on research and development within the community mental health field.

Community mental health is a relatively new discipline, still under development, in Norway. The Mental Health Research and Development Group hopes to have some influence over that development. We can contribute to seeing that the experiences of users are taken account of in the organization of mental health services. This is easier said than done. Amongst the goals of the Norwegian Government's substantial funding of the mental health field since the decade after 1998 was that the users of the services should themselves have a voice in the planning of their care (*St. meld. 25, 1996-1997; Opptrappingsplanen for psykisk helse, 1999-2006/8*). But

³ A diploma programme was instituted in 1998 and a master's programme in 2008.

a series of evaluation studies of this large-scale, 10-year programme show that user-participation in the mental health field has not developed the way it was intended (Helgesen, 2003, 2004, 2006; Sverdrup, Kristoffersen & Myrvold, 2005, 2007; Sverdrup 2007).

At the same time that the Ministry of Health and Care Services planned changes in the mental health care field (*St. meld. 25, 1996-1997; Opptrappingsplanen for psykisk helse, 1999-2006/8*), the Ministry of Education and Research instituted changes in the education field. The three post-graduate areas of psychiatric nursing, psychosocial work and psychomotor therapy were replaced in 1997 by an interdisciplinary programme in community mental health, as part of a cultural shift in the understanding, description and treatment of mental distress. Expert knowledge was given less emphasis and user voices more (Kirke- utdannings- og forskningsdepartementet, 1997; *Videreutdanning i psykisk helsearbeid. Rammeplan og forskrift. 1997. ajourført 18.12.08*).

In other words, the interdisciplinary post-graduate programmes in Norway now put more emphasis on user voices and the knowledge derived from lived experience. For that reason, the training programmes can no longer be run only by teachers with merely academic and professional competence. People with user experience were brought in on an hourly basis at UiA and later a person with user experience was employed on a part-time basis. Currently user voices are managed through cooperation with erfaringskompetanse.no.

When the Mental Health Research and Development Group was founded at the Faculty of Health and Sports Sciences at UiA it was therefore also necessary to bring in people with user experience as participants. The concept of *user-researchers* became known through the cooperation of ROM-Agder and Livorno in Italy. The purpose of including users in research work is to ensure that user voices are given as much weight in the framework for the interpretation of data as theoretical perspectives. For the same reason it is necessary that the group is jointly led by a user-researcher and a researcher, and more user-researchers will be involved in all parts of the project. Results from the subprojects will also be examined jointly by both researchers and user-researchers.⁴

We will also introduce the concept of *researcher-user*. The R&D group has invited Dr. Ingrid Kristine Hasund to join the group as an associate. Dr. Hasund is Associate professor at UiA in Norwegian and English Linguistics. She has experience of discourse analysis of written, verbal and visual texts and is also a writer and illustrator. In addition she is a “user” with experience of the mental health care system, experience to which she has given “voice” in literary texts and images. Dr. Hasund’s combination of academic, artistic and user competency will greatly contribute to fulfilling the goals of the project.

Since mental health work is a field under development, it will also be valuable to associate with the project group representatives of other educational fields, in particular from the bachelor programmes in nursing and social education (*vernepleie*). This will contribute to developing the field of community mental health as well as ensuring that the changes in the sector initiated by the Government will be reflected in the relevant educational programmes of

⁴ *User-researchers* are people that have life experiences of mental distress and where this is regarded as an important competency in the context of research. “User Asks User” (Bruker Spør Bruker, BSB) is a method being developed at Mental Helse Sør-Trøndelag for involving users in improving the quality of services. This project is led by Dagfinn Bjørgen. People with life experience as users carry out investigations and evaluations of services in local communities, health trusts and other service-providers. Marit Borg and Kristjana Kristiansen (2009) have written a book on this approach.

the Faculty. This will also contribute to giving the Institute for Psychosocial Health a common profile and a more integrated knowledge base. The R&D group has currently 12 members (see Annex 1 for the members' CVs).

The R&D wishes to develop a common research project where the experiences of people suffering from mental distress will be brought to the fore and made use of for professional development in the field of community mental health. Here it is necessary that as much as possible of the material gathered comes from the people concerned – adults, young people and children.

In addition, if the changes recommended by the Norwegian Ministry of Health and Care Services in the *Opptrappingsplanen* (1999–2006/8) have been realized, this should be reflected in the care reports of the staff in local community service. For that reason this will also be a focus of the study.

Research Approaches

The research project's main approach will be to investigate text and film where people communicate their own experiences. However, the project will also be open to works where literary authors have written poetic or fictional texts, or where professionals in the community health services have written care reports about various user groups. These literary and professional texts will serve to give depth and clarity to the user voices.

In order to give a broad description of user experiences the projects will consist of five sub-projects. The overarching goal is to bring out users' experiential knowledge of mental health. The sub-projects will attack this issue from different angles:

1. One approach will be to focus on what adult users of the Scandinavian health and care services write in autobiographies in the past and in the present. Bringing in older literature will enable us to consider whether user experiences are universal or tied to the conditions of the times, including social and cultural factors. By making use of literature from several Scandinavian countries we should be able to say something about possible similarities and differences between these countries.
2. It will also be necessary to seek more knowledge about the mental health of children and young people. Here we will investigate literature written by adults *about* childhood. In this sub-project we will emphasize how a childhood perspective is presented. Anna Luise Kirkengen (2009) says in her book *Når krenkede barn blir syke voksne* ["When Humiliated Children Become Sick Adults"] that the problems of earlier years can be expressed as incomprehensible illnesses in adulthood. This project should be able to contribute to increasing knowledge about how life experiences and causal conditions in the here and now of daily life can contribute to mental health and mental distress in adult life – and through that to a greater understanding of risks and coping strategies from a salutogenic perspective.
3. There are now many websites which present experience-based material on mental health. We will examine YouTube⁵ to see what young people communicate in their own films about mental distress. The project will draw out what young people

⁵ YouTube (<http://www.youtube.com/>) is a website where videos can be shared with family, friends or the general public.

themselves see as causes of mental distress and needs for prevention and treatment, as well as examine social and cultural factors.

4. Experience-based knowledge will be put in perspective by comparing texts written by users in Italy and Norway. Both countries have a number of professional journals where people write of their experiences as patients and users. This material will place the project in an international context where cultural factors, for example, organization of services, can be highlighted.
5. How user experiences are described by professionals is another approach to putting the experiences of users themselves, the focus of subprojects 1-4, in perspective. The focus here will be on how staff in local community mental health services describe their meetings with users in written reports.

The superordinate research question is:

How are experiences of health and distress communicated in text and film?

Subordinate questions and research responsibilities are summarized in the following chart ⁶ :				
What can adults who have written books tell us about their experiences facing public community health services in Scandinavia?	What information about the mental health of children and young people is communicated in literary texts?	What narratives do young people with mental distress communicate via YouTube?	A comparison of user-voices in two cultures, the Italian and the Norwegian: What are the narratives, what is common, and what differentiates the two countries?	How are the voices of users presented in care reports in a local community?
<ul style="list-style-type: none"> • Associate Professor Inger Beate Larsen • Senior Lecturer and Research Fellow Anders J. W. Andersen • Associate Professor /Researcher User Kristine Hasund 	<ul style="list-style-type: none"> • Senior Lecturer and Research Fellow Anne Brita Thorød • University Lecturer Erna Ulland 	<ul style="list-style-type: none"> • University Lecturer John Olav Bjørnstad • University Lecturer / Research Fellow Espen Marius Foss 	<ul style="list-style-type: none"> • University Lecturer Trine Habberstad • Cand.paed. and user activist/user-researcher Odd Volden 	<ul style="list-style-type: none"> • University Lecturer Janneke Quarles van Ufford • Master's student in community mental health
Professor Malvern Lumsden, professor Kjell Kristoffersen and Senior Lecturer Magnhild Høie will, along with two user-researchers and researcher-user Kristine Hasund, participate as consultants in all parts of the project.				

Methods

⁶ The five subsidiary research questions and subprojects will be developed in detail later.

The research method is characterized by well-established cooperation between the R&D group and the participating users. Professional and user groups will collaborate closely during the whole research process. The work is organized so as to ensure the project's relevance both to training and practice in the community mental health field.

The material for the project consists of written *texts* and *films* made by users themselves – as well as texts written by professionals and literary authors on them subject of the study. We will focus on the underlying messages and means utilized. This approach has much in common with phenomenon-near content analysis. Here the focus will be on the phenomena as they are revealed by the analysis of actual texts and films. A phenomenon-near interpretation will add to already existing knowledge in the field in such a way that user voices will find a natural place in the academic world.

What are the strengths of such a method? Firstly, the texts presented in books and films represent direct, sometimes first-hand, efforts by users to communicate their experiences. It is the users themselves that decide the contents of the messages they wish to communicate to the public. This means that the research material is not produced with the aid of traditional scientific methods such as interviews, field notes or questionnaires, and is therefore not in the same way controlled by the researcher.

Secondly, the focus will be on people's subjective *experiences* of mental health and distress. Marit Borg and Alain Topor demonstrate through their research that knowledge acquired through practical experience can be compared and validated on a level with knowledge acquired through the methods of natural science (Topor, 2003, 2006; Borg & Topor, 2007).

Thirdly, the inclusion and involvement of users in the research process – user-researchers – has the potential to generate new hypotheses and to change the direction of research.⁷ For this reason it is necessary to involve user-researchers and researcher-users in all phases of the project so that user voices will be better integrated and enhanced.

A limitation of the method can be that the text is detached from both the author and the time and context in which it was produced (Ricoeur, 1993). It will, so to speak, live a life of its own in its meeting with the researchers' interpretive framework. There is a danger that the researchers will interpret the message very differently from what the author intended.

By involving user-researchers and a researcher-user, each with their own experiences of mental distress, in the research process it should be possible to derive a more sound understanding of the relationship between text and interpretation. It may be a risky and sensitive approach but we believe that it has the potential to produce very valuable insights which are rarely available in an academic context.

The project's data will be obtained from different contexts and the research questions and methods used in each subproject will be adapted to these contexts.

Analysis

⁷ The method is described by Mental Helse in South Trøndelag in 2006. It is based on involving users in all aspects of an investigation from the formulation of research questions, to data collection, analysis, interpretation of results and subsequent evaluation of health services both as informants and as collaborators in the project (<http://www.brakererfaring.no/Studieturrapport>).

The analysis will be adapted to each subproject as the initial survey is completed. In general we can say that the focus of the analysis, both of text and film, will be on the understanding of mental health and distress. Content analysis, with a phenomenon-near focus, will be a necessary component of this analysis. Here we can make use of Kvale’s (2001) three levels of understanding of qualitative data: the interpretation, the analysis and the validation.

- Interpretation level a) *self-understanding*, where the interpreter attempts to formulate the author’s understanding of meaning through a re-formulation of the author’s views, as the researcher understands them.
- Interpretation level b) *critical understanding, based on common sense*. At this level, the interpretation goes further than a reformulation of the original author’s presentation of his own understanding. The researcher’s interpretation keeps within the boundaries of a “reasonable” interpretation but can include a critical component though still based on common sense.
- Interpretation level c) *theoretical understanding* makes use of a theoretical framework (interpretive framework) and can go further than a) or b). At this level the researcher stands in *critical dialogue* with other researchers in the same discipline, nationally and internationally (Kvale, 2001)

Research Design

The researchers responsible for the subprojects will themselves collect the data, using appropriate strategies. Members of the Research and Development Group who are not directly involved in the subprojects will, along with users with experience as patients, contribute to the analysis across the various studies. This will ensure that both competence at the professorial level and competence at the level of practical experience will both be represented.

Timeline

Project period	Jan.	Feb.	Mar.	April	May	June	July	Aug.	Sept.	Oct.	Nov.	Dec.
January 2011 – December 2011												
<i>Initial survey:</i> What relevant texts are available? What relevant films are available? Apply for permission to examine care reports												
<i>Operative phase:</i> Analysis of selection of texts and films												
Project period January 2012 – December 2012												
<i>Report phase:</i> Write five articles												
Submit articles for publication												

Finance

Item		Total hours	Estimated costs (NOK) Including overheads
Project leadership	100 hours for Odd Volden 100 timer for Inger Beate Larsen	200 timer	98 000
Research hours for surveying texts	75 hours x 11 team members	825 hours	403 000
Hours for text and film analyses for subprojects	75 hours x 11 members	825 hours	403 000
Hours for writing	150 hours x 11 members	1650 hours	825 000
Employment of two user-researchers, half-time	825 hours x 2	1650 hours	825 000
Employment of one researcher-user, half-time	850 hours	850 hours	413 000
Hours for three senior staff to supervise the subprojects	50 hours x 3	150 hours	73 000
Expenses			101 000
Publication costs (estimate)			105 000
Total			3 296 000

The project is partly financed indirectly by the University of Agder as follows UIA:

Leadership and subproject	Inger Beate Larsen	400 hours
Subproject	Erna Ulland	300 hours
Subproject	Trine Habberstad	17 hours
Consultant	Kjell Kristoffersen	50 hours
Consultant	Malvern Lumsden	50 hours
Total from UIA		817 hours pr year over 2 years

Total costs NOK 4 121 000
From UIA: - NOK 825 000
Sum applied for to NFR: **NOK 3 296 000**

References

- Borg, M. og Topor, A. (2007). *Virksomme relasjoner: om bedringsprosesser ved alvorlig psykiske lidelser*. Oslo: Kommuneforlaget.
- Borg, M. og Kristiansen, K. (2009). *Medforskning: Å forske sammen for kunnskap om Psykisk helse*. Oslo: Universitetsforlaget.
- Grondin, J., (2002). *Gadamer's Basic Understanding of Understanding. I: Dostal, R. J. (Red.). Cambridge Companion to Gadamer*. Cambridge: Cambridge University Press

- Helgesen M, oktober 2003: *Brukerinvolvering i psykisk helsearbeid i kommunene*. NIBR-notat 2003:117.
- Helgesen M, desember 2004: *Brukerinvolvering i psykisk helsearbeid i kommunene*. NIBR-notat 2004:136.
- Helgesen M, juli 2006: *ORGANISERING - for samarbeid og samordning?* NIBR-notat 2006:129.
- Helgesen M, mars 2007: *Mange vil ha alt de får, andre vil ikke ha noe. Om brukermedvirkning i psykisk helsetjeneste i kommunene*. NIBR-rapport 2006:21. Sluttrapport.
- Hellesnes J., (1988). *Hermeneutikk og kultur*. Oslo: Det Norske Samlaget.
- Kirkengen, A. L. (2009). *Hvordan krenkede barn blir syke voksne*. Oslo: Universitetsforlaget.
- Kjeldstadli, K. (1999). *Fortida er ikke hva den engang var. En innføring i historiefaget*. Oslo: Universitetsforlaget.
- Lauveng, A. (2005). *I morgen var jeg alltid en løve*. Oslo: Cappelen.
- Lauveng, A. (2006). *Unyttig som en rose*. Oslo: Cappelen.
- Lauveng, A. (2008). *Arbeidsmaur med gipset hjerte*. Oslo: Universitetsforlaget.
- Pini, P., (2009). *Multicentric research: Italy, Finland, Norway, England*. (Upublisert).
- Ricoeur, P. (1993). *Från text til handling*. Stockholm/Stehag: Brutus Östlings Bokförlag.
- Szasz, T. (2007). *Coercion as cure. A critical history of psychiatry*. New Brunswick, N. J.: Transaction Publishers
- St.m. nr. 25 (1996-1997). *Åpenhet og helhet. Om psykiske lidelser og tjenestetilbudene*.
- St.prp. nr. 63 (1997-1998). *Opptrappingsplanen for psykisk helse 1999-2006*. Endringer i statsbudsjettet for 1998.
- Sverdrup S, Kristofersen L, Myrvold T, september 2005: *Brukermedvirkning og psykisk helse*, NIBR-rapport 2005:6.
- Sverdrup S, Myrvold T, Kristofersen L, mars 2007: *Brukermedvirkning i psykisk helsearbeid: idealer og realiteter*, NIBR-rapport 2007:2. Sluttrapport.
- Sverdrup S, april 2007, Diakonhjemmets Høgskole: Syntese om brukermedvirkning.
- Taylor, C., (2002). Gadamer on the Human Sciences. I: Dostal, R.J. (Red.). *Cambridge Companion to Gadamer*. Cambridge: Cambridge University Press.
- Topor, A. (2003). *At komme sig efter alvorlige psykiske lidelser*. København: Hans Reitzel Forlag.